

Transition to university for autistic students in Australia: A phenomenological study

By

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Bachelor of Behavioural Science
Master of Disability Studies

*Thesis
Submitted to Flinders University
for the degree of*

Doctor of Philosophy

College of Nursing and Health Sciences
27th February 2024

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ABBREVIATIONS

ACT	Australian Capital Territory
ADCET	Australian Disability Clearinghouse on Education and Training
ADHD	Attention Deficit Hyperactivity Disorder
AIHW	Australian Institute of Health and Welfare
ASD	Autism Spectrum Disorder
DDA	Disability Discrimination Act
DSE	Disability Standard for Education
DSM	Diagnostic and Statistical Manual of Mental Disorders
DSM-IV-TR	Diagnostic and Statistical Manual of Mental Disorders – Fourth Edition – Text Revision
DSM – 5	Diagnostic and Statistical Manual of Mental Disorders – Fifth Edition
IPA	Interpretative Phenomenological Analysis
NDIA	National Disability Insurance Agency
NDIS	National Disability Insurance Scheme
NSW	New South Wales
PDD-NOS	Pervasive Developmental Disorder – Not Otherwise Specified
QLD	Queensland
RTA	Reflexive Thematic Analysis
SA	South Australia
TAFE	Tertiary and Further Education
UK	United Kingdom
UNCRPD	United Nations Convention on the Rights of Persons with Disabilities
US	United States of America/United States
WA	Western Australia

GLOSSARY

Academic staff	Tutor, lecturer, practical demonstrator, topic coordinator/course coordinator/unit coordinator.
Access plan	Also known as disability access plan or learning access plan, outlines the study and assessment accommodations the student is eligible for. May also include statements which provide an overview of the impact of the student's disability.
Disability advisor	Specialist staff within the university setting who provide support, advice, and guidance to students with disabilities. Also known as accessibility advisors, equity practitioners, disability support staff, or disability liaison officers.
Disability Services	University Disability Services office. Also known as Disability Support Office or Accessibility Office.
Full-time	Enrolment in 75% or more of the standard full time study load (usually equivalent to 30-40 hours per week).
High school	In Australia, typically attended by students aged between 13 and 18 years. Also known as secondary school.
National Disability Insurance Scheme (NDIS)	A direct payment scheme in Australia which provides funding packages for people with disability to enable access to reasonable and necessary supports.
Orientation program	Program of activities and information sessions, often provided in the week before classes commence, or during the first few weeks of the semester.
Part-time	Enrolment in less than 75% of the standard full-time study load.
Technical and Further Education (TAFE)	A publicly funded, tertiary education system which provides vocational education courses in Australia.
Transition period	The transition to, and first year of university.
University pathway program	Program of preparatory courses that is designed to provide students with the skills needed to study at university. Available for students who do not meet university entry requirements.

ABSTRACT

Background

Autistic students are increasingly enrolling in higher education. However, their completion rates remain lower than that of their peers both with and without disabilities. Previous research has investigated the support needs of autistic students at university. However, a systematic literature review conducted by the researcher revealed there was a paucity of research, both nationally and internationally, exploring the experiences of autistic students during their transition to, and first year of university. The first year of university is critical for enabling successful university experiences for all students, with negative first year experiences resulting in negative impacts for students and universities alike.

The experience of transition to university does not occur in isolation. Throughout the transition period, students interact with family members, peers, friends, and university staff, with each interaction impacting on and influencing the student's experience. Previous research has highlighted the role of family support for autistic students during post-secondary education. In addition, autistic students are likely to engage with Disability Services and academic staff to request and access reasonable adjustments and accommodations. The current research sought to better understand these interactions, to identify barriers and facilitators to transition for autistic students. The bioecological theory model was used as a framework for exploring these factors at the individual, systemic and cultural level.

The lack of current research exploring the experiences of autistic students during their transition to university makes it difficult to establish evidence-based strategies to enable successful transition experiences for autistic students. Therefore, the current research addressed the gap in the existing literature by exploring the following question: *What are the facilitators and barriers to transition to university for autistic students in Australia?* The research question was addressed by considering the following three research objectives:

1. To explore the experiences of autistic students during their transition to, and first year of university;
2. To explore the experiences of family members supporting autistic students during their transition to, and first year of university;
3. To explore the experiences of university staff supporting autistic students during their transition to, and first year of university.

Methodology and Methods

The current research used an interpretive phenomenological approach to explore the experiences of autistic students and their support network members (e.g., family and university staff) during the transition to, and first year of university. Semi-structured interviews were conducted with eight autistic students and six support network members from universities across Australia. In addition, online survey data were gathered from family members and university staff.

Student experiences were analysed using Interpretative Phenomenological Analysis (IPA) to enable an in-depth and detailed exploration of their individual experiences. Support network members' experiences were analysed using Reflexive Thematic Analysis (RTA), to better understand their experiences of providing support to autistic students during their transition.

Main Findings

Findings identified factors at each of the bioecological theory model levels which can act as facilitators and barriers to transition, depending on the context within which they occurred. Using the bioecological theory model framework, the researcher has highlighted the interrelated nature of each of these factors. At the individual level, students identified the importance of sense of self and identity, and the challenges they experienced with help-seeking and disclosure. Students also demonstrated persistence and resilience in the ways they overcame barriers and challenges. The microsystem level highlighted the role of parents, friends, peers and university staff, and the existing lack of high school transition support in Australia. Additionally, findings showed that family and university staff work to balance the student's support need, with their right to autonomy and independence. At the mesosystem level, the research reinforced the impact of policies and legislation which prevent direct interaction between family members and university staff. Institutional policies and practices such as orientation and peer-mentoring programs were highlighted at the exosystem level, with students reporting mixed experiences of both. Participants also highlighted the benefits of autistic safe spaces on campus. Finally, the current research highlighted the importance of university-wide practices which support the inclusion of autistic students.

Conclusion

The current research contributes to existing understanding of the experiences of autistic university students, and highlights the complex interrelationship between individual, systemic, and cultural factors which impact on the experience of transition to university for autistic students. Findings provide a valuable evidence base for individual and systemic strategies, which will not only benefit autistic students, but other neurodivergent students, and students with disabilities more broadly.

DECLARATION

I certify that this thesis:

1. does not incorporate without acknowledgment any material previously submitted for a degree or diploma in any university;
2. and the research within will not be submitted for any other future degree or diploma without the permission of Flinders University; and
3. to the best of my knowledge and belief, does not contain any material previously published or written by another person except where due reference is made in the text.

No editor was used in the creation of this thesis.

Signed by Alison Louise Nuske on the 6th of October 2023

ACKNOWLEDGEMENTS

I am deeply grateful to have reached this milestone, and I could not have done it without the support and guidance of many individuals who have contributed to this journey. My heartfelt appreciation goes out to each and every one of them.

Firstly, I am extremely grateful to my supervisory panel, Dr Fiona Rillotta, Associate Professor Michelle Bellon, Professor Amanda Richdale, and Dr Jessie Shipman. Fiona, thank you for your unwavering support, limitless patience, and mentorship throughout my candidature. I probably owe you a lot of chocolate! To Michelle, Mandy, and Jessie, your expertise, advice, and feedback have been invaluable, and I am greatly appreciative of the support and guidance each of you has provided throughout my candidature. Thank you!

I would also like to extend my appreciation to the Disability and Community Inclusion team and Flinders University for providing me with the resources, facilities, and academic environment necessary to pursue my doctoral studies. Additional thanks to Nikki May for her assistance with my systematic literature review.

I am also thankful to the participants who generously contributed their time and insights to this research. Their willingness to share their experiences, especially during a very unusual couple of years, has been essential in shaping this thesis. Additionally, thanks to the members of my advisory group who provided invaluable feedback and advice throughout this project.

On a more personal note, I would like to thank my cats, Allegra and Willow. Sitting on my keyboard or mouse, or sleeping on my analysis, was not very helpful, but your companionship has been a source of comfort throughout this journey.

To my online study buddies, Natalie and Ellen, thank you for the writing “lock-ins”, the weekend study sessions, accountability check-ins, and your moral support. To my PhD peers, Judith, Eleanor, and Felicity, I feel so grateful to have made so many valuable friendships throughout this journey.

To my family, friends, and colleagues thank you for your patience, support, and encouragement.

My deepest gratitude also goes to my husband, Travis, for his support, patience, and understanding. Your encouragement and belief in me have been invaluable in persisting throughout my candidature.

This research project stands as a collective effort, and I am grateful for the contributions of all those mentioned above.



Image used with permission of Alison Ryan.

A note about the image:

The above image was painted by a close friend of the researcher and represents the researcher's own journey of self-discovery as an autistic person.

LIST OF PUBLICATIONS AND CONFERENCE ABSTRACTS OVER CANDIDATURE

Publications relating to PhD project

Nuske, A., Rillotta, F., Bellon, M., & Richdale, A. (2019). Transition to higher education for students with autism: A systematic literature review. *Journal of Diversity in Higher Education*, 12(3), 280-295. <https://doi.org/10.1037/dhe0000108>

Publications during candidature relating to other projects

Nuske, A., Brett, M., & Knight, E. (In Press). Disability services in higher education: An Australian perspective. In J. W. Madaus & L. L. Dukes III (Eds), *Handbook of Higher Education and Disability*. Elgar.

Conference abstracts & presentations

Nuske, A. (2022, November 28–29). *Experiences of autistic students in their transition to, and first year of university in Australia* [Conference Presentation]. Australian Society for Autism Research 2022 Conference, Victoria, Australia.

Nuske, A., Wall, Natalie., & Sesterka, A. (2022, November 28–29). *Retroactive participatory research: Highlights, hurdles, hopes for the future* [Conference Presentation]. Australian Society for Autism Research 2022 Conference, Victoria, Australia.

Nuske, A. (2022, September). *It's time for change: Improving the university experience for autistic students* [3MT Finalist]. Flinders University, South Australia, Australia.

Nuske, A. (2021, July 5–9). *Transition to university for students on the autism spectrum in Australia* [Poster]. STARS 2021 Conference, Online, Australia.

Nuske, A. (2018, December 6–7). *Transition to higher education for students with autism: A systematic literature review* [ePoster Presentation]. Australian Society for Autism Research 2018 Conference, Queensland, Australia.

THESIS STRUCTURE OVERVIEW

Chapter 1 presents an introduction to the thesis and provides a rationale for the importance of research on the topic of transition to university for autistic students. This chapter provides clarification of the language and terminology used within this thesis and presents an overview of the methodology employed to undertake this research. It also outlines how this thesis contributes to new knowledge in this field.

Chapter 2 presents an overview of the relevant background literature relating to disability and inclusion in higher education both nationally and internationally. It also presents existing literature relating to the experiences of autistic students in higher education. The chapter also provides an overview of transition models and theories which form the basis for this research.

Chapter 3 presents the theoretical framework used throughout this research project: the bioecological theory model. An overview of the model is provided, followed by a description of how the model relates to the current research.

Chapter 4 presents a systematic literature review of autistic students' experiences of transition to university. The review was published in the *Journal of Diversity in Higher Education* (See Appendix A) and provides an evaluation and critical analysis of previous literature exploring the experiences of autistic students during their transition to university.

Chapter 5 presents the methodological and philosophical approaches underpinning the research project, including an outline of the researcher's perspective and positionality. It also outlines the research question and objectives addressed by this research project.

Chapter 6 presents the methods of data collection and analysis that were utilised to address the research objectives. This chapter also outlines the inclusive research practices and ethical considerations relevant to this research.

Chapter 7 presents a narrative overview of autistic student participants who took part in interviews. This chapter introduces participant characteristics and describes the bioecological theory model elements relevant for each participant.

Chapter 8 presents an in-depth, detailed analysis of interview data from autistic student participants, using Interpretative Phenomenological Analysis (IPA). This chapter addresses research objective one and provides an understanding of the experiences of autistic students during their transition to, and first year of university in Australia.

Chapter 9 presents a thematic analysis, using Reflexive Thematic Analysis (RTA), of interview data from support network members (e.g., family, support workers, and university staff). This

chapter addresses research objectives two and three and provides an understanding of the experiences of these participants in providing support to autistic students during their transition to, and first year of university in Australia.

Chapter 10 presents the final analysis of this thesis; a thematic analysis of survey data collected from family members and university staff, using RTA. This chapter addresses research objectives two and three and provides additional broader understanding of the experiences of family and staff members in providing support to autistic students during their transition to, and first year of university in Australia.

Chapter 11 presents a discussion of the overall findings of this research. The chapter identifies facilitators and/or barriers to transition to university for autistic students and discusses them within the context of the bioecological theory model framework.

Chapter 12 concludes the thesis by providing suggestions for future research, as well implications and practice recommendations. This chapter also summarises the thesis aims and findings and highlights the unique contribution of this research project.

1 INTRODUCTION

Research has shown that autistic students experience many challenges when engaging in university studies. Previous research has explored the difficulties that autistic students may experience during their studies, but there has been a lack of research examining the transition and first year experience specifically. As such, little is known about the transition experiences of autistic students, in particular from their own perspective. In order for universities to provide successful transition strategies for autistic students in the early stages of their degree it is vital for research to examine more closely the experiences of autistic students during this time. Exploration of the roles, relationships, and interactions of students' support networks is also needed, to develop a deeper understanding of the facilitators and barriers which may impact autistic students' experiences of transition. To develop best practice strategies to support autistic students' successful transition to university we need to better understand their experiences, as well as the internal and external factors which contribute to these experiences.

This chapter presents an introduction to the thesis and overview of the current research project. The chapter begins by providing an outline of important language and terminology used throughout the thesis and research project. The chapter then presents the background and rationale for the research project and an outline of the purpose and aim of the research. An overview of the theoretical framework and methodology is then presented. The chapter concludes with an outline of the original contribution to knowledge made by this research project and thesis.

1.1 Language and Terminology

In Australia, the primary set of criteria used to diagnose autism is the Diagnostic and Statistical Manual of Mental Disorders (5th ed.; DSM-5; American Psychiatric Association, 2013). The DSM-5 was the first version of the manual to combine the diagnostic criteria for the previously separate conditions of Autistic Disorder, Asperger's Disorder and Pervasive Developmental Disorder – Not Otherwise Specified (PDD-NOS). These diagnostic labels were more commonly referred to as autism, Asperger Syndrome, and PDD-NOS. These diagnostic labels are now combined under one condition: Autism Spectrum Disorder (ASD; American Psychiatric Association, 2013).

Depending on the year of their diagnosis, some people may continue to identify with the diagnostic label they originally received. For example, someone who was diagnosed with Asperger's Disorder prior to the introduction of the DSM-5, may continue to identify with the

label Asperger's Disorder or syndrome. In addition, some people with a diagnosis of one of the above conditions may identify as being on the autism spectrum. For the purposes of this thesis the term 'autism' has been used throughout to refer to the range of diagnostic labels and preferences.

The neurodiversity paradigm recognises autism and other neurodivergences as just one aspect of bioecological diversity (Anderson-Chavarria, 2022; Walker, 2021), and highlights the value in all forms of neurological diversity (den Houting, 2019). The term neurodivergent is used to refer to people whose brain differs from the dominant norm within the context of neurodiversity. The concept of neurodiversity shifts the narrative away from that of disorder and instead focuses on differences in learning and communication (Anderson-Chavarria, 2022). It does not disregard the significant challenges neurodivergent people experience. Instead, the neurodiversity paradigm recognises these difficulties as arising from living within a society which often fails to accommodate different ways of thinking and learning (den Houting, 2019). It is within the context of the neurodiversity paradigm that this research has been undertaken. As such, the project recognises both the strengths and challenges experienced by autistic people and frames them as differences rather than deficits.

The researcher acknowledges that language choice when referring to autistic identity is a personal preference, with no one preferred term (Bury et al., 2023; Kenny et al., 2016). It is recommended where possible to seek clarification from each person as to their preference (Kenny et al., 2016; Shakes & Cashin, 2019). Students who took part in interviews for this research were asked to indicate their own personal language preference and this terminology has been used when describing their experiences.

The researcher would like to note the shift in language and terminology that has occurred throughout this research project. The first publication from this research was a systematic literature review (Nuske et al., 2019), originally published using person-first language, as was the requirement for APA journal publications at the time of submission. While APA publishing guidelines now allow for the use of identity-first language, the publication itself has been presented within this thesis as it appeared in the journal publication.

After consultation with autistic community members the phrase "on the autism spectrum" was used in the initial stages of the project in an attempt to be inclusive of both person-first and identity-first language preferences. In line with current research findings, suggesting that identity-first language is preferred by a majority of autistic people (Bury et al.,

2023; Monk et al., 2022; Shakes & Cashin, 2019), and following the author's own diagnosis of autism in late 2019, the researcher has chosen to use identity-first language (e.g., "autistic") throughout this thesis. Language and terminology used throughout this thesis also reflects the recommendations suggested in Bottema-Beutel et al. (2021) to avoid use of potentially ableist or patronising language. Further details regarding the researcher's positionality and autistic identity are provided in Chapter 5.

For the purpose of this thesis, 'transition' is loosely defined as the period directly prior to commencement of university through to the point at which students have completed their first full year of studies. Throughout this thesis, this has been referred to as the "transition period" or "transition to university". It is important to note that for some students the 'transition' period may extend beyond their first year of enrolment.

Support networks within the context of this research consist of family members (e.g., parents, siblings, grandparents), support workers (external to the university), professional university staff (e.g., disability advisors, library staff, security staff), and academic university staff (e.g., coordinators, lecturers, tutors). Facilitators are the factors which contribute to positive experiences of transition and first year, while barriers are the factors which inhibit positive transition experiences.

1.2 Background and Rationale

According to the American Psychiatric Association, autism is a lifelong, neurodevelopmental condition, characterised by difficulties in two core areas, social communication skills and patterns of restricted or repetitive behaviours, interests, or activities or sensory sensitivities (APA, 2103). These are the current clinical diagnostic criteria for autism used in Australia. Social-communication difficulties, often include difficulties with understanding and use of verbal and non-verbal communication, engaging socially with others, and developing and maintaining social relationships. Restricted or repetitive behaviours, interests or activities may present as stereotyped behaviours, a preference for routine, focused interest in a particular topic or area, and/or sensory processing difficulties (either hyper or hypo sensitivity to sensory input) (APA, 2013). In addition, autistic people are likely to experience difficulties with executive functioning skills such as planning, organising, problem solving, and time management. They may also demonstrate challenges with theory of mind (i.e., the ability to see things from another person's perspective) (Geurts et al., 2014).

Alternative descriptions of autism provide another perspective with a focus on the individual autistic experience. Two examples of these descriptions, presented by Australian autism associations, are provided below:

- “a condition that affects how a person thinks, feels, interacts with others, and experiences their environment. It is a lifelong disability that starts when a person is born and stays with them into old age” (ASPECT, n.d)
- “a neurological developmental difference that changes the way an individual relates to the environment and people in it. Autism changes the way that an individual sees, experiences and understands the world” (Autism SA, 2021).

According to a recent systematic review, global prevalence of autism in children is estimated at approximately 1 in 100 (Zeidan et al., 2022). Other reports of prevalence rates vary from 1 in 59 children (Baio, 2018), to 1 in 40 children (Kogan et al., 2018). Studies conducted by Brugha et al., (2011; 2016) in England suggested the prevalence rate of autism in adults was approximately 1 in 100. Prevalence estimates have been increasing in the past 20 – 30 years (Baio, 2018; Christensen et al., 2018; Zeidan et al., 2022). Zeidan et al. (2022) attributed this increase in prevalence rates to several factors including increasing community awareness of autism, changes in diagnostic criteria, and increased diagnosis of autism in previously overlooked populations “defined by sex, geography, race/ethnicity, or SES [socio-economic status]” (p. 786).

Over the past 30 years there has been an increased focus on improving participation rates for previously under-represented groups in higher education, including students with disabilities (Brett, 2016; Kift, 2015; Widman & Lopez-Reyna, 2020). Globally, this has resulted in an increase in enrolment rates for students with disabilities, which is underpinned by anti-discrimination and equal opportunity legislation, alongside a cultural shift towards inclusion (Nuske et al., In press). A more detailed overview of disability and equity in higher education, both nationally and internationally, is provided in Chapter 2.

The focus on improving participation rates of students with disabilities along with the increase in prevalence rates for autism have likely contributed to the increasing number of autistic students enrolling in higher education (Mulder & Cashin, 2014; Widman & Lopez-Reyna, 2020). However, while higher education enrolment rates for autistic students are increasing (Bakker et al., 2019, Netherlands; Barnhill, 2016, US), their completion rates remain lower than that of their peers (Australian Bureau of Statistics, 2019; Newman et al.,

2011). An overview of existing literature exploring autistic students' experiences in higher education is presented in Chapter 2.

Autistic people are also reported to have higher levels of un- or under-employment than their peers both with and without disability (Bush & Tassé, 2017, US; Flower et al., 2021, Australia; Nicholas & Klag, 2020, Canada). Given that higher education is a key predictor for successful employment outcomes for autistic students (Baldwin et al., 2014, Australia; Ohl et al., 2017, US), there is a need for further research to support the successful participation and completion of autistic university students. This thesis builds upon existing literature exploring the experiences of autistic university students by examining their experiences of transition to, and first year of university. The first year has been identified as crucial for student success, with research suggesting that negative experiences in the first year result in negative impacts for both students and universities (Kift, 2015, 2021). The importance of transition and first year experiences in supporting successful university participation is described further in Chapter 2.

1.3 Purpose

The overall purpose of this thesis is to examine the facilitators and barriers to transition to university for autistic students in Australia, from the perspectives of autistic students themselves, and members of their support networks. Through analysis of interview data collected in 2019 and 2020, and survey data collected between 2019 and 2021, the experiences of autistic students and their support networks during the transition to, and first year at university is presented. Priority is given to in-depth detailed analysis of the experiences of autistic students themselves, to better understand their experiences from their own perspectives. Data collected from family members, support workers, and university staff has provided an opportunity for examination of the broader bioecological elements which may impact students' experiences. There has been a lack of previous exploration of the experiences of autistic students during their transition to, and first year of university, with previous research focusing on the support needs of students during their studies. While research exploring the experiences of autistic students in higher education, including within Australian universities, has been increasing in recent years (e.g., Anderson et al., 2020, Australasia; Bakker et al., 2023, Netherlands; Cage et al., 2020, UK; Evans et al., 2023, US; Kim & Crowley, 2021, US), understanding of the transition and first year experiences of autistic students is limited. With the critical importance of successful first year experiences in improving student retention and outcomes already established (Bell et al., 2017; Kift, 2008, 2015; Moriña, 2017), the current project is vital in improving our understanding of these experiences, to provide practical recommendations and guidelines for future practice.

The aim of this project was to generate new knowledge and understanding of the experiences of autistic students, their family members and support networks during the transition to, and first year of university in Australia. The project was designed to identify and examine the existing facilitators and barriers to successful transition to university for autistic students. The findings of this research project will inform best practice recommendations for future transition support for autistic students in university.

1.4 Overview of Theoretical Framework

The use of a theoretical framework provides a foundation for the research project and supports the strength and structure of the resulting thesis (Grant & Osanloo, 2016; Kivunja, 2018). In addition, a theoretical framework provides the conceptual grounding for decision making throughout the research process, as well as a lens through which the research findings can be explored and understood (Grant & Osanloo, 2016; Kivunja, 2018). The theoretical framework used throughout this thesis was the bioecological theory model (Bergen, 2008; Bronfenbrenner, 1979; Bronfenbrenner & Morris, 2006). The bioecological theory model provides a framework for exploring the interrelationship of elements at the individual, systemic, and cultural level, and their impact on individual experiences. This framework has provided the lens through which the phenomenon of autistic experiences of transition to and first year of university has been explored. The bioecological theory model is described in more detail in Chapter 3.

1.5 Overview of Methodology

This research utilises an interpretive phenomenological approach. The gaps identified in the systematic literature review (see Chapter 4) resulted in three research objectives, which were addressed using two sets of data, interview data and survey data. The first research objective was addressed using Interpretative Phenomenological Analysis (IPA), which enabled in-depth detailed analysis of interview data collected from autistic university students. The second and third research objectives were addressed using Reflexive Thematic Analysis (RTA) of interview and survey data collected from family members, support workers, and university staff. A detailed description of the methodology and methods used for this research is presented in Chapters 5 and 6.

1.6 Original Contribution to Knowledge

An expanding area of research has begun to focus on the supports that autistic students require during their higher education studies. However, there is limited qualitative research exploring the direct lived experiences of autistic students in higher education. In

particular, there is a paucity of research exploring their transition and first year experiences specifically.

Awareness of the types of supports students require is only beneficial if we can find ways of positively and successfully engaging autistic students with these supports in the early stages of their university experience. The current research not only adds to the existing literature on supporting autistic students in higher education but also addresses the current gap in existing literature by examining the transition period and first year experiences of autistic university students.

Previous research exploring university experiences for autistic students has predominantly focused on identifying strategies and supports aimed at developing social and academic skills in autistic students. For example, the majority of studies examined by Widman and Lopez-Reyna (2020) in their systematic review exploring supports for post-secondary autistic students, focused on areas such as social support, academic support, communication development, and developing of functional skills. Similarly, more recent studies related to autism and higher education have focused on specific areas such as self-determination (e.g., Lei & Russell, 2021), social anxiety and adaptation (e.g., Goddard & Cook, 2022; Lei et al., 2020), or peer mentoring programs (e.g., Duerksen et al., 2021; Morris et al., 2022). While each of these areas is important for supporting autistic students in their university experience, it fails to recognise the significant barriers to inclusion posed by existing university environments and cultural and academic expectations. In addition, implications for systemic change appear to be an outcome of the research rather than an intentional consideration of the research itself. Additionally, according to the social model of disability, barriers to participation in higher education are generated by the institution and wider society (Moriña, 2017). It is these social barriers which limit or restrict participation of students with disabilities in higher education settings. As such the focus must shift from requiring the individual to change and instead address systemic barriers to higher education, such as policies, practices, and attitudes (Moriña, 2017).

The current research addresses this gap in the literature by taking a holistic approach to exploring the experiences of autistic students during the transition period. The use of the bioecological theory model as a framework for the current research facilitated the exploration and identification of facilitators and barriers not only at the individual level, but also at the systemic and cultural level. To the author's knowledge this thesis is the first research project to utilise the bioecological theory framework as a lens to examine the facilitators and barriers to transition for autistic students.

In addition, autistic experiences of transition to university in Australian higher education institutions is an area that has yet to be examined. Existing research in the Australian context (e.g., Anderson et al., 2020; Cai & Richdale, 2016) has explored broader university experiences, or focused on specific phenomena such as experiences of anxiety, or sense of belonging for autistic university students. While a small number of studies have explored the transition to university for autistic students internationally (see Chapter 4), to the researcher's knowledge the current research is the first to specifically focus on the experiences of transition to university for autistic students in the Australian higher education context. Given the systemic and socio-political differences between higher education in Australian and overseas, research exploring the experiences of autistic university students in Australian universities is critical. This research therefore makes a significant contribution to the existing knowledge base relating to Australian autistic students' experiences of transition to, and first year of university.

Using qualitative methodologies, the current research addresses existing gaps in the literature by exploring broader systemic issues from the perspectives of those who face them, autistic students. In doing so, it seeks to shift the deficit-based narrative of autistic university students, often evident in higher education practice and policies, towards a more holistic and systemic approach to supporting their experience. The current research therefore fills a significant gap in the literature and provides an evidence base for recommendations to support the successful transition to, and first year of university for autistic students.

1.7 Chapter Summary

This chapter has presented the background and rationale of the research project, along with an overview of the purpose of the research. The chapter has introduced the theoretical framework and methodological approaches used within this research project. Finally, this chapter has highlighted the research project's original contribution to knowledge. The following chapter presents background literature relevant to the current research, from both a national and international perspective.

2 BACKGROUND AND CONTEXT

This chapter is presented in two main parts. Firstly, an overview of literature related to disability in higher education, both nationally and internationally, is presented. Followed by a narrative review of existing literature related to autistic experiences of higher education. Secondly, an overview of literature relating to the first year experience in higher education and relevant transition models and theories is provided.

2.1 Disability and Equity in Higher Education

Internationally, an increasing number of students with disabilities have been participating in higher education (Brett, 2016; Ebersold, 2008; Katsiyannis et al., 2009; Kauffman et al., 2023; Moriña, 2017; Swart & Greyling, 2011). This may in part be due to the implementation of legislation and government policies concerning discrimination and equal opportunity for people with disabilities designed to ensure people with disabilities have equal access to educational opportunities, on the same basis as those without disabilities (Brett, 2016; Järkestig Berggren et al., 2016; Moriña, 2017). In many countries, ratification of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD; 2006), has further strengthened the underlying legislation designed to support the inclusion of people with disabilities (Moriña, 2017; Shpigelman et al., 2022).

While participation rates are increasing for people with disabilities, they continue to remain an under-represented group within higher education (Gibson, 2012; Hubble & Bolton, 2021; Moriña, 2017). Students with disabilities are at greater risk of withdrawing from their studies before completion (Hubble & Bolton, 2021; Moriña, 2017), and may also be unaware of support services available, or their legal rights in relation to their participation in higher education (Moriña, 2017). Research shows students with disabilities face many barriers to participation in higher education including negative attitudes of faculty members, architectural and physical access barriers, and inaccessible information and technology (Moriña, 2017), as well as stigma, discrimination, and a lack of disability awareness (Kauffman et al., 2023; Shpigelman et al., 2022). Students are also required to self-disclose and provide supporting evidence of their disability to gain access to reasonable and necessary accommodations or adjustments (Nuske et al., In press). This can create a significant barrier for some students (Järkestig Berggren et al., 2016; Pumfrey, 2008; Shpigelman et al., 2022), particularly those who have difficulties with disclosure and help-seeking. It also creates barriers for students who do not wish to be identified or labelled as “disabled” but still require reasonable and necessary adjustments to successfully participate

in their studies (Järkestig Berggren et al., 2016; Shpigelman et al., 2022). The requirement for students to repeatedly self-disclose adds to the challenges experienced by the student (Thomas, 2020). This need for repeated self-disclosure and self-advocacy throughout their studies was identified by participants in Thomas' (2020) study as "unfair, unnecessary, and demeaning" (p.24).

2.2 Disability in Higher Education: The Australian Context

With the release of the discussion paper *A fair chance for all* in 1990, came a significant shift in focus on disability as an equity group within the higher education sector in Australia (Brett, 2016). The report emphasised the need to increase participation rates in higher education for people from a range of equity groups and highlighted the importance of access to higher education in promoting equal opportunities for people with disabilities (Dawkins, 1990). This became commonly known as 'widening participation'. The national objectives set out in the paper, outlined a plan to double participation rates of commencing students with disabilities by the year 1995, and identified strategies which could be implemented to meet these targets (Dawkins, 1990). Such strategies included: provision of necessary equipment and modification of facilities, modifying curriculum and course materials, flexibility with timetables and course requirements, and access to disability advisers or similar contact people to assist with navigating the range of difficulties students with disabilities may experience (Dawkins, 1990).

In 1992, the Commonwealth Disability Discrimination Act (DDA; Australian Government, 2018) was introduced in Australia, providing protection against discrimination and harassment for people with disabilities. The DDA protects the rights of people with disabilities to participate in society, including in higher education institutions, on the same basis as those who do not have a disability. The DDA contributed to the improvement of higher education admission practices to make them more inclusive, as well as the provision of disability support and implementation of Disability Services offices within higher education institutions (Nuske et al., In press). To assist educational settings to ensure they are compliant with the DDA, the Disability Standards for Education (DSE; Australian Government, 2005) were introduced. The standards (Dickson & Cumming, 2018) cover all educational sectors and provide clarification for educational settings regarding the rights of students and legal obligations of the educational institutions.

To collect data on the enrolment and characteristics of students with disabilities in higher education in Australia, a group of equity performance indicators, known as the Martin Indicators, were developed and introduced to enrolment data collection in 1994 (Martin

1994, cited in Brett, 2016). At enrolment, students were asked to indicate whether they had a disability, impairment, or medical condition which may affect their studies and if so, to indicate the area of impairment: hearing; learning; mobility; vision; medical; or other. Students were also asked to indicate whether they wished to receive information about the support available within their institution (Martin 1994, cited in Brett, 2016). Updated enrolment questions and disability indicators were implemented in 2021, with an amended categorisation of disability, which remains broad and imprecise:

Hard of Hearing/deaf/Deaf; Physical disability; Intellectual disability; Specific Learning Disability; Mental health condition; Acquired brain injury; Low Vision/Blind; Medical condition; Neurological condition; Other disability; Not specified. (Australian Government, 2021)

The use of such broad categories makes this data difficult to utilise in order to truly understand the characteristics of students with disabilities in Australian higher education institutions. Given the self-report nature of the data collected, figures gathered using these indicators may underestimate the actual number of students with disabilities enrolled in higher education in Australia (Australian Institute of Health and Welfare, 2014; Brett, 2016). In addition, students with conditions such as autism are not clearly included within these indicators. As such, the exact number of autistic students enrolling in higher education in Australia continues to remain unclear (Brett, 2016).

Under the requirements outlined in the DDA and the DSE, universities in Australia must make reasonable adjustments to support the participation and learning of students with disabilities (Dickson & Cumming, 2018). To achieve this, Australian universities will typically have a Disability Services office, staffed by disability advisors who work with students with disability to identify and implement reasonable adjustments and accommodations. While universities are required to have disability support services and resources available to students, the onus is on the student to initiate contact with the Disability Services and to disclose their disability. Access to these supports is therefore dependent on the student identifying as having a disability, seeking out support, and requesting assistance. Students are also required to provide documentary evidence of their disability (e.g., diagnostic reports). Therefore, students who require assistance with their studies must possess effective self-determination and self-advocacy skills to seek and negotiate adjustments and support. This is often in contrast with students' experiences in high school, where identification and provision of educational supports is the responsibility of the education provider. To communicate a student's support needs and reasonable adjustments, disability advisors will typically develop an access plan (or similar learning support document) in

consultation with the student. The access plan will outline the impact of the student's disability on their studies, and any reasonable adjustments or accommodations they may require. The access plan is developed in consultation with the student. In most cases, the student is then responsible for providing a copy of their access plan to their relevant academic staff, again relying on students to have well developed self-advocacy skills.

The National Disability Insurance Scheme Act (2013) is one of the most significant political reforms to influence the disability sector in Australia in recent history. The full implementation of the National Disability Insurance Scheme (NDIS) was completed in 2020 and provides support to people with a disability up to the age of 65 years. The NDIS, managed by the National Disability Insurance Agency (NDIA), aims to provide reasonable and necessary supports to people with a disability, through individualised funding direct to the participant (Australian Government, 2013). A similar system using "direct payments" has been implemented in the United Kingdom (UK; Riddell et al., 2005), while elements of individualised funding have also been implemented in the United States (US; Hutchison et al., 2006; Pearson, 2012). While services and supports enabling participation in higher education remain the responsibility of higher education institutions, more general supports, such as personal care and transportation, that enable community participation, are funded under the NDIS (NDIS, 2022). Given that the full roll-out of the NDIS has only recently been completed and was undertaken in phases across the country, it is possible that some students have had extensive experience accessing NDIS funded supports, while others may have only recently had the opportunity to explore and access these, and some students may not have had access to NDIS funded supports at all.

2.3 Autistic Students in Higher Education

Internationally, the number of autistic students enrolling in higher education is increasing (Bakker et al., 2019; Barnhill, 2016), and research exploring their experiences has also been increasing significantly in recent years (Davis et al., 2021). Research suggests that autistic students experience similar difficulties in higher education as they do throughout their primary and secondary education (Lubin & Brooks, 2021). These difficulties are often described as relating to the core and associated characteristics of autism, including difficulties with social-communication, sensory processing, emotional regulation, and executive functioning (Dijkhuis et al., 2020; Lubin & Brooks, 2021). Davis et al. (2021) conducted a systematic review of experiences and supports for autistic students in higher education, as reported by students themselves. The review included studies from the US, UK, Australia, Canada, Ireland, Netherlands, and Belgium. Autistic students reported experiences of social isolation, loneliness, stress, anxiety, and depression, as well as

difficulties with executive functioning, and social communication (Davis et al., 2021). Similarly, an Australasian study conducted by Anderson et al. (2020), reported autistic students experienced difficulties with time management and organisation, social skills, adapting to change, stress and anxiety, and sensory sensitivities (Anderson et al., 2020). Autistic students in a study conducted by Gurbuz et al. (2019) in the UK reported feeling as though staff and peers demonstrated a lack of understanding and awareness of autism, leading to a lack of acceptance and inclusion for autistic students. Research also suggests that the difficulties experienced by autistic students may be exacerbated by the change in structure, routine, and expectations of higher education settings in comparison to high school (Clouder et al., 2020; Davis et al., 2021).

Research has also shown that autistic students may delay seeking assistance or support in higher education, or not seek assistance at all, often only seeking support in response to a crisis situation (Anderson et al., 2020; Cai & Richdale, 2016; Davis et al., 2021). In doing so these students may be missing out on access to reasonable and necessary adjustments to support their learning. Studies have suggested that this delay in support seeking may result from autistic students' difficulties with communication (Davis et al., 2021), or students feeling that they are not eligible or do not require supports (Anderson et al., 2020).

Autistic students commonly experience co-occurring mental health difficulties such as anxiety or depression (Lai et al., 2019). Research has shown that the mental health status of students in higher education with and without disabilities is quite poor, with many students indicating they have experienced high levels of stress and anxiety during their studies (Usher, 2020). Given the common co-occurrence of mental health issues for autistic people, it can be argued that autistic students are at an increased risk of mental health issues during their time in higher education. Increased levels of stress and anxiety among autistic students during the transition to higher education have also been reported in a number of studies (Nuske et al., 2019). Effective and timely preparation and planning has been highlighted as an important factor during the transition to higher education to minimise mental health impacts for autistic students (Nuske et al., 2019).

While autistic students may experience many challenges in higher education, they can also demonstrate skills and characteristics which can be strengths to participation in higher education. These include: open-mindedness; authenticity; love of learning; creativity; and fairness (Kirchner et al., 2016), a strong attention to detail, strong memory skills, dedication, and the ability to focus on their area of interest for extended periods of time (Russell et al., 2019; Van Hees et al., 2015). In a study conducted by Anderson et al. (2020)

autistic students reported strengths including “persistence, determination, resilience, academic knowledge, and the ability to develop strategies to cope with weaknesses” (p. 6).

Previous research has highlighted the importance of family support for autistic students during their transition to, and participation in higher education (Davis et al., 2021; Widman & Lopez-Reyna, 2020). Family members often take on an emotional support role (Cai & Richdale, 2016; Nuske et al., 2019). Anderson et al. (2020) found that family members may also assist with everyday living tasks, as well as providing academic support, advocacy, and financial support. Privacy legislation and policies designed to protect the confidentiality of the student can create systemic barriers that prevent family members from engaging with higher education staff to support their autistic family member (Nuske et al., 2019). Research suggests, this creates additional difficulties for autistic students to successfully connect with support services, especially if they have not had adequate opportunities to develop the necessary skills in self-determination, self-disclosure, and self-advocacy (Nuske et al., 2019).

2.4 Transition Models and Theories

Transition is a complex phenomenon to define. However, for the purposes of this research project it was important to identify key characteristics that define the concept of transition as it applies to the experiences of university students during their first year of studies. Three key transition models and theories have been utilised to inform the conceptualisation of transition for the purposes of the current research and are described in more detail in the following sections.

2.4.1 Transition as Induction, Development and Becoming

Gale and Parker (2014) proposed three conceptions of student transition to higher education: transition as induction (T_1), transition as development (T_2) and transition as becoming (T_3). T_1 conceptualises transition as the experience of initially entering and engaging with university. It most commonly focuses on the first year experience, suggesting that this period is crucial for student success (Gale & Parker, 2014). T_1 is often associated with ‘whole-of-institution’ approaches to transition. T_2 conceptualises transition as a shift in identity (Gale & Parker, 2014). It focuses more closely on the individual or student, rather than the organisation. This conceptualisation is most frequently associated with approaches that focus on the development of a student identity. T_3 conceptualises transition as a process of ‘becoming’ (Gale & Parker, 2014). The T_3 concept of transition highlights the importance of recognising diversity within the student cohort and rejects the notion that transition is a period of crisis. It also emphasises the fact that transition is not fixed or linear

and suggests that higher education policy and practice should embrace the diversity of students in an attempt to become more socially inclusive.

2.4.2 Transition Characteristics

According to Schlossberg (2011), transitions have distinct characteristics: a change in a person's role, relationships, routines, and assumptions, which result in a significant life change. Transitions can include both anticipated and unanticipated events; as well as events which were anticipated but did not eventuate (non-events) (Schlossberg, 2011). These core characteristics of transition are evident during a student's first year in higher education. The role of the student changes in higher education settings. Students are now expected to take on more responsibility, and undertake a new role as 'an adult learner', with students needing to be more self-directed in managing their own needs (Moriña, 2017); their relationships are likely to change; their routines are changed significantly with a new, less structured routine; and added emphasis is placed on private study tasks, and the need to plan one's time accordingly. Assumptions and understandings developed through the school years may no longer be accurate, as systems, environments and expectations may change significantly. This not only applies for students moving directly from high school to higher education, but also for those moving from employment or other daily activities into the higher education setting.

2.4.3 Transition to Higher Education

Lizzio's Five Senses of Successful Transition model (2006), later renamed the Five Senses of Success (Griffith University, 2017; Lizzio, 2011), provides a framework for describing the needs of students as they relate to their early success and engagement in higher education. The model was developed to assist in the development of quality orientation and transition strategies at the university level. The five areas as described by Lizzio include: a sense of capability, a sense of connectedness, a sense of purpose, a sense of resourcefulness, and a sense of academic culture.

A sense of capability, as described in Lizzio's (2006) model, refers to how well prepared a student is for their role as a university student and the tasks they may be required to undertake. To achieve this, students need to understand the expectations of university study, have basic academic skills, and a commitment to contributing to their academic community (Lizzio, 2006). To enable this sense of capability universities must ensure expectations and assumed knowledge are clear; provide support for the development of entry level academic skills; and engage students as active members of the university community (Lizzio, 2006).

A sense of connectedness refers to the way in which students develop connections with peers and university staff and develop a sense of belonging within their university (Lizzio, 2006). This can be supported by providing students with opportunities to develop working relationships with university staff and peers and providing opportunities for students to get involved with their university (Lizzio, 2006).

A sense of purpose refers to a student's ability to see the relevance of their learning and feeling engaged with their studies. Where a student has a strong sense of purpose, they are more likely to find study rewarding, and more likely to be committed to their studies (Lizzio, 2006). To support the development of this sense of purpose, universities should ensure that students are able to clarify their reason for attending university and their degree choice, as well as provide students with opportunities to develop their strengths and talents (Lizzio, 2006). Larsen et al. (2020) explored the effectiveness of embedding Lizzio's Five Senses model within a university transition program. They suggested that another important factor which contributes to the development of a sense of purpose is the ability to identify role models within the university, such as experts in their chosen field, that students can identify with.

A sense of resourcefulness relates to the ways in which students know how to study and how to manage challenges throughout their university experience (Lizzio, 2006). This sense depends on a student's ability to navigate university systems, and access help when needed. This includes students being aware of how to access information and support services (Larsen et al., 2020). Universities can support this sense of resourcefulness by making sure roles, procedures and resources are clear and easily accessible. According to Larsen et al. (2020) this sense also encompasses help-seeking behaviour from the student.

Finally, a student's sense of academic culture refers to the ways in which students have an understanding and value of the culture of the university. Larsen et al. (2020) also suggested that this sense ties together the previous senses, but also refers to the student's ability to understand independent learning, and academic integrity, in addition to improve their ability to think critically. In order to achieve this, students need to develop an understanding and appreciation of the university's values, and the ways in which these inform the expectations of both students and staff (Lizzio, 2006). Further development of the Five Senses model saw the sense of academic culture, reframed to a sense of identity as a university student (Griffith University, 2017; Lizzio, 2011). This sense of identity develops and evolves throughout the various stages of the student lifecycle, from 'student identity' in the early stages of their studies to 'graduate identity' as students near the end of their studies (Lizzio, 2011).

2.4.4 Definition of Transition

Elements of each of the above theories and models of transition have informed the conceptualisation of transition as it applies to this research, to ensure that it appropriately reflects the experiences of autistic students. This research has conceptualised transition as not fixed or linear, but a period of time through which students adapt and adjust to a new environment, with changes to identity, as well as new expectations and requirements. Additionally, it acknowledges the significant role changes not only for the student, but for those supporting them in their transition to university. In line with Gale and Parker's (2014) T₃ concept of transition, this research also recognises the need for higher education policy and practice to embrace inclusivity and the diversity of the student cohort. Throughout this research the concept of transition has focused on the "first year"; however, the use of this term has been left intentionally fluid to reflect the more flexible, and potentially extended experience of "first year" for autistic students.

2.5 The First Year Experience

There is an increasing awareness that the first year of higher education is critical to student success and retention (Bell et al., 2017; Kift, 2008, 2015; Moriña, 2017). As Kift (2015) noted: "The cost of early student departure - for institutions, individuals, professions and societies across a spectrum of reputational, ethical, personal, economic and legal implications - is at its highest in the first year of university." (p. 53). Therefore, a successful transition is important not only for students themselves, but also for higher education institutions. Researchers also agree that the first year in higher education can be particularly difficult for many students (Freixa-Niella et al., 2019), including students with a disability (Moriña, 2017).

Research investigating the experiences of students in their first year in higher education has been increasing in recent years, as the diversity of the student population has also increased (Brooker et al., 2017). The challenges faced by students in their first year is different for each student, but difficulties in time management, managing expectations, and student workload appear to contribute to these challenges (Brooker et al., 2017). Difficulty with the transition to university has been identified as a factor that may play an imperative role in the risk of non-completion for autistic students (Cage et al., 2020).

2.6 Chapter Summary

The first part of this chapter has provided an overview of literature relating to disability in higher education nationally and globally. While policies, legislation and

government directives have been implemented to improve the participation rates and inclusion of students with disabilities, there is still work to be done to improve the experiences of students with disabilities, including autistic students, in higher education.

The second part of this chapter has presented an overview of literature relating to the experience of first year, as well as an overview of transition models and theories relevant to the current research, highlighting core characteristics of transition reflected in this research. Transition is also highlighted as critically important to supporting successful participation for a diverse range of students. The following chapter presents the bioecological theory model which has been used as the theoretical framework throughout this research project.

3 THEORETICAL FRAMEWORK: BIOECOLOGICAL THEORY MODEL

This chapter presents an overview of the bioecological theory model (Bergen, 2008; Bronfenbrenner, 1979; Bronfenbrenner & Morris, 2006), the theoretical framework that was used throughout this research. A theoretical framework provides a critical lens through which the phenomenon of interest can be examined and is an important epistemological element of interpretive phenomenological inquiry (Mayoh & Onwuegbuzie, 2015). The bioecological theory model provided the lens through which the complexity of the transition experience for autistic students was explored and understood in more detail to address the overarching research question.

3.1 Background

The bioecological theory model was originally proposed and developed by Urie Bronfenbrenner in 1979 to explore human development (Bergen, 2008). It highlights the importance of the interaction between individual (person) characteristics; the interactions (processes) or activities the person engages with; the environment within which these experiences take place (contexts); and the time during which these experiences occur (Bronfenbrenner & Morris, 2006).

At the centre of the bioecological theory model sits the individual, surrounded by four systems of elements which interact with and influence the individual and their experience. The microsystem level identifies key people and settings that directly interact with the individual, while the mesosystem describes the interactions which occur between two or more of these microsystem elements (Bergen, 2008; Bronfenbrenner, 1979). Settings and elements not directly related to the individual, but that may impact on the individual's development indirectly are identified at the exosystem level. Finally, the macrosystem encompasses elements at a broader cultural and societal level which may also impact on or influence the individual (Bergen, 2008; Bronfenbrenner, 1979). In later revisions of the model, Bronfenbrenner added a fifth system, the chronosystem, which provides the historical and chronological setting or time period within which these systems exist (Bronfenbrenner & Morris, 2006). In refining the bioecological theory mode, Bronfenbrenner emphasised the importance of the interactions and interrelationships between each of the systems and the individual.

3.2 Application to the Current Research Project

The bioecological theory model provides a framework for exploring ecological transitions in human development throughout the lifespan. Bronfenbrenner identified these ecological transitions as times when a person's situation is altered due to changes in their "role, setting, or both" (Bronfenbrenner, 1979, p. 26). In the context of transition to higher education there is a clear change in setting, as higher education settings differ significantly from the traditionally more routine and structured environment of high school. Similarly, students face a significant change in their role, with an increase in expectations, particularly in relation to their role as an adult learner; with higher education students expected to self-advocate, independently seek support, and in some cases live independently for the first time (Zeedyk et al., 2016).

The bioecological theory model was used as the theoretical framework underpinning the researcher's systematic literature review (Nuske et al., 2019) of the extant literature within this area (see Chapter 4). The model, along with the findings from this systematic literature review, was then used to guide the development of the design, method, and research tools (survey and interview questions) used within this research. It was also utilised as a lens through which the lived experience of autistic students during their transition to university was examined. Understanding the complexities and processes that exist within these system elements enabled close examination of the complex, and often interacting factors that influenced the transition experiences of participants.

Utilising a framework such as the bioecological theory model when researching the experiences of students with a disability in higher education settings enables the researcher to develop a more comprehensive understanding of the proximal and distal influences on the students' experiences (Kimball & Thoma, 2019). Pinder-Amaker (2014) previously utilised the bioecological theory model as a framework for exploring autistic students' experiences of secondary and post-secondary education; however, the current research is the first to apply this model to the experiences of autistic students during their transition to higher education. Figure 3.1 provides a visual representation of the model as it has been utilised throughout the current research and outlines the various system elements identified in the bioecological theory model as they apply to autistic students within an Australia university context.

In the context of the current research, the autistic student exists at the centre of the model (individual). The student brings to the transition experience their own personal characteristics, such as their personal disposition, past experiences, and personal

resources. Autistic students also bring to this transition experience their own individual autistic characteristics, that each autistic person will experience in their own unique way.

In addition to these individual characteristics, broader contextual elements also influence the student's experience during this transition period. These broader external elements exist within the microsystem (people such as family and peers, and settings within which the individual engages); the mesosystem (the interactions between these microsystem elements); the exosystem (broader settings within which events may occur that could impact on the individual, such as state and national legislation and institutional policies and practices); and the macrosystem (societal and cultural elements, such as cultural views of inclusive education, and societal understanding of autism) (Bergen, 2008; Bronfenbrenner, 1979). The time element (chronosystem) of the bioecological theory model is also important to highlight. This element, less prominent in Bronfenbrenner's earlier iterations of the model (Bronfenbrenner & Morris, 2006), is now recognised as a critical component of the bioecological theory model. The model explains that the effect of external processes on an individual's development are influenced not only by the interaction between the characteristics of the individual themselves and the environment in which these experiences occur, but also in response to the social and cultural changes across the individual's life course and the "historical period during which the person has lived." (Bronfenbrenner & Morris, 2006, p. 798).

While elements at the individual, microsystem and mesosystem level are relatively common across most geographical locations, there are differences between Australian and international settings at the exosystem level. For example, the Disability Discrimination Act and the Disability Standards for Education will influence the experience of autistic students at an Australian university. In addition, the recent implementation of the NDIS may also influence the experiences of autistic students at an Australian university, as students who are participants of the NDIS may be accessing additional external support services.

For the purposes of this research the release of the discussion paper "A Fair Chance for All" (Dawkins, 1990) has been identified as a key chronosystem element. The paper (see Section 2.2 for more details) was a key influence on institutional policy changes, prompting an increased focus on widening participation objectives for higher education institutions nationally. It can be seen as the foundation for disability supports as they exist in higher education in Australia today. By highlighting the elements at each of these system levels, the bioecological theory model provides a lens through which the researcher can explore the experience of transition to university in Australia for autistic students, while acknowledging

the social and cultural context and timeframe within which these experiences have taken place.

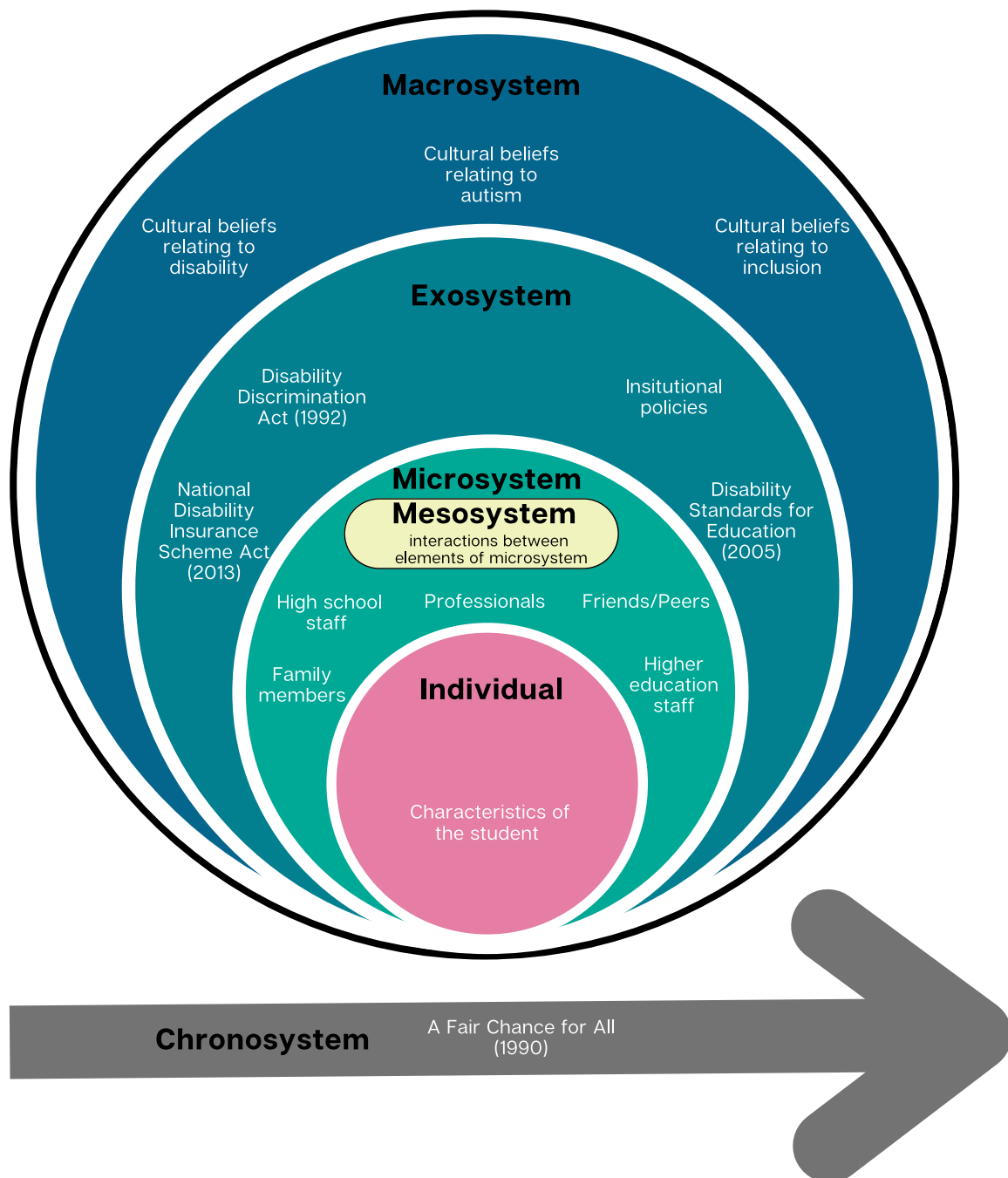


Figure 3.1: The bioecological theory model in the Australian higher education context. Adapted from Pinder-Amaker (2014).

3.3 Chapter Summary

This chapter has provided an overview of the bioecological theory model and described its application in the context of this research project, including as the theoretical framework for the systematic literature review. The chapter has provided an outline of the system elements within the model and their relationship to the experiences of transition to, and first year of university for autistic students. The following chapter will present a systematic review of the existing literature exploring experiences of transition to higher education for autistic students.

4 SYSTEMATIC LITERATURE REVIEW

This chapter presents a systematic review of the literature exploring transition to university for autistic students, to provide an understanding of the extant literature addressing this phenomenon. A systematic literature search and review was conducted to examine the existing literature relating to transition support for autistic students internationally. This systematic review has been published in “Nuske, A., Rillotta, F., Bellon, M., & Richdale, A. (2019). Transition to higher education for students with autism: A systematic literature review. *Journal of Diversity in Higher Education*, 12(3), 280”¹ (see Appendix A for the published version) and was used to prepare this chapter. AN contributed 80% to the research design, 80% to the data collection and analysis and 80% to writing and editing of the manuscript. Co-authors MB, FR and AR collectively contributed 20% to the research design, and 20% to the editing the manuscript. Co-author MB contributed 20% to data collection and analysis (see Appendix B for Co-authorship Approvals Form).

The manuscript has been formatted to remain consistent with the formatting for this thesis, as per the requirements of Flinders University’s Higher Degree by Research (HDR) thesis rules. There is direct overlap in content and phrasing with the published version. In addition, as required by Flinders University’s HDR thesis rules, the following modifications from the published version have been made to avoid unnecessary repetition:

- The abstract has been removed.
- Paragraphs one to four of the introduction have been removed, as the relevant introductory information has already been presented in Chapter 2.
- Paragraphs two and three of the section “Bioecological theory and transition to higher education” have also been removed as the relevant information is presented in Chapter 3.
- Table and Figure captions, headings and formatting, and references to Tables and Figures, have been modified to ensure consistency with the overall thesis.

Person-first language is used throughout the systematic literature review, in line with the APA requirements for publication at the time.

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4.1 Introduction

There is a wide range of literature on the barriers to, and facilitators for individuals with ASD while undertaking studies in higher education (Barnhill, 2016; Brown & Coomes, 2015; Knott & Taylor, 2014; Kuder & Accardo, 2018; VanBergeijk et al., 2008). However, there is a paucity of research that has focused specifically on the transition period. In addition, there are limited studies that explore the experiences of individuals with ASD in higher education directly (Anderson & Butt, 2017; Baric et al., 2017; Bell et al., 2017; Cai & Richdale, 2016; Madriaga & Goodley, 2010; Mitchell & Beresford, 2014; Van Hees et al., 2015).

Literature investigating the experiences of students with disabilities in higher education has highlighted a range of difficulties and barriers. For students with ASD, many of these difficulties relate to the need for self-disclosure, self-awareness, and a desire to “fit in”, often resulting in a delay in seeking or accessing disability support services (Adreon & Durocher, 2007; Bell et al., 2017; Cox et al., 2017). As Hewitt (2011) highlights, this may in fact be the first time that the student has been required to advocate for themselves in order to access supports or accommodations. Disclosure to Disability Services is the first step in successfully accessing services and supports (Rocco, 2001); however, research has shown that some students may be reluctant to disclose their disability (Adreon & Durocher, 2007; Anderson et al., 2018; Shattuck et al., 2014), and this may result in delayed access to services. For this reason, a broad definition of ‘transition’ has been considered for this review, to encompass the transition into and the first year of studies in higher education.

Family members, in particular parents, play a significant role in supporting and advocating for an individual with ASD, especially during their primary and secondary educational years (Volkmar et al., 2014). Previous studies exploring needs and facilitators for individuals with ASD attending higher education have also highlighted the importance of family support in the pursuit of higher education (Anderson & Butt, 2017; Bell et al., 2017; Cai & Richdale, 2016; Dymond et al., 2017; Peña & Kocur, 2013; Simmeborn Fleischer, 2012; Zeedyk et al., 2016). However, research exploring the experiences of parents or other family members during the transition to higher education for students with ASD is lacking. Therefore, studies that have examined the perspectives of family members during this transition have also been included within this review.

The experiences of students with disabilities in higher education have been an expanding area of focus in educational research in recent years (Lang, 2015). There has also been an increase in the number of studies focused on the experiences of students with

ASD enrolled in higher education. A number of systematic reviews into these experiences had been conducted between 2012 and 2017, the five years prior to when the present systematic review was undertaken (Anderson et al., 2017; Gelbar et al., 2014; Toor et al., 2016; Zeedyk et al., 2016), with varying focus and purpose. In particular the study conducted by Toor et al. (2016), examined the literature on the experiences of students with ASD, their family members and staff in the higher education setting. This review identified the facilitators, obstacles, and needs of individuals with ASD in accessing higher education. While not specifically focused on transition itself, it highlights the transition period as a significant aspect of students' successful participation in higher education. The latest article reviewed by Toor and colleagues, was published in 2015. Since this time, several additional studies have been conducted exploring these experiences for students with ASD and their family members. In addition, the study conducted by Toor et al. (2016) excluded studies with a quantitative or mixed methods design. While the purpose of only including studies with a qualitative design was to ensure that all included studies had directly explored the experiences of individuals with ASD in this transition process, exclusion of mixed methods studies may have resulted in relevant qualitative data being excluded from their evaluation. In order to gather a wide range of literature on the subject, the current review has therefore included articles with a qualitative or mixed methods approach to ensure qualitative discussion of experiences are not overlooked.

Another review, conducted by Sims (2016), was geographically limited, only including research conducted within the United Kingdom. While differences in educational practice between the UK and other countries was cited as the reason for this limited geographical scope, one can argue that, given the paucity of literature on the subject, a systematic review of studies conducted with an international perspective is warranted. Regardless of systemic differences between various countries' higher education systems, the needs and experiences of individuals with ASD and their families are likely to be similar across international boundaries. This in turn can assist in the development of recommendations for best practice globally and identification of areas for future research.

As a result of the increase in the number of students with ASD likely to be enrolling in higher education, and the growing research being undertaken in this area, it is critical for higher education institutions (HEIs) to develop an in depth understanding of the experiences of these students in order to implement best practice transition support strategies. Systematic review methodology is designed to do just this; provide an analysis and synthesis of current available knowledge within a specific area. Bearman et al. (2012) highlight the benefits of systematic review methodology, in particular as it relates to the

higher education sector and acknowledges the limited uptake of this methodology within this setting. While Bearman et al. (2012) recognise the challenges in undertaking this methodology, they also identify the importance of the systematic review in potentially increasing the quality of future research conducted in the field.

4.1.1 Aim

The first aim of this review is to provide an update of current research, with a focus on the transition experiences of students with ASD, and the experiences of their family members during this time.

An additional aim was to further understand the experiences of individuals with ASD and their family members in their transition to higher education, in order to inform best practice strategies for supporting students with ASD in their first year in higher education. The review question is: What are the experiences of individuals with autism spectrum disorder and/or their family members regarding transition to higher education?

From the available literature on transition to higher education for students with ASD, there does not appear to be a standard practice or approach to transition or orientation to university for students with ASD. In policy development and implementation, it is important to consider the views of those effected by these decisions; therefore, the goal of this systematic literature review is to provide an analysis and synthesis of available studies that have investigated the experiences of students with ASD and/or their family members. This will provide an important insight into these experiences, which in turn can help to inform future policy and intervention decisions in relation to this complex transition process. To better understand the complex systems and interactions involved in this transition process, a bioecological systems theory (Bronfenbrenner, 1979) framework has been adopted to explore and describe the outcomes of the studies reviewed.

4.2 Methods

A systematic review was conducted following the PRISMA guidelines (Moher et al., 2009). Systematic searches were conducted across six databases during August of 2017: Medline, CINAHL, ProQuest limited to articles only, PsycINFO, Scopus and Informit.

Searches were conducted using a combination of free text and subject headings terms (such as MeSH terms) and were combined using Boolean operators. Examples of subject heading terms are provided in Table 4.1 and Table 4.2. The free text search terms used included synonyms for each keyword such as: Autism spectrum disorder OR Asperger;

higher education OR further education OR tertiary education OR post-secondary education OR university OR college; transition.

The primary focus of this review was on studies that included a qualitative component to their investigation of the experiences of individuals with ASD or their family members in their transition to higher education. For this reason, mixed-methods studies were included in order to ensure that relevant articles or experiences were not overlooked. Articles were excluded if they contained less than 10% qualitative data on the experiences of individuals or their family members in the transition to higher education. Articles were also excluded if less than 10% of the participants had ASD or were the family member of an individual with ASD. Articles in which less than 10% of the data described transition experiences (i.e., commencing in higher education, first year of higher education) were also excluded.

References returned through the search strategy outlined above were downloaded into the systematic review software Covidence. Using this software, articles were screened by title and abstract, by two independent reviewers (AN and MB). Where there was uncertainty about whether a specific article met the eligibility criteria, the full article was included for detailed review against the inclusion criteria. Conflicts were resolved through discussion between the two reviewers and an agreement was made as to the inclusion of these articles.

The same reviewers conducted an autonomous review of the full text versions of potentially relevant studies using the eligibility criteria outlined above. Reviewers recorded reasons for exclusion using the Covidence software. Any disagreements in determining eligibility of an article was resolved by discussion between the two reviewers. Reference lists of all articles selected were also hand searched to identify additional articles for inclusion. Hand searches were conducted in two key journals in ASD and in disability and diversity in higher education: Focus on Autism and Developmental Disabilities; Journal of Autism and Developmental Disorders; Journal of Diversity in Higher Education and Journal of Further and Higher Education.

Table 4.1: Medline search terms

1.	Exp Autistic Disorder/
2.	Exp Autism Spectrum Disorder/ or exp Asperger Syndrome/
3.	(autis* or asperger* or ASD or ASC).tw.
4.	1 or 2 or 3
5.	Exp Universities/
6.	Exp Vocational Education/
7.	(universit* or college* or higher education or further education or post-secondary education or postsecondary education or post secondary education or tertiary education or TAFE or vocational education).tw.
8.	5 or 6 or 7
9.	(transition* or prepar*).tw.
10.	4 and 8 and 9

Table 4.2: PsycINFO Search Terms

1.	exp Autism Spectrum Disorders/
2.	(autis* or asperger* or ASD or ASC).tw.
3.	1 or 2
4.	exp COMMUNITY COLLEGES/ or exp COLLEGES/
5.	exp Higher Education/
6.	(universit* or college* or higher education or further education or post-secondary education or postsecondary education or post secondary education or tertiary education or TAFE or vocational education).tw.
7.	4 or 5 or 6
8.	exp SCHOOL TRANSITION/ or exp TRANSITION PLANNING/
9.	(transition* or prepar*).tw.
10.	8 or 9
11.	3 and 7 and 10

4.2.1 Bioecological Theory and Transition to Higher Education

Previous literature reviews conducted within this area have not used a theoretical framework in analysing study findings; however, given the complex elements involved in the transition to higher education for individuals with ASD, the bioecological theory model (see Chapter 3) provides a useful framework for exploring these experiences in more depth. Therefore, studies examined in the current systematic review will be discussed using the bioecological theory model as a framework to consider the impact of the complex and interrelated systems within which the student engages.

As Pinder-Amaker (2014) highlights, a complex interaction occurs in the student's educational environment, between the individual, family members, educational staff, and other professionals (*mesosystem*); relevant policies and legislation (*exosystem*); and cultural and societal beliefs about the inclusion of individuals with ASD (*macrosystem*), which may impact directly on outcomes for the individual when they commence higher education. In addition, these elements may be influenced by significant changes in history during the individual's lifespan (*chronosystem*), for example, the adoption of the UN Conventions on the Rights of Persons with Disabilities (United Nations, 2006).

Adapted from Pinder-Amaker's (2014) example of the bioecological theory model of development applied to individuals with ASD in education, Figure 4.1 illustrates specific elements of each of these systems as they apply to individuals with ASD, in the higher education setting.

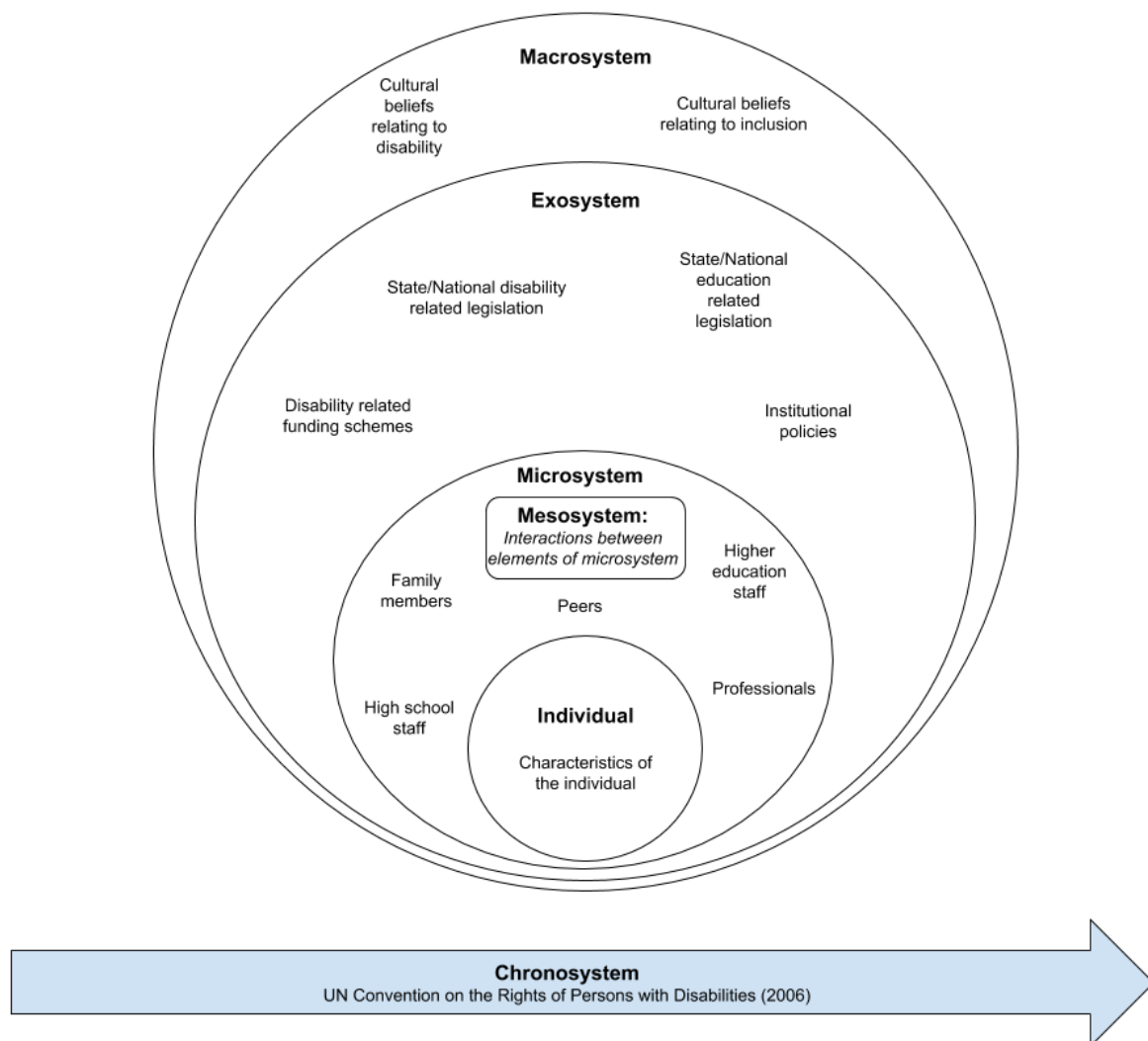


Figure 4.1: Bioecological theory model of transition to higher education (adapted from Pinder-Amaker, 2014).

4.3 Findings

Database searching resulted in the identification of 587 studies after duplicate removal and screening (refer Figure 4.2). An additional 10 studies were identified through hand searching reference lists and journal indexes. Following title and abstract screening 526 articles were excluded as they did not meet inclusion criteria. A further 60 articles were excluded during full-text article review for the following reasons: not primary research study (32); not focused on transition (10); not focused on higher education (5); not a qualitative study (4); no or less than 10% inclusion of individual or family perspectives (4); wrong population (i.e. less than 10% of participants were individuals with ASD or family members) (3); focus on pre-transition expectations (1). After independent review and consensus by AN and MB, 11 articles were agreed upon for inclusion within this review.

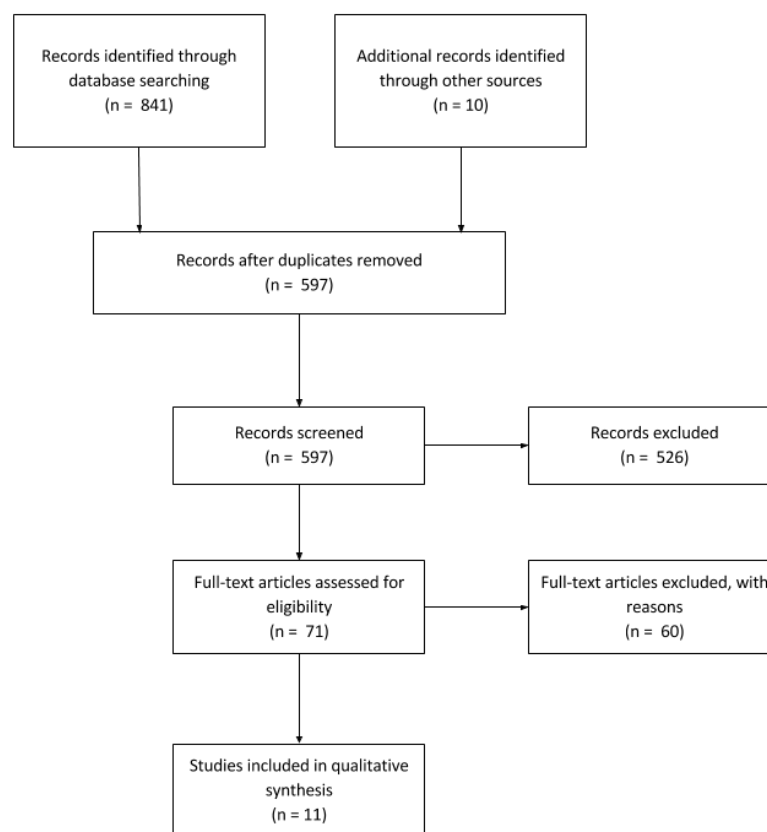


Figure 4.2: PRISMA flow diagram for articles identified through database searches.

4.3.1 Quality of Study Methodology.

Using the McMasters Critical Review form: Qualitative Studies (Letts et al., 2007), articles that met the inclusion criteria were assessed for methodological quality by two reviewers (AN and MB). The studies reviewed ranged in quality score from 11 to 19 points (maximum possible score 21), on the McMasters critical appraisal tool (see Table 4.3). Of

these 11 studies, the highest score (19), was achieved by two studies (Baric et al., 2017; Dymond et al., 2017), with one study scoring only 11 points (Peña & Kocur, 2013).

Two studies had evidence of a clearly described decision trail supporting auditability of the studies (Baric et al., 2017; Dymond et al., 2017). Only three studies clearly identified a theoretical perspective within which their studies were framed (Alverson et al., 2015; Baric et al., 2017; Madriaga & Goodley, 2010) and only three studies clearly identified the assumptions and biases of the researcher/s (Baric et al., 2017; Dymond et al., 2017; Madriaga & Goodley, 2010). The two studies with the lowest quality scores (Madriaga & Goodley, 2010; Peña & Kocur, 2013) did not address rigour in data collection strategies and demonstrated limited evidence of trustworthiness.

4.3.2 Study Characteristics

Articles within this review were all published between 2010 and 2017. Four studies were conducted in the United States (US), two in the United Kingdom (UK), two in Sweden, one in Belgium, one in the Republic of Ireland and one in Australia. An overview of the studies is presented in Table 4.4.

Study designs included grounded theory (Anderson & Butt, 2017; Madriaga & Goodley, 2010; Van Hees et al., 2015), phenomenology (Alverson et al., 2015; Baric et al., 2017), naturalistic inquiry (Peña & Kocur, 2013) and case study (Simmeborn Fleischer, 2012). Data were collected using interviews in 10 of the studies and by focus groups in one study. Four studies did not specifically state a study design (Bell et al., 2017; Cai & Richdale, 2016; Dymond et al., 2017; Mitchell & Beresford, 2014).

Participant characteristics are outlined in Table 4.5. There were a total of 180 participants across the eleven studies, of these a total of 158 participants were individuals with ASD or family members of individuals with ASD. Other participants included staff; individuals with a diagnosis other than ASD; or individuals who were not attending a HEI. These participants have not been discussed in this review. A total of 92 individuals with ASD (M=71, F=21) participated in the studies reviewed. Parents made up a total of 64 participants, across 10 of the studies, with one study (Alverson et al., 2015) including an unclear number of family members as participants. Only two studies included a sibling of an individual with ASD as a participant.

Table 4.3: McMaster University Critical review form – qualitative studies

Criteria (McMaster University Critical Review Form)	Alverson et al., 2015	Anderson & Butt, 2017	Baric et al., 2017	Bell et al., 2017	Cai & Richdale, 2016	Dymond et al., 2017	Madriaga & Goodley, 2010	Mitchell & Beresford, 2014	Peña & Kocur, 2013	Simmeborn Fleischer, 2012	Van Hees et al., 2015
Was the purpose and/or research question stated clearly?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Was relevant background literature reviewed?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Was a theoretical perspective identified?	Y	N	Y	N	N	N	Y	N	N	N	N
Was the process of purposeful selection described?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Was sampling done until redundancy was reached?	NA	NA	NA	NA	NA	Y	NA	NA	NA	N	NA
Was informed consent obtained?	Y	Y	Y	Y	Y	Y	Y	Y	NA	Y	Y
Clear & complete description of participants?	Y	Y	Y	Y	Y	Y	N	Y	Y	N	Y
Role of researcher & relationship with participants?	N	N	N	N	N	N	N	N	N	N	N
Identification of assumptions & biases of researcher?	N	N	Y	N	N	Y	Y	N	N	N	N
Procedural rigour was used in data collection strategies?	Y	Y	Y	Y	Y	Y	NA	Y	NA	Y	Y
Data analyses were inductive?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Findings were consistent with & reflective of data?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Decision trail developed?	NA	NA	Y	NA	NA	Y	NA	NA	NA	NA	NA
Process of analysing the data was described adequately?	Y	Y	Y	Y	Y	Y	NA	Y	Y	Y	Y

Table 4.3: continued

Criteria (McMaster University Critical Review Form)	Alverson et al., 2015	Anderson & Butt, 2017	Baric et al., 2017	Bell et al., 2017	Cai & Richdale, 2016	Dymond et al., 2017	Madriaga & Goodley, 2010	Mitchell & Beresford, 2014	Peña & Kocur, 2013	Simmeborn Fleischer, 2012	Van Hees et al., 2015
Did a meaningful picture of the phenomenon under study emerge?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Credibility	Y	Y	Y	N	Y	Y	N	N	N	Y	Y
Transferability	Y	Y	Y	Y	Y	Y	N	Y	Y	N	Y
Dependability	Y	Y	Y	Y	Y	Y	N	Y	N	Y	Y
Confirmability	Y	Y	Y	N	Y	Y	Y	Y	N	Y	Y
Conclusions were appropriate given the study findings?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Findings contributed to theory development & future practice/ research?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Total	17	16	19	14	16	19	12	15	11	14	16

Table 4.4: Overview of studies included in review

Study (Design)	Method(s)	Future research recommendations	Limitations
Alverson et al., 2015 (Phenomenology)	Semi-structured interviews (twice, 6-12 months apart) <i>(protocol derived from special education, transition & ASD literature)</i> Family background questionnaire + field notes	More extensive longitudinal & experimental studies.	Small sample size. Sample selection represents only one portion of those with ASD (prior to 2013 diagnostic criteria change). Participants from narrow demographic. No longitudinal data to explore college completion.
Anderson & Butt, 2017 (Grounded theory)	Unstructured interviews Open-ended questions	Larger, more diverse samples. Investigate practices, policies & programs associated with success.	Small convenience sample. Only included white, high income. Limited number of young adults with ASD (7) included.
Baric et al., 2017 (Hermeneutical)	Semi-structured interviews Open-ended questions	To understand preparatory transitional activities & services during compulsory school which support move to employment or enrolling in HE.	Limited number of participants with ASD in university studies setting. All participants from community-based vocational training centres. Only individual view (parents, teachers not included).
Bell et al., 2017 (Not stated)	Semi-structured interviews (twice, pre-transition & post-transition)	Tracking students through post-secondary education to identify quality of transition process, appropriateness of support, & whether students become socially integrated.	Limited scope

Table 4.4: continued

Study (Design)	Method(s)	Future research recommendations	Limitations
Cai & Richdale, 2016 (Not stated)	Semi-structured focus groups (9 with students, 6 with family members) <i>(themes derived from literature relating to needs of students with ASD in higher education)</i>	Research into providing appropriate educational support & into social supports.	
Dymond et al., 2017 (Not stated)	Questionnaire Semi-structured interviews <i>(questions derived from literature relating to post-secondary students with disabilities & information gathered from university support staff)</i>	Explore whether experience of parents (and university personnel) consistent with experiences of students with ASD. Case studies of specific students + parents + university personnel + support providers. Examine perspective through lens of students with ASD themselves. Examine relationship between university experience & post-university outcomes.	One large public research university with a history of providing disability accommodations. Only parents of students registered with Disability Services eligible to participate. Small sample size Unable to include students with ASD due to insufficient number of participants. Researchers undertaking study affiliated with the university being investigated.
Madriaga & Goodley, 2010 (Grounded theory/Dialectical & cyclical)	Interviews (over 12 month period)		
Mitchell & Beresford, 2014 (Not stated)	Semi-structured interviews. <i>(Topic guides piloted with young people with ASD)</i>	Explore cost effectiveness of school/college links, extended visits to college campus.	Self-selecting sample. Presence of parents/carer during approx. half of interviews.

Table 4.4: continued

Study (Design)	Method(s)	Future research recommendations	Limitations
Peña & Kocur, 2013 (Naturalistic inquiry/emergent design)	Semi-structured interviews.	Include voice of students with ASD to understand transition from their point of view.	Sample only included highly-educated, middle-class families from one county. Did not include voice of students with ASD.
Simmeborn Fleischer, 2012 (Case study)	Interviews. <i>(Interview guides based on interviews with young people with ASD participating in main study)</i>		Small sample size.
Van Hees et al., 2015 (Grounded theory)	Semi-structured interviews	Examine perspectives of parents, disability service providers, informal support networks. Parent's potential role in student transition to HE. Use of standardised measures of anxiety & stress. Development of intervention services which are evidence based & can moderate impact of mental health issues.	Possible selection bias. Self-report qualitative data.

Table 4.5: Overview of Participant Characteristics

Study	Location	Number of participants					Characteristics of Individuals with ASD*					HE setting
		Total	Individuals with ASD in Higher Ed.	Family member			Age (Mean)	Gender	Diagnosis	Confirmation of diagnosis		
				Parent	Sibling	Other						
Alverson et al., 2015	US	5	5	unclear	0	0	21	M=5	ASD=1 AS=4	Medical diagnosis	4 year university=1 Community college=4	
Anderson & Butt, 2017	US	25	7	18	0	0	22.9	M=14 F=4	Autism=1 AS=13 PDDNOS=2 ASD (other)=2	Parent report, no medical confirmation	4 year college (graduated)=4 2 year college (attending)=5 4 year college attending=4 2 year college (left)=2 2 or 4 year college (left in crisis)=5	
Baric et al., 2017	Sweden	15	2	0	0	0	25.5	M=1 F=1	AS=2	Formal diagnosis	University studies	
Bell et al., 2017	Republic of Ireland	8	6	2	0	0	18	M=6	ASD	Not stated	Further education College=4 University/Institute of Technology=2	
Cai & Richdale, 2016	Australia	38	23	14	1	0	26	M=16 F=7	ASD	Formal diagnosis	University=15 TAFE (college)=8	

Table 4.5: continued

Study	Location	Number of participants					Characteristics of Individuals with ASD*					HE setting
		Total	Individuals with ASD in Higher Ed.	Family member			Age (Mean)	Gender	Diagnosis	Confirmation of diagnosis		
				Parent	Sibling	Other						
Dymond et al., 2017	US	16	0	10 (2 father, 6 mother, 1 mother + father pair)	0	0	Not stated	M=9	ASD	Registered with university Disability Services	University	
Madriaga & Goodley, 2010	UK	8	8	0	0	0	(between 18 and 30)	M=5 F=3	AS	Registered with university Disability Services	University	
Mitchell & Beresford, 2014	UK	18	18	0	0	0	18.6yrs	M=14 F=4	HF autism/ AS	Self-reported	College	
Peña & Kocur, 2013	US	18	0	18 (2 father, 16 mother)	0	0	Not stated	Not stated	AS Autism PDDNOS	Not stated	Community college	
Simmeborn Fleischer, 2012	Sweden	6	0	2 (1 father, 1 mother)	1	0	Not stated	M=3	Not stated	Not stated	Not stated	
Van Hees et al., 2015	Belgium	23	23	0	0	0	(between 18 and 25)	M=17 F=6	Autism AS PDD-NOS	Medical diagnosis	University=1 University colleges=2	

*Characteristics of individual with ASD whose experience is being explored within the study (includes individuals with ASD as participants, and individuals about whose experience family members had reported on).

Key findings from each of the studies were categorised according to the bioecological theory model discussed earlier and are presented in Table 4.6. Results indicate the experiences of transition to higher education by individuals with ASD and their family members are complex and varied and are now examined within the framework of the bioecological theory model.

4.3.2.1 Individual.

4.3.2.1.1 Challenges Related to the Characteristics of ASD.

Six studies described issues related directly to the core characteristics of ASD. Challenges reported during the transition to higher education included: social communication difficulties (Bell et al., 2017; Cai & Richdale, 2016; Dymond et al., 2017; Mitchell & Beresford, 2014; Van Hees et al., 2015); sensory processing difficulties (Cai & Richdale, 2016; Simmeborn Fleischer, 2012; Van Hees et al., 2015); and the need for structure and routine (Cai & Richdale, 2016; Van Hees et al., 2015). Difficulties related to characteristics associated with ASD included: executive functioning difficulties (Cai & Richdale, 2016; Dymond et al., 2017; Simmeborn Fleischer, 2012; Van Hees et al., 2015); and difficulties with independent living skills (Dymond et al., 2017; Mitchell & Beresford, 2014; Simmeborn Fleischer, 2012).

While challenges experienced by students with ASD were similar across a number of studies, two studies also highlighted the importance of considering the difference in manifestation of these core characteristics of ASD for each individual (Alverson et al., 2015; Madriaga & Goodley, 2010). Strengths and unique skills associated with the core characteristics of ASD, such as strong memory, dedication, focus, and an eye for detail were also highlighted by Van Hees et al. (2015).

4.3.2.1.2 Self-awareness/Disclosure.

Self-awareness and disclosure were also identified as key requirements for transition to higher education and were highlighted across five studies (Alverson et al., 2015; Cai & Richdale, 2016; Dymond et al., 2017; Peña & Kocur, 2013; Van Hees et al., 2015). Alverson et al. (2015) found that levels of self-awareness varied significantly among participants. Issues relating to disclosure across the studies reviewed included: doubts about the benefits of disclosing (Van Hees et al., 2015), deficits in self-determination skills or initiative to seek help (Dymond et al., 2017; Peña & Kocur, 2013), or a lack of acceptance to seek support until a crisis or significant challenge had arisen (Cai & Richdale, 2016; Van Hees et al., 2015).

4.3.2.1.3 Mental Health and Emotional Wellbeing.

Experiences of increased levels of stress and anxiety were reported by participants across five studies (Anderson & Butt, 2017; Baric et al., 2017; Cai & Richdale, 2016; Mitchell & Beresford, 2014; Van Hees et al., 2015). In addition, preparation for transition, and timely, appropriate support was recommended in order to minimise negative impacts on mental health and wellbeing (Baric et al., 2017; Cai & Richdale, 2016; Van Hees et al., 2015).

4.3.2.2 Microsystem

At the microsystem level, individuals with ASD described within these studies had support from family members, as well as professionals and staff within both the secondary school and post-secondary education settings.

4.3.2.2.1 Family Support.

All 11 studies addressed the significant role played by parents during the transition period. Family members were reported as playing a significant role in providing emotional and psychosocial support to individuals with ASD during this transition period (Baric et al., 2017; Cai & Richdale, 2016; Dymond et al., 2017; Mitchell & Beresford, 2014; Van Hees et al., 2015). Three studies also described parents taking on an active role in supporting their son or daughter with disclosing or initiating access to support services (Bell et al., 2017; Cai & Richdale, 2016; Peña & Kocur, 2013).

4.3.2.2.2 Professional Support.

Participants in three studies described positive experiences associated with professionals involved in the transition process (Bell et al., 2017; Cai & Richdale, 2016; Mitchell & Beresford, 2014). Participants who took part in the study conducted by Mitchell and Beresford (2014) described professionals as undertaking two specific roles: (1) supporting and engaging with planning, and (2) providing information. The participants reportedly valued support provided by professionals who were honest, reliable, provided information that was clear and easy to understand (written and verbal), and who had a knowledge and understanding of ASD. The importance of professional's knowledge of ASD was also echoed by parents in Pena and Kocur's (2013) study. Parents within this study reported feeling that faculty members were unprepared for students with ASD and lacked awareness or knowledge of the disability.

4.3.2.3 Mesosystem.

At the mesosystem level, studies demonstrated the importance of effective collaboration between all elements of the microsystem, including family members, professionals, and educational staff.

4.3.2.3.1 Collaboration.

Six studies highlighted the importance of secondary schools, families and higher education staff working collaboratively together (Alverson et al., 2015; Anderson & Butt, 2017; Baric et al., 2017; Cai & Richdale, 2016; Dymond et al., 2017; Simmeborn Fleischer, 2012) to support the transition process.

4.3.2.4 Exosystem.

Issues related to the exosystem level were noted in six studies (Alverson et al., 2015; Anderson & Butt, 2017; Cai & Richdale, 2016; Dymond et al., 2017; Peña & Kocur, 2013; Van Hees et al., 2015). These issues predominantly revolved around the impact of legislation relating to transition and higher education.

Issues related to the influence of policy and legislation were most commonly present in US studies. Difficulties were associated with the implementation of transition support programs or services as outlined within the Individuals with Disabilities Act (IDEA) (2004). While it is a requirement of IDEA to implement a formal post-secondary transition plan (VanBergeijk et al., 2008), experiences of these processes varied greatly (Alverson et al., 2015; Anderson & Butt, 2017; Dymond et al., 2017). Where participants experienced effective formal transition support they developed clear post-secondary goals, eventually leading to successful adaptation and adjustment to higher education (Alverson et al., 2015; Dymond et al., 2017). However, some participants described transition services which did not provide this same level of coordination, experiencing a lack of formal planning, or effective follow up of goals and plans (Anderson & Butt, 2017; Dymond et al., 2017). Australian participants reported similarly varied experiences (Cai & Richdale, 2016). Where formal transition planning was not evident, students consequently felt unprepared for the transition to higher education (Cai & Richdale, 2016). In Ireland, where formal transition planning is not mandated, formal transition planning was lacking (Bell et al., 2017). Transition to higher education or work was not specifically included in the participant's individual education plans, and in some cases this resulted in students needing to find alternative pathways into higher education as the result of undertaking courses that did not lead directly to higher education opportunities.

Another exosystem element, which affected the experiences of students and family members within three of these studies, was that of privacy legislation (Cai & Richdale, 2016; Dymond et al., 2017; Peña & Kocur, 2013). A number of parents reported barriers presented by the implementation of privacy and confidentiality policies within higher education settings in response to legislative requirements. While these policies are implemented to protect the individual's privacy and confidentiality, it is also evident that individuals with ASD rely heavily

on support from family members, in many cases to assist them in the process of disclosure, as required in order to access necessary supports and reasonable adjustments (Bell et al., 2017; Cai & Richdale, 2016; Peña & Kocur, 2013). In addition, Mitchell and Beresford (2014) found no evidence that support provided by family members was unwelcome, which raises the question of whether this legislation may in fact be creating unnecessary barriers for students with ASD transitioning to higher education.

4.3.2.5 *Macrosystem and Chronosystem.*

Discussion of macrosystem and chronosystem elements of student experiences was absent in these studies. Only three studies included within this review were from the UK or Australia, where individualised payment systems are already in place, it is interesting to note that none of the participants described experiences associated with supports accessed through these systems.

Table 4.6: Overview of key concepts within each study categorised using the bioecological theory model

Study	Individual			Micro-system	Meso-system	Exo-system	Macro-system	
	Characteristics of ASD	Self-awareness and Disclosure	Mental Health and Wellbeing	Family Support	Professional Support	Collaboration	Transition Prog/Planning Privacy Legislation	Not addressed
Alverson et al., 2015		x		x		x	x	x
Anderson & Butt, 2017			x	x		x	x	x
Baric et al., 2017			x	x		x		x
Bell et al., 2017	x			x	x			x
Cai & Richdale, 2016	x	x	x	x	x	x	x	x
Dymond et al., 2017	x	x		x		x	x	x
Madriaga & Goodley, 2010				x				x
Mitchell & Beresford, 2014	x		x	x	x			x
Peña & Kocur, 2013		x		x	x		x	x
Simmeborn Fleischer, 2012	x			x		x		x
Van Hees et al., 2015	x	x	x	x			x	x

4.3.3 Methodological Limitations of Studies Reviewed

Scores on the McMasters Critical Review Form: Qualitative Studies (Letts et al., 2007) varied significantly. A clearly defined theoretical perspective was missing from all but three of the included studies, and only two studies clearly identified assumptions and potential bias of the researcher/s conducting the study. Further research using a clearly defined theoretical perspective and acknowledgement of existing assumptions or bias may help to improve the quality and interpretability of the research conducted.

The studies included in this review all had relatively small sample sizes, which while appropriate to the case study methodology used in most, provided only a limited snapshot of the experiences of individuals with ASD transitioning to higher education. Participants in a number of studies were also recruited from relatively narrow demographic groups (e.g., white, high income, middle class), which significantly limited the generalisability of the results. In over half of the studies, participants were only eligible if they could provide evidence of a formal diagnosis or if they had already registered with their institution's disability service. Therefore, individuals who identified as having ASD but had not received a formal diagnosis were not represented in these studies. The majority of studies also only explored the perspectives of one group (individual, family, or staff/professionals), and did not compare these perspectives simultaneously. Only three studies included perspectives of both the individual and family members concurrently (Anderson & Butt, 2017; Bell et al., 2017; Cai & Richdale, 2016). Concurrent exploration of these perspectives may have helped to clarify the issues experienced and determine whether the perspectives of individuals with ASD and other members of their support network are in fact similar. The inclusion of siblings was also minimal, with only two studies including a sibling when exploring perspectives of family members (Cai & Richdale, 2016; Simmeborn Fleischer, 2012).

4.4 Discussion

This systematic literature review extends upon previous research in the experiences of individuals with ASD in higher education. In addition, this review utilised the bioecological theory model to examine in detail, the experiences of individuals with ASD, and their family members, during the transition to higher education. The following discussion will explore these findings in more detail, with consideration of the ways in which the various elements of the bioecological theory model within which this transition exists, interact to impact on the experiences of the individual and their family member.

4.4.1 Bioecological Theory and Experiences of Higher Education.

Findings from these studies suggest the core and associated characteristics of ASD may create additional challenges for students with ASD when transitioning to higher education. In particular, difficulties associated with social-communication skills, executive functioning skills and independent living skills may result in students needing supports and accommodations beyond those typically provided within higher education. In addition, the differences in manifestation of these characteristics of ASD for each individual (Alverson et al., 2015; Madriaga & Goodley, 2010) will necessitate an individualised approach to supports provided.

Regardless of diagnosis, no two individuals will have the same difficulties, experiences or needs. This is particularly the case for individuals with ASD who may exhibit the core and associated characteristics of ASD across a broad spectrum. Students with ASD are often provided with traditional adjustments such as additional time in exams or tests, or an alternative setting within which to sit these assessments, yet these adjustments may be inappropriate or may not effectively address the specific needs of this population (Barnhill, 2016; Brown & Coomes, 2015; VanBergeijk et al., 2008). For higher education to be truly inclusive, institutions need to go beyond providing these traditional adjustments, and consider the needs of the individual, to ensure all students can participate fully within their educational setting. The need for individualised approaches to support strategies was also noted in the studies included within this review. For example, in the study conducted by Madriaga and Goodley (2010) not all participants felt that accommodations provided, were necessary or appropriate. Some participants felt that the accommodations they received benefited them, for example having a separate location for sitting their exams or test, allowed them to access adjustments without having to disclose or explain their reasons for accessing these to their peers; however, others felt that these arrangements resulted in feelings of segregation.

Similar to recommendations made by Kuder and Accardo (2018), this review highlighted the importance of the provision of adjustments and supports which are individualised and address the non-academic needs of individuals with ASD. In order to appropriately address the diverse needs of individuals with ASD, early engagement with relevant disability service staff within the HEI is critical in order to identify and implement effective and relevant adjustments and supports in a timely manner. However, as studies within this review have identified there are a number of individual and systemic (exosystem) barriers which may make this process more challenging for individuals with ASD.

In order to access supports and accommodations within higher education, a student must first identify and acknowledge their need for these supports. Students must then disclose their disability to relevant staff in order for supports and adjustments to be identified and implemented (Adreon & Durocher, 2007; Rocco, 2001; Zeedyk et al., 2016), yet some students with ASD may not identify as having a disability (Shattuck et al., 2014). Consistent with the findings of Anderson et al. (2018), some participants within the studies reviewed, delayed disclosing their disability to academic or professional staff within their HEI. Whether the decision to delay disclosure is made due to difficulties with understanding or navigating the process, or is a conscious choice by the individual, the delay in disclosing and accessing support may impact on the individual's overall higher education experience (Anderson et al., 2018). The need to develop skills in self-advocacy and self-disclosure prior to commencing higher education has been highlighted in previous literature (Barnhill, 2016; Elias & White, 2017). However, it appears these difficulties continue to pose challenges, and there remains a gap between the skills of individuals with ASD in disclosing and self-advocating, and the expectations of the HEIs within which they are enrolling. While emphasis should continue to be placed on developing effective self-advocacy skills prior to commencing higher education, perhaps HEIs should consider new strategies for engaging with students with ASD who are transitioning into higher education, to provide a more effective mechanism for self-disclosure and consequently accessing relevant support and accommodations they may require. Providing online mechanisms for disclosure and registration with disability support services within HEIs or developing formal processes which allow for effective parental support in the early stages of transition, may help to address some of these disclosure related difficulties.

As Pinder-Amaker (2014) suggests, the transitional years moving from secondary to post-secondary education, are a "peak period of onset of major psychiatric illnesses" in typically developing individuals (p. 126). The transition to higher education has also been associated with an increase in stress and anxiety levels for students with ASD (VanBergeijk et al., 2008). It is therefore not surprising that the mental health and wellbeing of students, was highlighted within a number of the studies reviewed. Cai and Richdale (2016) suggest effective early preparation and planning, which ensures timely access to supports, is important in minimising the increases to stress and anxiety, which are commonly reported by individuals with ASD during this transition period. This was a recommendation also supported by Baric et al. (2017) and Van Hees et al. (2015). It would appear that formal transition planning is linked to better adjustment and wellbeing in the transition to higher education; however, even in the US, where this was mandated through legislation, it was not always implemented consistently or effectively. This demonstrates a significant gap between legislation (exosystem) and implementation (individual/microsystem). As such, there is

clearly a need for further investigation of how this legislation is being implemented, with the aim of developing more effective links between the legislative requirements and implementation of these programs to improve the transition and adjustment of students with ASD to higher education.

Support from family members, in particular parents, was by far the most common microsystem element described by participants within these studies. Parents were seen to be providing supports such as 'coaching' and 'encouraging' (Peña & Kocur, 2013). Other supports provided by parents included coordination of the transition process, help with organisation, and financial support (Alverson et al., 2015; Cai & Richdale, 2016; Dymond et al., 2017; Mitchell & Beresford, 2014). These findings further demonstrate the complex interaction between the individual and their support networks, which exist within the microsystem level, to support effective transition to higher education.

In addition to family members, participants also reported receiving support from professionals in roles across both the secondary school (e.g., career guidance, teaching staff) and higher education settings (e.g., Disability Services staff, counselling, faculty staff). In some situations, participants also described support provided by other external support services (e.g., therapists, psychologists or counsellors).

Similar to disclosure, collaboration can only occur when the student has acknowledged and accepted the need for assistance (Simmeborn Fleischer, 2012). Collaboration between family members and HEI staff was also made more difficult as the result of barriers imposed by relevant privacy legislation and institutional policies (Cai & Richdale, 2016; Dymond et al., 2017; Peña & Kocur, 2013). Elements such as these, at the exosystem level appear relatively distant from the individual, yet their impact on the individual and their support networks can be significant. As Lester (2014) points out limited research has been conducted into how individuals view and make sense of the relevant policies and programs that have been developed to support their post school transitions. This is therefore a key area for further consideration in future studies.

Pinder-Amaker (2014) noted, societal beliefs about inclusion and resulting emphasis placed on inclusive practice within higher education may impact on individuals with ASD at the macrosystem level. However, experiences related to macrosystem elements were not discussed in the studies reviewed. While historical events, such as the adoption of the UNCRPD may have influenced the experiences of students with disabilities in higher education in recent years, these chronosystem elements were also not discussed by participants within the studies reviewed, therefore warranting further exploration.

4.4.2 Strengths and Limitations.

This systematic literature review included five major strengths. For the first time it: (1) included an examination of the perspectives of both students with ASD and their family members; (2) included a purposive focus on the experience of transition to higher education; (3) included qualitative data from mixed methods studies; (4) was conducted within a theoretical framework, the bioecological theory model (Bronfenbrenner, 1979); and (5) used the McMasters Critical Review form: Qualitative Studies (Letts et al., 2007) to evaluate the quality of the studies reviewed.

This review also extended upon the studies included in the systematic review by Toor et al. (2016), with five articles in the current review published since 2016. The focus on transition experiences specifically and the inclusion of family members were also unique to the present review.

Nevertheless, there are some limitations, which should be acknowledged. While the critical appraisal tool used to evaluate the included studies provided a valuable method of assessing the quality of the studies, it did not necessarily allow for more in depth consideration of methodological differences among studies. The review was also limited to an exploration of published, peer reviewed research articles. Additional, potentially relevant data from theses and published reports, were excluded from this review. Given this is a rapidly expanding area of investigation these additional sources may have provided additional, valuable information.

4.4.3 Recommendations for Future Research

Recommendations for future research identified within the included studies are outlined in Table 4. Recommendations focused on conducting longitudinal studies to explore outcomes of transition support and social integration; investigating the experiences of individuals with ASD during their transition and studies in higher education; and exploring the concurrent experiences of students, staff and family members. Given these recommendations, and the limitations of these studies, future research should consider a larger and more diverse participant group, exploring experiences across a broad range of HEIs. Longitudinal studies should also be considered, to further explore strategies and experiences that are related to successful outcomes for students with ASD transitioning into higher education. The lack of research providing data on outcomes for students with ASD in higher education is also highlighted in recent reviews conducted by Kuder and Accardo (2018) and Zeedyk et al. (2016). Future research may need to examine the impact of transition processes, support and accommodations on longer-term outcomes for students

with ASD in higher education. It should also explore the perspectives of individuals, family members, professionals and educational staff in order to develop a deeper understanding of the needs and experiences of individuals with ASD during this transition process. Given the complex nature of this transition experience, bioecological theory model provides a valuable framework for further exploration of these experiences.

While a number of studies identified challenges directly linked to the core characteristics of ASD, interestingly, there was limited use of comparison groups within these studies. Further exploration and comparison to other commencing student cohorts may help to more clearly identify those experiences unique to students with ASD. Van Hees et al. (2015) also suggested further exploration of the impact of mental health issues using standardised measures would provide the opportunity for further examination of the impact of comorbid conditions such as anxiety and depression on the transition process for individuals with ASD. Studies comparing the experiences of students with ASD to those of students without ASD, both with and without anxiety may provide additional clarification concerning the contribution of these co-occurring conditions.

4.4.3.1 Implications for Practice.

It is important for those who work to support students with disabilities in the higher education setting to be aware of the complex interaction of elements, which affect the transition experiences for individuals with ASD. Consideration needs to be given to the challenges faced by individuals with ASD and their family members during this transition process. For individuals with ASD these challenges may relate to the core characteristics and associated characteristics of, and comorbid conditions associated with ASD; however, it is important to also acknowledge the unique strengths and skills which these students also possess. It is imperative that an individualised approach is taken, to ensure accommodations provided are effective and appropriate to meeting the specific needs of each student (Anderson et al., 2018; Barnhill, 2016; Brown & Coomes, 2015; Cai & Richdale, 2016; Madriaga & Goodley, 2010; Van Hees et al., 2015). While traditional supports and accommodations available for students with disabilities may benefit some students with ASD, others may find these to be unnecessary or irrelevant to their specific needs. This may require consideration of implementing social communication and organisational support strategies beyond those typically provided to commencing students in higher education. This finding reiterates previous recommendations which suggest students with ASD in higher education may require supports beyond those typically provided for students with disabilities which consider both academic and non-academic skills (Gelbar et al., 2014; Kuder & Accardo, 2018). An individualised approach may not only apply to the accommodations

made for students once they have enrolled and commenced their studies. Individualised and targeted transition support opportunities may also be beneficial for individuals and their family members when preparing for and undertaking the transition to higher education.

Ideally, staff who provide disability support and services within HEIs should provide a first point of contact for students with ASD who are seeking adjustments or accommodations to engage with their studies. These staff should have a sound knowledge and understanding of ASD and the needs of these students, and should provide information in a clear and easy to understand format. The provision of this information in a written format may provide students with a valuable opportunity to discuss this information with their relevant support networks such as family members or professionals in order to better identify and voice their needs for support within the higher education setting. Implementing these strategies and providing the opportunity for simple and effective disclosure to occur, is likely to lead to supports and strategies being implemented in a timely and efficient manner. However, as Cai and Richdale (2016) point out, this may require the provision of additional staff, and thus an increase in funding for disability support services within higher education.

As highlighted in this review, consideration must be given to the difficulties students with ASD may experience in expressing and discussing the challenges they face or the supports they require when commencing higher education studies. Disability service staff within HEIs may need to consider developing an alternative approach to providing assistance to students with ASD during this transition period. This approach must be a careful balance between the student's right to privacy, confidentiality, and self-determination, and the identified need for additional parental or family support in accessing services to manage difficulties they may experience during their transition to higher education. Ways in which family members of students with ASD can be involved in the transition process without interfering with the growth and development of the student as an adult learner within the higher education setting also need to be addressed. Developing a new approach may appear challenging when faced with institutional policies and privacy legislation; however, delays in seeking the required support and adjustments to successfully engage in higher education may have a detrimental effect on these students' higher education experience.

The varied experiences of transition support programs described by participants within these studies highlights the need for effective programs to facilitate the transition of students with ASD into higher education. Further exploration of existing transition support programs and identification of key stakeholders in this area may help to define and improve future transition support practices. Transition programs developed collaboratively between the secondary education and higher education setting, may also be beneficial.

4.5 Conclusion

The present review updates our insights into a rapidly expanding and significant area of research investigating the experiences of students with ASD who are transitioning to higher education. Additionally, this review explored the experiences of family members, in supporting students with ASD during this period. By examining the perspectives of individuals and their family members using the bioecological theory model, this review demonstrates the complex interactions, which impact on the experiences of students with ASD in their transition to higher education. A deeper understanding of the experiences of individuals with ASD and their families during this transition period to higher education, will allow HEIs to consider more targeted and effective approaches to transition for these students. This will lead to more effective and successful transition experiences for individuals with ASD who are commencing their studies in the higher education setting and inform more inclusive practices for supporting these students.

4.6 Chapter Summary

This chapter has presented a published systematic literature review of qualitative literature relating to transition of autistic students to higher education. The transition to university can be a difficult experience for all students, but research suggests it can be particularly challenging for autistic students. The systematic review provides a summary of existing understanding of transition to higher education for autistic students and highlights the lack of literature in this area.

Chapters 2 and 4 have demonstrated the critical importance of positive experiences in the first year and the need for effective transition practices to support the retention and success of all students. Although research exploring the experiences of autistic students in higher education has been increasing in recent years, there remains a lack of research into the experiences of autistic students and their support networks during the transition period. Therefore, the current research addresses this gap by exploring the experiences of autistic students, their family members, and staff during the transition to, and first year of university. There is also a significant gap in the literature in relation to the experiences of autistic university students within Australia. The present research therefore adds to existing understanding of the experiences of autistic university students in Australia. The following chapter details the rationale, research question, and objectives for this study, along with outlining the philosophical and methodological underpinnings of this research project.

5 METHODOLOGY

This chapter provides details of the philosophical foundations and methodology that informed this research project, to explore the facilitators and barriers to transition for autistic university students. Firstly, this chapter outlines the rationale, research question and objectives, followed by an overview of phenomenological approaches to qualitative research. The qualitative research approaches, Interpretative Phenomenological Analysis (IPA) and Reflexive Thematic Analysis (RTA), used within this study are then presented. The chapter also presents an outline of the researcher's perspectives and assumptions, along with the ontological and epistemological assumptions underpinning the research.

5.1 Rationale

This research used a qualitative, phenomenological approach to address a gap in the academic literature, identified through a systematic literature review (presented in Chapter 4), specifically examining the experiences of transition to university for autistic students in Australia. As noted in previous chapters, while the number of studies exploring strategies for supporting autistic students at university has been increasing in recent years, the supports and strategies identified in these studies were only available to students after they had successfully engaged with, and accessed disability supports within their university (Nuske et al., 2019). This highlights the importance of research which explores the transition to university to ensure students have timely access to relevant support. Within her own professional experiences, the researcher has also identified a lack of clear recommendations and guidelines for disability practitioners in higher education to support the successful transition to university for autistic students.

As discussed in Chapters 2 and 4, autistic students may receive support from a family member or professional during their transition to university. However, as highlighted in the systematic literature review (presented in Chapter 4), barriers exist that make providing this assistance challenging. It is therefore important to understand the role these support networks play in the transition to university. For this reason, the lived experiences of a range of stakeholders (family, academic and professional university staff, and support workers) were also examined in this research.

Limited research has been conducted into the experiences of autistic students during their transition to university (Nuske et al., 2019). In particular, there is a paucity of literature exploring the transition to university for autistic students in Australia specifically (Nuske et

al., 2019). This research project addresses this gap by exploring in detail the experiences of autistic students and their support network during the transition to and first year of university.

5.2 Research Question and Objectives

The overarching research question for this research project was: What are the facilitators and barriers to transition to university for autistic students in Australia? This was addressed by considering the following three research objectives:

1. To explore the experiences of autistic students during their transition to, and first year of university;
2. To explore the experiences of family members supporting autistic students during their transition to, and first year of university;
3. To explore the experiences of university staff supporting autistic students during their transition to, and first year of university.

5.3 Research design

To address the research question and objectives outlined above the research project included two components, (1) online surveys (student, family member, university staff) and (2) case studies involving interviews with students and members of their support networks. Figure 5.1 provides an overview of the data collection methods and analytic approach used to address each of the research objectives, along with the chapters in which these analyses have been presented. The first component of this research comprised three online surveys (student, family member, university staff) which were administered using Qualtrics online survey platform (www.qualtrics.com). Section 6.3.1.1 provides further details of the development and implementation of the survey component of this research. Survey data were analysed using RTA (see Section 6.5 for detailed description of analysis) and are presented in Chapter 10.

The second component of this research involved semi-structured interviews undertaken with eight autistic university students, a family member of an autistic university student, four university staff, and one support worker. Data from the semi-structured interviews with students were analysed using IPA (see Section 6.5 for detailed description of analysis), presented in Chapters 7 and 8. Data collected from semi-structured interviews with support network members (family, support worker, and university staff) were analysed using RTA (see Section 6.5 for detailed description of analysis) and are presented in

Chapter 9. A discussion of the overall findings and their relationship to existing literature is then presented in Chapter 11.

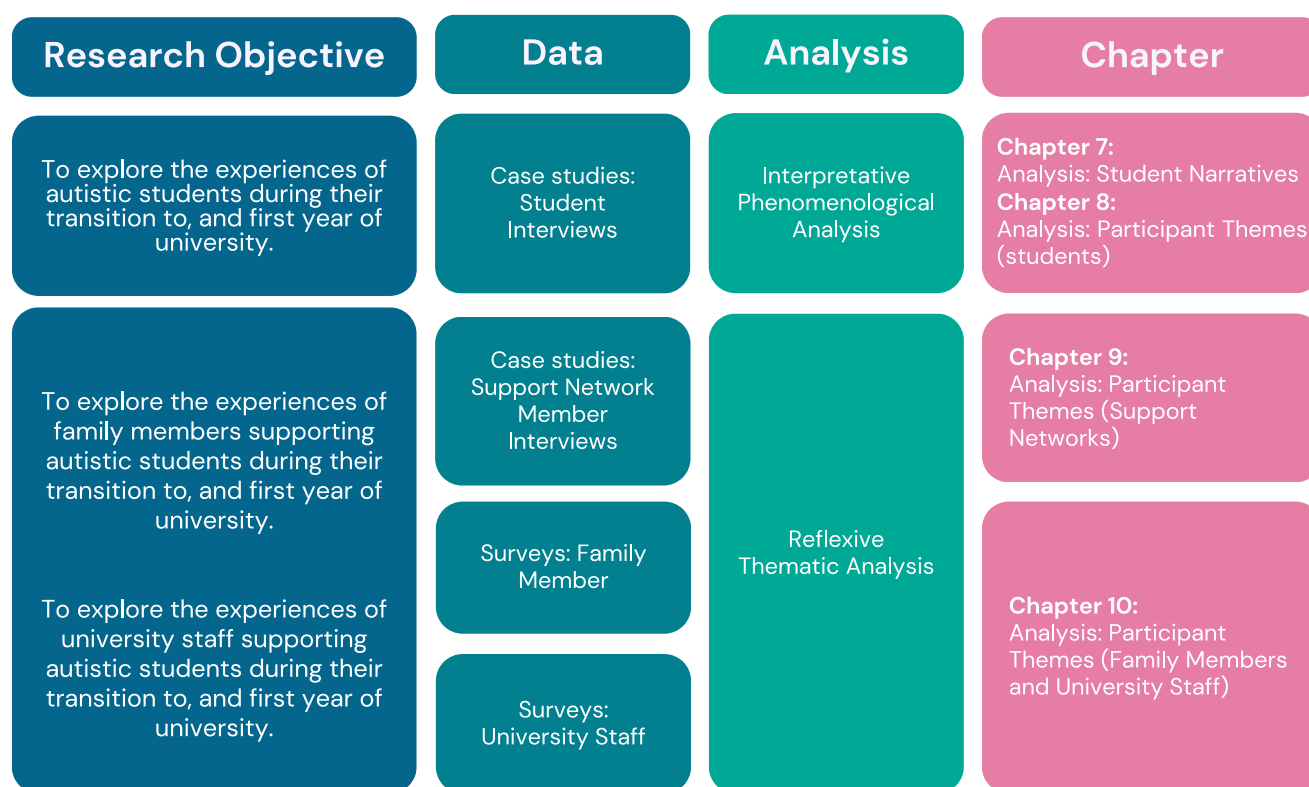


Figure 5.1: Overview of data collection methods and analytic approaches.

5.4 Qualitative Research

A qualitative research approach was primarily utilised for data collection to address the research objectives. Qualitative research does not assume there is one version of reality; instead, it argues that there are multiple versions of reality, which are directly linked to the context within which they occur (Braun & Clarke, 2013). Qualitative research is also not focused on measurement of specific and standardised data, as is found in quantitative studies (Braun & Clarke, 2013; Patton, 2002). Instead, qualitative research enables the researcher to explore meaning, by “capturing some aspect of the social or psychological world” (Braun & Clarke, 2013, p. 20). A qualitative approach allows the researcher to study issues in depth, enabling them to capture detailed information from participants, in their own words, in order to develop a deeper understanding of a particular phenomenon as participants have experienced it (Patton, 2002). As such, a qualitative approach was appropriate for this research as it enabled the researcher to explore the experiences of transition to, and first year of university from the perspectives of autistic students. It also

enabled the researcher to explore the experiences of individuals who have provided support to autistic students during this transition period. In addition, qualitative research approaches can provide detailed understanding of current issues and perspectives, to inform the development of nuanced policy and practice recommendations.

There is a wide range of approaches that could be used within qualitative research, with varied and nuanced focus and purpose. For example, grounded theory aims to generate a theory or explanation of a particular process, action, or interaction, which is grounded in the data (Creswell & Poth, 2018). Ethnographic approaches, on the other hand, enable the researcher to develop a holistic view of a particular culture or group of people through observation and immersion within that culture or group (Creswell & Poth, 2018). In contrast, phenomenology is focused on understanding the essence of participants' lived experience through engagement with individuals who have experienced a particular phenomenon (Creswell & Poth, 2018). Given the objective of this research to understand the experiences of transition to, and first year of university for autistic students and their support networks, phenomenology was identified as the most appropriate qualitative research approach for this project.

5.4.1 Phenomenology

Phenomenology is one approach to qualitative research which enables the researcher to develop a deeper understanding of the lived experience of a particular phenomenon of interest (Creswell & Poth, 2018; Mayoh & Onwuegbuzie, 2015; Van Manen, 1990). Phenomenological research is primarily focused on describing or interpreting human experiences as they have been lived by the experiencer in such a way that these experiences can be used as qualitative evidence (Mayoh & Onwuegbuzie, 2015). As such, phenomenological research is well suited to addressing the research objectives outlined above.

The phenomenological approach requires the researcher to first identify a phenomenon of interest (Creswell & Poth, 2018). In the current research this phenomenon was the experience of transition to, and first year of university for autistic students. After identifying the phenomenon of interest, the researcher must collect data from those individuals who have direct lived experience of the phenomenon (Creswell & Poth, 2018). The people identified as having lived experience of this phenomenon were autistic students. The researcher also wanted to understand the experiences of people who provide support to autistic students during their transition to university. As such, family members, and university staff were also identified as having lived experience of this phenomenon. In the current research, data collection was undertaken using online surveys with open-ended questions

and interviews. The data were then analysed to develop an understanding of how this phenomenon is experienced by those who have lived it (Creswell & Poth, 2018). In this research, analysis was conducted using two approaches to qualitative analysis. Interpretative Phenomenological Analysis (IPA, Smith et al., 2009, 2022) was used to undertake detailed in-depth analysis of data collected from autistic students, and Reflexive Thematic Analysis (RTA, Braun & Clarke, 2006, 2022) was used to analyse data collected from support network members.

There are two primary approaches to phenomenological research; descriptive, based on the work of Edmund Husserl (1859 - 1938), and interpretive (hermeneutic) based on the work of Martin Heidegger (1889 - 1976) (Creswell & Poth, 2018; Mayoh & Onwuegbuzie, 2015). Both descriptive and interpretive approaches to phenomenology acknowledge that there are multiple constructions of reality; however, their views on how this reality can be known and understood by the researcher differ. The following sections provide an overview of each of these approaches to phenomenological research.

5.4.1.1 Descriptive Phenomenology.

Descriptive phenomenology assumes that reality is in fact internal to the person who has experienced the phenomenon; that although a person's experiences are subjective there are features of this experience that are common to all who have had the same experience (Mayoh & Onwuegbuzie, 2015; Neubauer et al., 2019). Descriptive phenomenology also assumes that the researcher can develop a subjective, bias-free understanding of the phenomenon, which is achieved by bracketing out the researcher's own subjectivity throughout the data collection and analysis process (Neubauer et al., 2019). To do this the researcher must acknowledge their own values and biases, and attempt to put these aside, in order to ensure they arrive at a descriptive understanding of the "essence of the phenomenon", as it exists for all who have experienced it (Mayoh & Onwuegbuzie, 2015; Neubauer et al., 2019).

5.4.1.2 Interpretive (hermeneutic) Phenomenology.

Interpretive phenomenology, also known as hermeneutic phenomenology (Neubauer et al., 2019), is based on the ontological assumption that a person's context and personal frames of reference influence their construction of reality (Mayoh & Onwuegbuzie, 2015). That is, that one's own lived experience is based on their own interpretation of this experience within the context of their own "lifeworld" (Neubauer et al., 2019, p. 92). In contrast to descriptive phenomenology, interpretive phenomenology believes that the researcher cannot remove themselves from the world within which the research is taking place (Mayoh & Onwuegbuzie, 2015; Neubauer et al., 2019). Therefore, rather than

attempting to take an unbiased approach to the data by purely bracketing off the researcher's own subjective perspective, interpretive phenomenology openly acknowledges the preconceptions the researcher may bring to the data, and reflection on the researcher's assumptions and preconceptions form part of the data analysis process (Neubauer et al., 2019).

The interpretive phenomenological approach was identified as appropriate for the present research, as it acknowledges the complex contextual factors which influence the transition experiences of autistic students. It also acknowledges the researcher's own past experiences, knowledge, expertise, and values, which are in fact considered valuable contributions in guiding the exploration of the phenomenon (Mayoh & Onwuegbuzie, 2015; Neubauer et al., 2019). The use of an interpretive phenomenological approach within the current work enabled the researcher to acknowledge and reflect on the influences of her own professional and personal experiences throughout the study, which are described in more detail in Section 5.8.

5.5 Approaches to Data Collection

The following sections provide an overview of the methodological approaches to data collection used within this research. Data collection was undertaken using qualitative online surveys as well as case studies to explore participants' experiences during the transition to university.

5.5.1 Online Surveys

The use of online surveys as a qualitative research tool can provide the opportunity to gather rich and complex data, yet they remain a relatively uncommon tool in qualitative approaches (Braun et al., 2020). Braun et al. (2020) argued that qualitative surveys provide researchers the opportunity to access diverse perspectives, from a range of people familiar with the experience under investigation. Online qualitative surveys also provide an opportunity to access a wider diversity of individuals, from geographically dispersed locations, while still gaining a rich insight into each individual's perspective or experience (Braun et al., 2020). This is particularly useful in studies that are exploring an area that has been traditionally un- or under-explored (Braun et al., 2020). Given that limited research has been conducted into the experiences of autistic students during their transition to university, and the researcher sought to explore a diverse range of experiences of this phenomenon, surveys with a qualitative focus were identified as appropriate tools for data collection.

Where anonymity is guaranteed, online qualitative surveys may also result in participants being willing to disclose information that they may be hesitant to disclose in a one-to-one interview setting (Braun et al., 2020). Online surveys are also a low cost and efficient data collection method that provides participants with the opportunity to undertake the survey at a time and place appropriate and convenient for them (Evans & Mathur, 2005). The online nature of this method was seen as a significant strength when attempting to engage autistic participants. As Davidson (2008) stated “[t]he Internet has been shown to be an appropriate and unusually accommodating medium for those on the spectrum” (p. 802). It provides a predictable, and virtual space for engaging in online activities, allowing participation for autistic people who may also be experiencing social isolation. Therefore, online surveys provided an opportunity for participation in the research in a way that may be more familiar and accessible than in-person methods such as interviews (Davidson, 2008). These strengths were important considerations when deciding to use this data collection method.

5.5.2 Case Studies

Case studies enable the researcher to gather data from participants to provide a deeper understanding of their real-life experiences of a specific phenomenon (Creswell & Poth, 2018). Case studies in IPA research enable a detailed analysis of “particular instances” of lived experience (Smith et al., 2009, p. 37). This detailed analysis enables the IPA researcher to make a significant contribution to the existing research into a particular phenomenon of lived experience. The use of case studies also enables the reader to examine each case from their own perspective and experiential knowledge base to consider how the findings may apply to their own professional practice or research interests (Smith et al., 2009, 2022). In the current research, case study methodology enabled utilisation of multiple sources of information to explore, in detail, the real-life experiences autistic students and their support networks during the transition to university. Case studies not only enabled gathering of in-depth information from autistic students themselves, but also enabled the gathering of information from additional sources, such as people in the student’s support network, and documentation used to support the student during their studies.

The inclusion of support network members (e.g., family, staff) within the case study component of this research was not for the purpose of validating or confirming student experiences. Instead, support network members were included to explore their experiences of providing support in more detail, which enabled the researcher to explore facilitators and barriers to transition for autistic students across each level of the bioecological theory model. Data were collected from support network members using semi-structured interviews. Semi-

structured interviews give participants the opportunity to provide their own rich and detailed accounts of their experiences (Braun & Clarke, 2013; Smith et al., 2009), which is particularly important for phenomenological research.

5.6 Approaches to Analysis

The use of IPA (Smith et al., 2009, 2022) was identified as an appropriate research methodology for addressing research objective one. IPA was appropriate due to its core focus on the lived experience and understanding of a phenomenon (such as a major transition in ones' life) from the perspective of those who have experienced it (Larkin et al., 2006; Smith et al., 2009). This methodology has also been effectively implemented in research which includes autistic people as research participants (Treweek et al., 2019). Research objectives two and three were addressed by analysing the data collected from interviews with members of autistic students' support network, and online (staff and family) surveys. The data were analysed using RTA (Braun & Clarke, 2006, 2022), which aligned with the overall interpretive phenomenological approach of the research.

Reflexivity is an important aspect of qualitative research (Braun & Clarke, 2013). The use of IPA within the current research supported this reflexivity as it enabled the researcher to engage in a cyclic and detailed process of analysis, which acknowledged the researcher's own personal lived experience as an autistic individual. The use of IPA also provided the researcher with the opportunity to reflect on her own preconceptions and experiences and note how these interacted with the process of analysis. This became particularly relevant as the researcher was also in the process of navigating her own autism diagnosis during this time (see Section 5.8 for further details of the researcher's positionality). Similarly, RTA was selected to address research objectives two and three as it provided the researcher with an opportunity to look across students' support networks, whilst also providing the opportunity for ongoing reflexivity and meaning making throughout the analysis (Braun & Clarke, 2022).

5.6.1 Interpretative Phenomenological Analysis (IPA)

At its core, IPA is focused on understanding lived experience. IPA research draws upon elements of phenomenology, hermeneutics, and idiography (Eatough & Smith, 2017; Smith et al., 2009, 2022; Smith & Shinebourne, 2012) to better understand participants' sense-making of their experiences (Smith et al., 2009). Unlike other qualitative approaches to analysis, such as thematic analysis, IPA provides the researcher with the opportunity to explore cases idiographically, enabling a depth of analysis of each case, prior to exploring more general themes across cases. Using this idiographic approach enabled the researcher to highlight the individual experiences of each student, privileging their voices in telling their

stories. It also enabled the researcher to respect and acknowledge the heterogeneity (Fletcher-Watson & Happé, 2019) among autistic participants and reflect on this throughout the analysis.

Drawing on the works of Heidegger in further developing interpretive (hermeneutic) phenomenology, IPA acknowledges that our understanding of a particular phenomenon is arrived at through an interpretive process undertaken by both the participant (experiencer) and the researcher (Braun & Clarke, 2013; Eatough & Smith, 2017; Smith et al., 2009, 2022; Smith & Shinebourne, 2012). The participant is trying to make sense of something that has happened to them, while the researcher is also trying to understand and interpret this experience (Braun & Clarke, 2013; Smith & Shinebourne, 2012) through “micro-analysis and synthesis” of this information (Smith et al., 2009, p. 24). This dual interpretive approach is referred to in IPA research as a ‘double hermeneutic’ (Braun & Clarke, 2013; Smith et al., 2009, 2022). To achieve this, the researcher must ensure they are aware of and continually reflecting upon their own prior experiences, assumptions, and preconceptions or “fore-conceptions” throughout the research process (Smith et al., 2009, p. 25). According to Alase (2017) this is particularly important during the design of the data collection tools, and during data collection. It is also important to realise that, given the complexity of the interpretive and reflexive process undertaken during data analysis, the bracketing out of one’s own preconceptions and experiences can only ever be partially achieved (Smith et al., 2009).

Since IPA is an interpretive approach to understanding experience, the approach to analysis is an iterative one, requiring the researcher to examine the data from the perspective of “the part” and “the whole” (Eatough & Smith, 2017; Smith et al., 2009, 2022; Smith & Shinebourne, 2012). The IPA researcher moves through the analysis examining the parts as they relate to the whole, and the whole as it relates to the parts, in a non-linear manner (Eatough & Smith, 2017; Smith & Shinebourne, 2012). This iterative process is known as the ‘hermeneutic circle’ (Smith et al., 2022). This requires the researcher to move between identifying possible meanings within the data, critically examining these meanings in relation to other possible meanings that are identified and comparing these to the researcher’s own pre-conceptions and experiences as these begin to shift and evolve throughout the research process (Smith et al., 2022; Smith & Shinebourne, 2012). Again, this reflects the process of sense-making from the perspective of the participant (during data collection) and the researcher (during analysis) (Smith et al., 2022; Smith & Shinebourne, 2012).

IPA is also an idiographic exploration of experience. According to Larkin et al. (2006) idiography as it applies to IPA refers to both the individual and the specific event or situation

being explored within the study. As Larkin described, many IPA studies focus on “specific individuals as they deal with specific situations or events.” (2006, p. 103). Idiographic analysis is not concerned with establishing generalisable claims or understandings of broader human behaviour, rather it is focused on a depth of analysis and level of detail that enables the researcher to understand the phenomenon from the perspective of the person who has experienced it in a particular context (Smith et al., 2009, 2022). As such, IPA research is focused on detailed examination of a relatively small sample of purposively selected cases (Larkin et al., 2006; Smith et al., 2009). A description of the IPA process undertaken to analyse the student interview data is outlined in Section 6.5.1.

5.6.2 Reflexive Thematic Analysis (RTA)

Through the process of coding and theme development, Thematic Analysis (TA) is focused on the development, analysis, and interpretation of patterns which occur across a qualitative dataset (Braun & Clarke, 2022). RTA is one approach to TA that specifically acknowledges the importance and value of reflexivity during the analytic process. As such, RTA encourages the researcher to critically reflect on their role and practices as a researcher, and the impacts and influences these may have on their research. In doing so, RTA highlights researcher subjectivity as “an essential resource” and “integral part of the analysis” (Braun & Clarke, 2022, p. 13). This method of analysing data was selected to address research objectives two and three, as it reflected the methodological, ontological, and epistemological assumptions and considerations for the current research, which are outlined in more detail in Section 5.7. A description of the RTA process undertaken to analyse the interview and survey data is outlined in Section 6.5.3.

5.7 Ontological and Epistemological Assumptions

It is important for qualitative researchers to clearly articulate their own ontological and epistemological position in relation to reality and how it can be known (Koro-Ljungberg et al., 2009). Articulating the researcher’s ontological and epistemological perspective helps to demonstrate that the selected methods utilised for a study are aligned with the knowledge the researcher wishes to gather. This also assists in the ability of the reader to interpret the findings of the study and determine the trustworthiness of the outcomes and conclusions drawn from it (Koro-Ljungberg et al., 2009).

Ontology refers to the nature and characteristics of reality (Creswell & Poth, 2018). It determines whether we see reality as existing entirely separate from human input and influence, or whether we perceive reality as being inseparable from human interaction (Braun & Clarke, 2013). Qualitative researchers embrace the ontological perspective that

there are multiple realities and acknowledge that these different realities are experienced by the researcher, the participants of the study, and by the readers of the research output (Creswell & Poth, 2018). In undertaking the current research, the researcher has adopted a critical realist position. Critical realism considers knowledge as being “socially influenced”, while also acknowledging the existence of an “authentic” reality which provides the foundation upon which knowledge can be built (Braun & Clarke, 2013, p. 27). Critical realism also acknowledges that there are multiple perspectives of reality and these can only be understood through interpreted meanings (Cuthbertson et al., 2020). In undertaking this research, the researcher does not believe it is possible for the researcher to remove themselves completely from the world to understand reality in some definitive sense. Instead, she recognises that reality is subjective and each individual constructs their own reality within their own context.

Epistemology refers to how we know what we know (Creswell & Poth, 2018). Epistemology determines what knowledge is considered valid and true knowledge within a particular setting or context (Braun & Clarke, 2013). In the current research, the researcher has taken an interpretivist approach. An interpretivist epistemology recognises the construction of reality as subjective and based on individual interpretation (Cuthbertson et al., 2020). Interpretivist perspectives also assume that knowledge can only be gained through personal experience, and this in turn requires in-depth systematic analysis and interpretation by the researcher, to understand these experiences (Cuthbertson et al., 2020).

5.8 The Researcher’s Perspective

In qualitative research it is important to acknowledge the influence of the researcher’s own experiences, views, qualifications, and occupation on the research being conducted. This provides the reader with critical information to assist them in determining the applicability of the findings to their own settings (Tong et al., 2007). This also allows the researcher to reflect on these perspectives and presumptions throughout the research project. This reflexivity is especially important when undertaking research using an interpretive phenomenological approach. As such, it is important for the current researcher to state her own identity as a white, tertiary educated, middle-class, straight, cisgender female. She also identifies as autistic/neurodivergent; however, her formal diagnosis did not occur until the age of 36, in late 2019, approximately mid-way through her PhD candidature. The researcher did not identify as autistic during her own transition to university in 2001. She has been an ally of the autistic community for over 20 years prior to her own formal diagnosis, as a family member, friend and professional working in the autism field.

The researcher has qualifications in Behavioural Science (Bachelor) and Disability Studies (Masters) and has worked in various roles supporting autistic students across a range of primary, secondary, and tertiary educational settings for over 15 years. She has experience providing 1:1 support, as well as consultation, and professional development and training in autism. She also has 10 years' experience as an equity practitioner in the higher education sector, as well as in academic roles. She has taught university topics in disability and technology, transition to adulthood for students with disability, and autism. The researcher was involved in the development and implementation of a transition support program aimed at supporting autistic students in their first few months at university. Although autistic students who participated in the program reported benefits from their involvement, she noticed that they were often initially reluctant to take part. This was one of the observations that led her to researching in this area. The current research therefore brings a variety of professional experiences to this project.

The researcher strongly believes that autistic students, like all students with disabilities, should have equitable access and opportunities to participate in higher education on the same basis as their peers without disability. As an experienced higher education equity practitioner, she has observed the difficulties experienced by autistic students during their transition to, and first year at university, especially when they have not had access to timely or appropriate support. She has also personally witnessed the limited knowledge and understanding of autism demonstrated by some university staff, including those who approach working with autistic students with a level of fear or anxiety. These experiences have highlighted the need for improved transition practices, grounded in the needs and experiences of autistic students themselves.

As a qualitative researcher, she also recognised that autistic people are the experts in their own lives. It is their experiences and knowledge which can provide a deeper understanding of the ways in which policy and practice can be improved to better support their transition to university.

5.9 The Importance of Inclusive Research

Historically, autism research has been conducted “on” autistic people as opposed to with autistic people (Chown et al., 2017; Poulsen et al., 2022), and research funding in Australia and internationally has been significantly skewed towards biological and genetic research (den Houting & Pellicano, 2019; Pellicano & Stears, 2011; Warner, 2019). In recent years there has been a shift towards more inclusive research priorities, where consideration is given to the areas of research most likely to contribute to positive quality of life outcomes

for autistic people, and address areas of priority as determined by the autistic community themselves (Chown et al., 2017; den Houting & Pellicano, 2019; Gowen et al., 2019; Poulsen et al., 2022; Warner, 2019).

The importance of including autistic people in autism research has been well recognised (Chown et al., 2017; Poulsen et al., 2022). In addition to addressing areas of research that improve the lives of autistic people, researchers must also ensure they include autistic people throughout the development and implementation of the research project. Including autistic people in the design and implementation of research projects not only improves the outcomes of the research, but also assists in the translation of research ideas into broader changes in policy and practice (Poulsen et al., 2022). Inclusive research practices implemented within the current research study are described in more detail in Section 6.2.

5.10 Chapter Summary

This chapter has presented an outline of the philosophical and methodological foundations that underpin the current research project. An overview of phenomenological approaches to qualitative research has been presented along with an outline of the research approaches (IPA and RTA) used within this research. The importance of using inclusive research practices has also been presented along with the researcher's own positionality as it relates to the current research project. The following chapter presents the general methods undertaken to complete this research, including the qualitative approaches to data collection and analysis.

6 METHODS

This chapter provides a detailed outline of the methods used within this research project. Firstly, the chapter presents an overview of the inclusive research practices implemented within this research, followed by a description of the data collection methods and ethical considerations relevant to this research. Finally, the chapter presents the data analysis techniques used, and addresses the importance of reflexivity, quality, and rigour in this research.

6.1 Ethics Approvals

Ethical approval was granted by the Flinders University Human Research Ethics Committee (HREC) in 2019 (Project No. 8242) (Appendix C). During recruitment for the online surveys the following organisations required completion of their own ethics application process via their own ethics or professional practice board: Autism SA, Autism Queensland, ASPECT and Amaze. The researcher completed each organisation's ethics application process and provided them with copies of the Flinders University HREC ethics approvals. Organisations that requested a copy of the full ethics application submitted to the Flinders University HREC were provided with an executive summary of the research proposal, approved by the Flinders University HREC, to protect the intellectual property of the project (Appendix D). Ethical considerations relevant to this research are discussed in more detail in Section 6.4.

6.2 Inclusive Research Practices

Inclusive research practices were used throughout both components of this research project and included consultation with autistic people and family members across all stages of project development. In addition, an autistic co-analyst was employed to undertake analysis of a selection of interview transcripts. Details of the inclusive practices incorporated within this research project are provided below.

The Autism Cooperative Research Centre (Autism CRC) has developed Inclusive Research Practice Guides and Checklists for Autism Research (Cooperative Research Centre for Living with Autism, 2016)². The researcher used the Inclusive Research Practice Guides (2016) to ensure inclusive practices were implemented where possible throughout the current project. Firstly, the researcher identified an area of research which had the

² An updated version of these guidelines were published in 2021: den Houting, J. (2021). Participatory and Inclusive Autism Research Practice Guides. Brisbane. *Autism CRC*.

potential to improve the lives of autistic people directly. Input was sought from autistic people in developing the research direction, and in the implementation of the study. Feedback was initially gained through informal feedback (e.g., via email, face-to-face or phone conversation) via the researcher's own professional and personal networks, to determine whether the proposed research focus would benefit the lives of autistic people. Feedback was positive and supported the significance of the research aim, confirming university transition for autistic students as an important focus that would have direct value and impact on the lives of autistic university students. Feedback was also sought during the development of online surveys, which led to the development of an advisory group (Autism CRC Guide 1 and 2), which is discussed in more detail in Section 6.2.1. Details about the feedback process as it related to the development of the surveys is provided in Section 6.3.1.1. The researcher also used multiple channels of recruitment (e.g., universities, autism associations, support networks, and social media) to ensure a range of autistic individuals and their family members would have the opportunity to participate in the research (Autism CRC Guide 1).

An autistic co-analyst provided an additional autistic perspective during the analysis phase (Autism CRC Guide 1 and 2) as well as an opportunity for debriefing, and analytical discussion during the initial stages of the interview data analysis. The co-analyst was a member of the advisory group and was employed in a casual research role for this work. The role of the co-analyst during the analysis process is described in more detail in Section 6.5.2.

The provision of research results to autistic people and their family members is also recognised as an important aspect of inclusive research practice (Autism CRC Guide 4 and 9). A summary of research outcomes is being developed for dissemination via the project's Facebook page. Participants and potential participants were informed of the Facebook page details in the project's information sheets. The researcher's details were also made available for those wishing to seek access to a summary of the results directly from the researcher. In addition, a final summary report of the outcomes of the research is being developed to provide to those state and national autism support organisations that were involved in recruitment for this research.

6.2.1 Advisory Group

After initially seeking feedback informally the researcher sought to implement an advisory group to provide opportunities for autistic people and their family members to give additional feedback at key points throughout the study. Individuals who had previously provided feedback in the early stages of the project were approached in late 2019 and asked if they would be interested in joining an advisory group to provide feedback in future

development and planning of the study. They were informed that this may involve a maximum of one or two hours per month, on an ad-hoc basis, and could be via email, or face-to-face depending on what was most convenient for them. Individuals who were contacted were also informed that participation in the group would be entirely voluntary, that their input would be acknowledged in production of a thesis and that there would be the possibility of contribution to future peer-reviewed journal articles.

All individuals who were approached regarding the opportunity to join the advisory group agreed to take part. The advisory group consisted of six members: three autistic university students, one parent of an autistic university student, one autistic professional and one autistic academic. All had attended university. The advisory group provided feedback on the Case Study component of the research project (see Section 6.3.2.1).

6.3 Data Collection

6.3.1 Online Surveys

The primary purpose of the online surveys was the collection of qualitative data, in line with the interpretive phenomenological approach to this research. Open-ended questions were included to enable an in-depth exploration of the experiences of autistic students in their transition to, and first year of university. Closed-ended, Likert scale style questions, such as asking participants to rate a particular experience as very positive, positive, negative, or very negative, were included to provide supplementary descriptive data alongside the qualitative data collected. A full copy of each of the surveys can be found in Appendix E.

6.3.1.1 Survey Development.

As there was no existing survey tool directly exploring transition experiences of autistic university students and their support networks, three separate surveys were developed to explore each of the research objectives: one for autistic students (Student Survey), one for family members (Family Survey), and one for staff (Staff Survey). Questions were initially drafted, in discussion with the researcher's supervisors, based on the findings of the systematic literature review presented in Chapter 4. Survey questions were also developed to address each element of the bioecological theory model (Bergen, 2008; Bronfenbrenner, 1979) described in Chapter 3.

Based on initial feedback the researcher determined to avoid person-first language within the survey (e.g., "students with autism"), and instead opted for "student on the autism spectrum" in an attempt to acknowledge the individual nature of language preference and

avoid prioritising one above the other (Bury et al., 2023; Kenny et al., 2016). A note was included in the survey information sheet addressing this language choice which read: *“*Please note the term “student/individual on the autism spectrum” has been used with the intention of being inclusive, we do not intend any offense by the use of this terminology.”*. This terminology was noted by autistic people who provided feedback as suitable.

Pre-testing is an important step in ensuring survey integrity (Sue & Ritter, 2012), as it can highlight difficulties in interpretation of questions or instructions, as well as missing questions (Meadows, 2003). Pre-testing involved seeking feedback to ensure the questions asked and language used was appropriate, and respected language preferences of the autistic community. Feedback on survey questions was also sought to minimise potential measurement error that can result from questions which are unclear or ambiguous, and to confirm that the instructions and terminology were clear and easy to understand (Toepoel, 2015). Feedback was provided via email, enabling feedback to be provided in a time and manner most convenient to those providing it.

Feedback indicated that most questions were clear and able to be interpreted by the respondents. Some open-ended questions were highlighted as requiring further clarification regarding the level of detail being requested. As such, their wording was revised and where appropriate additional clarification was incorporated in the form of additional prompts, such as *“e.g., what you found helpful or unhelpful”* or *“e.g., Why did you use this support? Who provided this support? How helpful or unhelpful did you find this? Why?”*. The additional prompts were designed to provide clarification about the information being sought, without potentially influencing the participant's responses. Key components of some questions were also underlined to clarify the focus of the question. For example: *“Please tell us more about your experiences of the first few weeks of university, including what you found helpful or unhelpful.”*

As suggested in the feedback, additional closed-ended questions were also added to supplement the information being gathered throughout the survey. For example, providing student participants with the option to respond to the following question: *“What were your experiences of planning and preparation for university?”* with a closed-ended response (very bad, bad, somewhat good, good) and/or an open-ended free text response.

Following pre-testing, survey questions were further reviewed. Additional questions were added to elicit further details in relation to participants' experiences and ensure aspects of all elements of the bioecological theory model were addressed. Further clarification and background information was also added to the survey during this review. For example: *“In*

the following questions we would like to find out a little more information about your preparation and planning for university, your transition to university and your first year as a university student. Please provide as much detail as possible about your experiences.” This was provided to encourage participants to continue to engage with the survey and to provide additional clarification about the information being sought in the questions which followed.

The full list of survey questions for each group can be found in Appendix E. Initial eligibility questions were used to confirm that interested participants met the inclusion criteria. The student survey questions addressed the following areas: demographic information, overall experiences of transition to university, legislation, support from family members and friends, support received from university services and staff during transition and first year, staff knowledge and awareness of autism, and health and wellbeing. Student surveys were estimated to take between 30 – 45 minutes to complete. The family survey included: demographic information, information relating to their autistic family member, and experiences of providing support during transition. The family survey was estimated to take approximately 30 minutes to complete. The staff survey questions addressed the following areas: general information relating to their role, their confidence in supporting autistic students at their university, and their experiences of engaging with autistic students and/or their family members. The staff survey was estimated to take approximately 30 minutes to complete.

6.3.1.2 Recruitment.

Inclusion criteria for each participant group were as follows: Autistic students (Students) were those who had undertaken at least six months of undergraduate university studies in Australia. Family members (Family) were those who provided direct support to autistic students who had undertaken at least six months of undergraduate university studies in Australia. Professional and academic university staff members (Staff) were those who had experienced interactions with first year, autistic university students.

Initial inclusion criteria and subsequent inclusion criteria (after modification) are outlined in Table 6.1. The criteria were reviewed and modified in the early stages of data collection. The initial intention of limiting participation to those who had commenced their undergraduate studies in the previous two years was to ensure recency of their experiences, and their ability to recollect the information being requested. However, upon review it was determined that this restriction significantly limited the opportunities for participation of students who may have relevant information to contribute to the study. It was also determined that restricting the year of commencement at university was not necessary in order to address the research question and objectives.

Table 6.1: Initial and revised inclusion criteria for survey recruitment

Participant group	Initial inclusion criteria* *prior to commencement of survey	Revised inclusion criteria 1	Revised inclusion criteria 2
	Ethics approval date: 5 March 2019	Ethics approval date: 27 March 2019	Ethics approval date: 23 Dec 2019
Students	Individuals on the autism spectrum Have commenced undergraduate study at an Australian university within the previous two years Have completed at least six months of university studies	Individuals on the autism spectrum Have commenced undergraduate studies at an Australian university within the previous four years and Have completed at least six months of university studies	Have a diagnosis of ASD as outlined in the DSM-5; or autism or Asperger's syndrome as outlined in the DSM-IV TR Have completed at least one semester (six months) of study at an undergraduate level at an Australian university
Family	Family member (e.g., parent, sibling, grandparent, carer) of an individual on the autism spectrum who had commenced undergraduate studies at an Australian university within the previous two years and Provided direct support to that individual during their transition to and first year at university	Family member (e.g., parent, sibling, grandparent, carer) of an individual on the autism spectrum who had commenced undergraduate studies at an Australian university within the previous four years and Provided direct support to that individual during their transition to and first year at university	Family member or carer (e.g., parent, sibling, grandparent, aunt/uncle, carer) of individual on the autism spectrum who has completed at least one semester (six months) of study at an undergraduate level at an Australian university and Provided direct support to the individual during their transition to and first year at university
Staff	Current academic or professional staff member within an Australian university and Have interactions with first year students on the autism spectrum at their university.	No change	No change

Surveys were open from July 2019 to July 2022. Participants were recruited via Australian universities, Australian state and national autism support organisations, and online through social media including LinkedIn, Facebook and Twitter. Universities were contacted in the first instance via the Aust-Ed mailing list, a closed list maintained by the

Australian Disability Clearinghouse on Education and Training (ADCET). Most registered members of the mailing list are employed in professional disability roles (e.g., Disability Liaison Officers/Disability Advisors) in Australian universities and Technical and Further Education (TAFE) centres. The ADCET project coordinator responsible for management of the Aust-Ed mailing list was contacted via email to request permission to distribute the study information via the mailing list. Permission was granted on 10 May 2019 (Appendix F).

A snowball sampling technique was used to recruit participants. This technique provided a method of purposeful sampling that allowed the researcher to seek additional participants through key informants (Patton, 2002) (e.g., those who have already participated in the study, or through the supervisors' professional networks).

An introductory email (from the researcher's primary supervisor, FR) was distributed via the Aust-Ed mailing list in May 2019 outlining the project's purpose (Appendix G). At the time of emailing, there were 26 universities represented on this mailing list. Attached to this email was the information sheet, which outlined the purpose of the study and the recruitment process, and a form granting permission to advertise the research (Appendix H), along with the ethics approval notice. Mailing list members were asked to seek permission from their Disability Services manager to disseminate recruitment notices for both the student and staff surveys within their university.

Universities who returned the signed permission form and agreed to assist with recruitment ($n = 3$) were sent the student and staff recruitment flyers (see Appendix I). Recruitment flyers outlined the inclusion criteria for each survey and provided a URL link and QR code for access to the relevant survey via Qualtrics. Universities were asked to display hard copies of the flyers within their university campus. A second round of recruitment took place via the Aust-Ed email list in Dec 2019 with the intention to seek additional survey responses from university staff (see Appendix J for revised introductory email and letter, and information sheet and permission request form, and Appendix K for revised recruitment flyers).

Eight state and national autism support organisations were identified through a Google search for Australian autism associations. Their details were available publicly online, and the organisations were approached individually via email. Organisations were contacted via an introductory email with a copy of the ethics approval notice and an information sheet and permission form attached (see Appendix L). Organisations who agreed to assist with study recruitment ($n=3$) were provided with the student and family

member recruitment flyers to advertise to their members (see Appendix I) and Facebook post text (Appendix M).

In an attempt to get further reach after the initial recruitment phase, 28 university student unions were also approached in October 2019 via introductory email (from the researcher's primary supervisor, FR). Student unions were provided with the same information as the universities emailed via the Aust-Ed emailing list. One student union agreed to share the research project, and they were asked to promote the research via their social media pages using the social media text provided (Appendix M).

Due to the limited number of survey responses received following these recruitment methods, additional recruitment was conducted using the social media platforms Facebook, LinkedIn and Twitter. Social media posts were shared by the researcher's supervisors. The social media posts provided details of the study and a link to the online survey, where additional details of the study could be found. Examples of the social media posts are provided in Figure 6.1 and Figure 6.2.



Figure 6.1: Social media recruitment post (staff) - Twitter

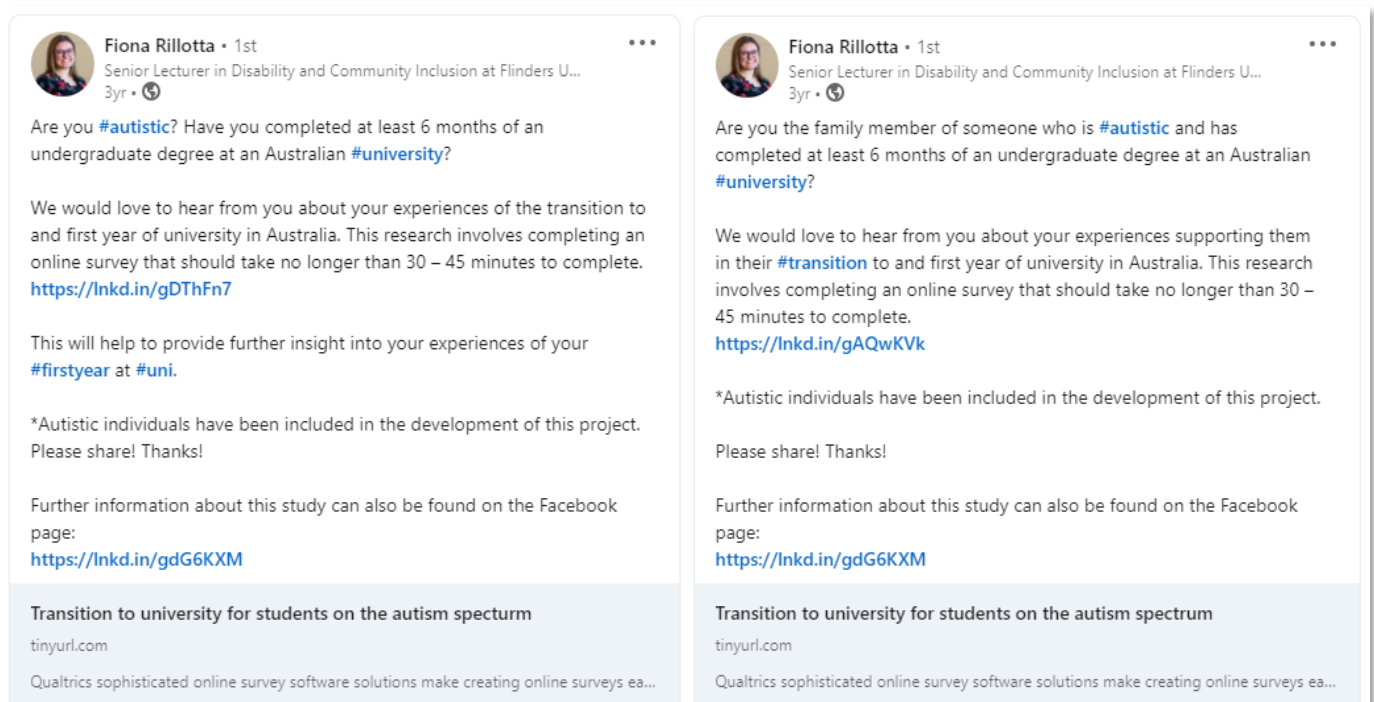


Figure 6.2: Social media recruitment posts (student and family) - LinkedIn

In early 2021 additional recruitment was undertaken. The researcher's primary (FR) and associate (MB) supervisor were provided with an email template which outlined the project objectives and provided the recruitment flyers for the online surveys (Appendix N). Emails were sent to the supervisors' (FR and MB) professional networks. Individuals who received this email were not asked to participate directly but were requested to forward the information on to people within their personal and professional networks.

As all survey responses were anonymous it is not possible to identify which responses were the result of which recruitment process; however, as evidenced in the above description, recruitment methods were revised several times to maximise potential response rates using a comprehensive and thorough recruitment process to enable broad reach of the research project to a wide audience of autistic people, their family members, and university staff.

6.3.1.3 Participants.

Despite the extensive recruitment methods utilised, the initial number of responses to the student survey was extremely low. There were 10 responses received from students who met the eligibility criteria for inclusion prior to the end of 2019. Of these 10 responses, only four contained answers to open-ended questions. Responses to open-ended questions were an important requirement to enable qualitative exploration of the experiences of autistic

students during their transition to university, in line with the methodological and epistemological foundations that informed the research project. In addition, minimal demographic data was provided by most students, which resulted in the responses also being inappropriate for IPA analysis, as there was not enough individual information to enable the level of in-depth idiographic analysis that IPA requires (Smith et al., 2009, 2022). All survey questions were made “optional” rather than “required”, which permitted participants to complete the survey without providing the relevant demographic information that would enable idiographic analysis. Forced answering in social science surveys is demonstrated to lead to increased survey dropout, false responses, and reduced length of answers to open-ended questions (Sischka et al., 2022). However, whilst the approach of non-forced answering was used in this study to increase participation, by not making the survey burdensome, in contrast it resulted in limited useable data relating to the aims of the study. As such, the researcher decided to adjust the data collection methods, resulting in the use of case studies to collect data from autistic students, which would enable in-depth, idiographic analysis to address research objective one.

The researcher was conscious of the input already provided by the four participants who had contributed to the online survey, sharing their experiences of transition to university as autistic students. Therefore, she decided to keep the student survey open online until June 2021, to enable additional responses that could be analysed and discussed in a future publication using an alternative analytic approach. This resulted in a total of 14 eligible surveys completed. While the data is not suitable for analysis using IPA, the researcher feels there is an opportunity to utilise Reflexive Thematic Analysis (Braun & Clarke, 2021a, 2022; Braun et al., 2020) to analyse the data and provide further insight into the needs and experiences of autistic students during their transition to, and first year of university, in a future publication.

Eleven family member survey responses were received, with eight providing sufficient qualitative data to be included in the analysis. Three family member responses were not included as they did not respond to any of the open-ended survey questions and thus there was no qualitative data about their lived experience. All family member participants included in the analysis identified as a parent of an autistic student. Thirty staff members responded to the survey. Three respondents did not meet the eligibility criteria for the survey, while ten respondents did not complete any open-ended questions and thus were not included in the thematic analysis. The remaining 17 responses were therefore included in the thematic analysis. Staff member participants identified as undertaking one or more of the following roles: Disability Services staff (n=4), degree coordinators (n=2), topic

coordinators (n=10), lecturers (n=10), and tutors (n=7). Overall, there were 25 valid responses that were included in the analysis (n=8 family and n=17 staff).

6.3.1.4 Survey Completion.

As the student survey was significantly longer than the family and staff member surveys and included several open-ended questions, additional information was included in the initial page of the student survey (prior to the purpose, eligibility, and consent information) which provided instructions for how to complete the survey. This information provided a link to a PDF document of the questions (see Appendix E), enabling participants to download and draft their responses before commencing the survey online should they wish to do so. This strategy also provided autistic participants with the opportunity to process and consider their responses before entering them into the survey.

As described in Section 6.3.1.2, interested participants could access the online surveys directly using the URL or QR code provided in the recruitment information. Important information regarding the purpose of the research, the eligibility criteria, anonymity and confidentiality, any anticipated risks of participation (including support service links), and the study requirements were provided in the introductory page of the online survey (see Appendix E). Participants were informed that information was stored anonymously and responses to each page were submitted upon clicking the “Next” button. Participants were also informed that they would have one month from the commencement of the survey to complete all of their questions. After reading this information, participants had to select either “I agree” or “I do not agree” to indicate their consent to participate in the study, with those agreeing proceeding to the relevant eligibility questions. Those who did not meet the eligibility criteria received an automatic response informing them of the fact that they were not eligible to participate in this survey and thanking them for their time and interest in the study. At the end of each survey, participants were thanked for taking part and provided with instructions on how to inform other eligible participants of the study using the link to the survey. Student participants were also provided with a link to enter their details in a separate survey if they wished to be included in a draw to win one of three \$100 gift vouchers (see Section 6.4.4).

Details regarding analysis of data collected via family and staff surveys is provided in Section 6.5.3.

6.3.2 Case Studies

Student experiences were further explored using a case study approach. Case studies, gathering data from autistic students and their support networks (family, university

staff, and other professional support members), provided a deeper understanding of experiences during the transition to university in Australia. Ethics approval for the case studies was provided via modification application to the Flinders University HREC.

6.3.2.1 Development of the Interview Questions.

Draft interview questions were informed by the systematic literature review (Nuske et al., 2019) presented in Chapter 4 and the bioecological theory model (Bergen, 2008; Bronfenbrenner & Morris, 2006) presented in Chapter 3. Interview questions were also developed to closely align to the questions included in the online surveys.

Members of the advisory group were asked to provide feedback on the case study component of this research project in early 2020. Members were provided with an outline of the case study component which included information about its purpose, and the proposed recruitment process and eligibility criteria. They were also provided with copies of initial draft interview questions. Feedback was provided via email.

Feedback was collated and reviewed by the researcher and primary supervisor (FR). The resulting modifications included additional questions to broaden the scope of the experiences being explored, clarification of question meaning, and inclusion of discussion prompts. For example, exploring areas such as: whether students preferred to study on campus or off campus; whether students had engaged with mentoring or other support programs; and whether students had disclosed their diagnosis to their peers or university staff. The topic areas covered in the final set of interview questions is outlined in Table 6.2. A full copy of all final interview questions can be found in Appendix O.

Table 6.2: Topic areas covered in semi-structured interviews

Student	Family member/other	Disability Advisor	Academic staff
First year at university	Support provided to family member	Supports provided to autistic students in their first year	Autism spectrum disorder
Support networks	Communication with university	Autism spectrum disorder	Supporting autistic university students
Autism spectrum disorder and first year at university	Legislation and services	Student specific questions -exploring the supports provided and the process for providing supports to the student	
Services and supports accessed			
Disclosure			
University staff			

6.3.2.2 Recruitment.

Initial student inclusion criteria and subsequent inclusion criteria are outlined in Table 6.3. The criteria were reviewed and modified following feedback from the advisory group. Feedback suggested that there should be an option for students to identify an academic staff member for interview as well as Disability Services staff, and to remove the requirement for students to be registered with their university's Disability Services, and subsequently to include students who do not have a formal diagnosis (i.e., those who self-identify as autistic). Year of commencement of undergraduate studies was also broadened to increase potential participant pool while still ensuring recency of experiences being examined.

Additional modifications to inclusion criteria were made in response to the COVID-19 pandemic restrictions being implemented in South Australia. Interviews were modified from being face-to-face, to being online (via Microsoft Teams) or by phone to limit potential disruptions resulting from frequently changing restrictions. This also enabled the inclusion of students studying at any Australian university.

Due to the limited number of initial interview respondents and to ensure that individuals who may have valuable contributions were not unnecessarily being excluded from participating, inclusion criteria were further reviewed and modified during the data collection phase. While inclusion criteria for the survey were quite broad, the inclusion criteria for the case studies were narrower, with a focus on exploring the experiences of autistic students who had transitioned to university in the previous five years.

Table 6.3: Initial and revised student recruitment criteria for case studies

Initial inclusion criteria (sent to advisory group)	Modified Inclusion criteria	Modified Inclusion criteria	Modified Inclusion criteria	Modified Inclusion criteria
	Ethics approval date: 20/04/2020	Ethics approval date: 12/08/2020	Ethics approval date: 02/10/2020	Ethics approval date: 16/12/2020
Students on the autism spectrum who are registered with the disability service at their university who have commenced their studies in either 2018 or 2019	Students who have a diagnosis of ASD as outlined in the DSM-5; or autism or Asperger's syndrome as outlined in the DSM-IV TR	Students who have a diagnosis of ASD as outlined in the DSM-5; or autism or Asperger's syndrome as outlined in the DSM-IV TR	Students who have a diagnosis of ASD as outlined in the DSM-5; or autism or Asperger's syndrome as outlined in the DSM-IV TR	Students who have a diagnosis of ASD as outlined in the DSM-5; or autism or Asperger's syndrome as outlined in the DSM-IV TR or self-identify as autistic/on the autism spectrum
Students must be enrolled in a university campus here in South Australia (Flinders University, University of Adelaide, University of South Australia)	Currently registered with their university's disability service Commenced undergraduate university studies in 2018 or 2019 in Australia	Commenced undergraduate university studies in 2016, 2017, 2018 or 2019 in Australia	Commenced undergraduate university studies in 2016, 2017, 2018, 2019 or 2020 in Australia	Commenced undergraduate university studies in 2015, 2016, 2017, 2018, 2019 or 2020 in Australia

6.3.2.2.1 Students.

Multiple recruitment strategies were implemented to reach potential case study participants. Disability Services managers from all three South Australian Universities were contacted directly via email (Appendix P) in May 2020. The email requested assistance with recruitment of autistic students who had recently transitioned to university. Attached to this email were a letter of introduction from the researcher's primary supervisor (FR) (Appendix Q), an information sheet (Appendix R) outlining the project's purpose and providing information about the case study process and an email template to inform registered students about the study (Appendix S).

To reach Disability Services staff across other Australian states, the primary researcher presented an online webinar about the research project for the ADCET network in April 2020. University staff who attended the online webinar were invited to contact the researcher directly for further information. Information regarding the study was also provided on the ADCET website and via the ADCET newsletter, including the email template to inform registered students about the study (Appendix S), and a recruitment flyer with additional information (Appendix T). Also available on the ADCET website was the letter of introduction

from the researcher's primary supervisor (FR) (Appendix Q), an information sheet (Appendix R), and the flyer outlining the purpose of the study (Appendix T).

Recruitment also took place via the Aust-Ed mailing list and an Australia-wide Peer Mentoring Community of Practice (CoP) list (see Appendix U), of which the researcher was a member after permissions were provided from relevant administrators (December 2020). In addition, recruitment information was shared via social media (Facebook, Twitter, LinkedIn) by the researcher's primary and associated supervisors (FR and MB) in August and September 2020. Figure 6.3 and 6.4 present examples of social media post text and image used for case study recruitment.

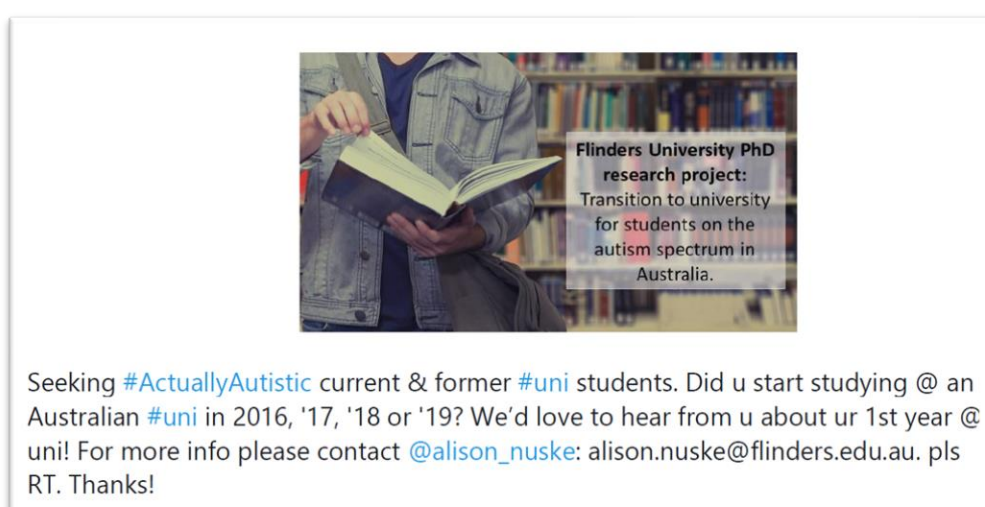


Figure 6.3: Social media post text (Case study recruitment) - Twitter

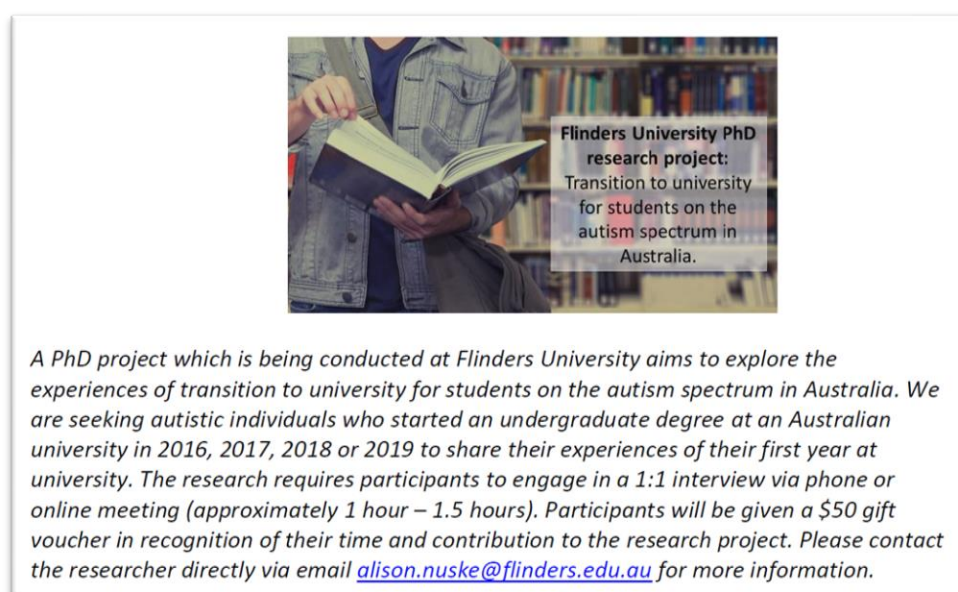


Figure 6.4: Social media post text (Case study recruitment) - LinkedIn/Facebook

Four Facebook groups were contacted directly to seek their permission to share the research information on their pages (September 2020). Only one group, responded and approved sharing the recruitment message. Students interested in participating in the research were invited to contact the researcher directly. The researcher replied via email, providing further details about the purpose of the research and a copy of the student participant information sheet (Appendix V) and consent form (see Appendix W). Interview questions (see Appendix O) were also provided in advance to reduce any anxiety that may be associated with participation.

The participant information sheet provided the details of the researcher and her supervision team; a description of the aim, and purpose of the research; an outline of what participation in the research would involve; information regarding remuneration (for student participants only); the anticipated benefits of participating; potential risks from participating in the research; information relating to anonymity and confidentiality; information relating to risks associated with participation; information regarding the voluntary nature of participation and the process for withdrawing from the study should participants wish to do so; and instructions for agreeing to participate. The information sheet also provided participants with information about how to access a summary of the research results via the project Facebook page.

The consent form was reviewed with each participant at the beginning of their interview. The consent form reminded participants of the voluntary nature of participation in the research, anonymity and confidentiality, and the option to withdraw from the research should participants wish to do so. Participants were required to provide written consent before taking part in the interview. Participants were also reminded at the beginning of the interview that participation was entirely voluntary and that they could refuse to answer any questions or withdraw from the research at any time.

6.3.2.2.2 *Support network members.*

Support network members were recruited via the student interview participants. Support network members could include a family member, academic staff, disability advisor, or other support provider. Figure 6.5 provides an overview of the process for support network member recruitment.

At the completion of their interview, students were given verbal information about the option for support network member interviews. A permission form (Appendix X) was emailed to each student participant after their interview which provided additional information. Interview questions (see Appendix O) were also attached to this email, so that students were

aware of the types of questions their support network member may be asked. This enabled student participants to consider the request in more detail before providing their permission.

Students provided permission for interviews with identified support network members by returning the permission form via email. Upon receipt of the permission form, the researcher provided the relevant participant information sheet (see Appendix Y) and interview questions. The student participant was asked to forward these to the support network members identified in their permission form. The participant information sheet provided the contact details of the researcher. To ensure the researcher was not provided with personal contact details of potential participants, support network members who were interested in participating in the study were asked to contact the researcher directly.

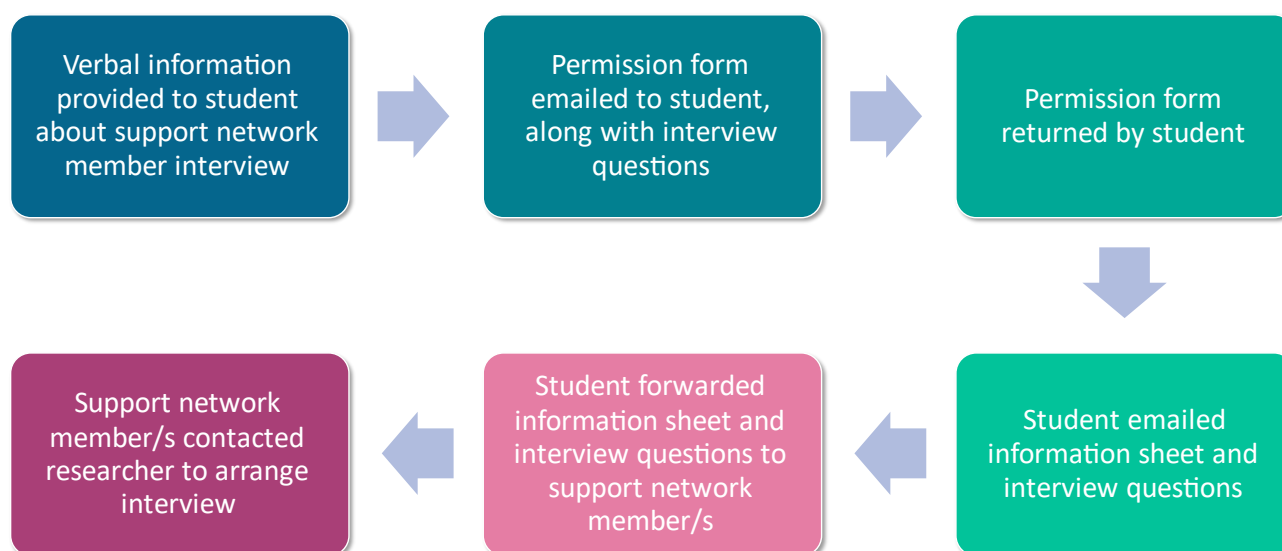


Figure 6.5: Overview of recruitment of support network members

6.3.2.3 Participants.

6.3.2.3.1 Students.

Nineteen students expressed their interest via email in participating in the research. Two who expressed interest did not meet the eligibility criteria to participate, and nine did not respond to the researcher's email to set up an interview time, resulting in eight participants. Interviews, ranging in length from 45 to 80 minutes, were conducted between September 2020 and March 2021. Four participants were located in South Australia, two in Western Australia, one in New South Wales, and one in the Australian Capital Territory. Two student

participants were female, five were male, and one said they preferred not to disclose³. Participant ages ranged from 19-36 years. See Table 7.1 for an overview of student participant characteristics.

6.3.2.3.2 Support Networks.

One family member (parent) took part in an interview via Microsoft Teams; the interview was 35 minutes in duration. Interviews, ranging in length from 30 to 55 minutes, were conducted with three university disability advisors via Microsoft Teams. Only one student provided permission for an interview with an academic staff member, but the staff member did not contact the researcher for an interview. Two interviews were conducted with additional support persons. One was employed outside of the university, while the other was employed in a professional role within the university. These interviews were each approximately 40 minutes in length and conducted via Microsoft Teams.

6.3.2.4 Interviews.

Data were collected via semi-structured interviews conducted by the researcher. These were conducted via phone or Microsoft Teams, as per each participant's preference, which enabled the researcher to include participants from geographical locations across Australia. This also enabled the participant to take part in the interview from a location where they felt comfortable.

Interviews were audio recorded using a handheld recording device. Consent forms were discussed at the commencement of the interview and participants signed the consent form at the commencement of the interview. Consent forms were then sent to the researcher via email. Verbal consent was also requested at the start of the interview.

Interview guides (see Appendix Z) provided a loose structure to the interview, offering the researcher with ways to best phrase specific questions and link together related areas of discussion. The guide allowed the researcher some flexibility in how each area was addressed, enabling her to follow the course of participants' thoughts and reflections. It also identified some possible prompts that could be used if the participant was having difficulty interpreting or responding to a particular question. Probes were also used to seek further clarification or elaboration as required. Interviews commenced with a series of short demographic questions, followed by questions exploring several different areas (see Table

³ Participants were asked during the interview to indicate which gender they identify with, with prompts including male, female and prefer not to identify. The researcher acknowledges that there is debate regarding terminology preferences and that the question unintentionally conflated sex and gender. The information provided here is indicative of the participants responses to this question.

6.2 for an overview of interview topic areas). Participants were also given an opportunity to add any additional relevant information at the end of the interview.

6.3.2.5 Access Plans.

Student participants were asked if they would be willing to share their disability access plan or other learning support plan, if one was created in their first year at university. Sharing of an access plan was entirely voluntary and confirmed by the participant through the completion of the relevant section on the permission form (Appendix X). Students were informed that whether or not they provided a copy of their access plan would not impact on their participation in the research. Six students provided copies of their access plans. In total, nine access plans were provided, as some students had undertaken cross-institutional study. Further details of the information provided in student access plans is presented in Section 7.2.

6.4 Ethical Considerations

Ethical considerations and how they were addressed are described in the following sections. Research practices and ethical considerations were informed by the National Statement on Ethical Conduct in Human Research (National Health and Medical Research Council [NHMRC], 2007 [updated 2018]).

6.4.1 Informed Consent

Ethical research must ensure that participants can make an informed decision about whether or not they wish to participate in the research (NHMRC, 2007 [updated 2018]). The following strategies, in line with requirements outlined in the National Statement, were implemented to ensure participants could provide informed consent before taking part in the research.

Researchers must ensure that no person feels coerced or pressured into taking part in the research project (NHMRC, 2007 [updated 2018]). Given the researcher's previous and current roles within the university setting⁴, sharing of study information with potential participants was conducted by third parties, from the researcher and supervisors' professional networks. This provided the opportunity to promote the research to potential participants, while limiting any possibility that participants may have felt coerced or

⁴ The researcher was employed as a disability advisor at the University of South Australia until the year prior to recruitment for the survey component of the research. During recruitment for the survey and case studies the researcher was employed as an academic staff member at Flinders University.

pressured to take part. In addition, participants were reminded of the voluntary nature of participation throughout the information provided to them.

Survey respondents were provided with an information sheet and consent form as the first page of the online surveys (see Appendix E). This page provided the aim and purpose of the research; eligibility criteria; anonymity and confidentiality; risks associated with participation; remuneration (for student survey only); and instructions for agreeing to take part. Participants were required to click “I agree” at the bottom of the information and consent page to indicate that they agreed to participate in the research. Due to the anonymity of the online survey, these participants could not withdraw consent once it had been provided. Interview participants were provided with a participant information sheet (Appendix V and Appendix Y), which included details of how to withdraw from the study should they wish to do so, along with a consent form (see Appendix W), and a copy of the relevant interview questions (Appendix O) prior to agreeing to take part in the interview. Consent forms also informed students that their participation or withdrawal from the research would in no way impact on their current or future studies. A full outline of the details provided in the participant information sheets and consent forms, including the voluntary nature of the study, have been presented in Section 6.3.2.2.

6.4.2 Anonymity and Confidentiality

Confidentiality of participant information is an important ethical consideration throughout human research and must be considered during the development and implementation of the research project (NHMRC, 2007 [updated 2018]). Survey responses were stored anonymously using Qualtrics (www.qualtrics.com) online survey platform. Interview participants were informed of the use of audio recording equipment for the purposes of transcription at the beginning of the interview, prior to commencement of recording. Recording was only started once the participant had the opportunity to ask any questions and had agreed to the recording of the interview. All transcription and de-identification of the interviews was completed by the researcher. Participants were required to provide written approval of the transcript of their interview before it was included in the analysis. This was done by emailing each participant a copy of their transcript and a copy of their consent form and requesting that they sign the Review/Approval of Interview Transcription section on the consent form (Appendix W).

Quotes from participants used within the thesis and related presentations were modified where necessary to remove identifiable information. Details such as geographical locations, university names, campus locations, or specific degree titles were deleted from the transcripts and replaced with generic notations (e.g., [University Name]) during transcription

to ensure the identity of participants was protected. All interview participants were provided with the opportunity to select their own pseudonym, those who did not wish to do so were allocated one by the researcher. The pseudonyms were used during the analysis, and throughout the thesis and associated presentations.

Participant data were stored electronically in a folder on the researcher's password protected cloud storage. Access to the folder was only available to the researcher and her primary supervisor (FR). The co-analyst was required to sign a confidentiality agreement (Appendix AA) and was only provided with access to de-identified transcripts for analysis. All written notes and reflections were de-identified and stored securely within the researcher's home office.

6.4.3 Risks to Participants

Researchers must undertake steps to minimise risks (i.e., the potential for harm, discomfort, or inconvenience) to participants (NHMRC, 2007 [updated 2018]). While it was not anticipated that participants would experience any harm or distress from participating in this research, details of university counselling services (for students), Beyondblue, and the 24-hour Lifeline counselling service were provided in the information and consent forms provided to participants.

6.4.4 Remuneration

Remuneration was provided to autistic student participants in line with recommendations outlined in the Autism CRC's Inclusive Research Practice Guides (Cooperative Research Centre for Living with Autism, 2016). Student participants who took part in the survey were provided with the opportunity to submit their contact details (stored separately to their survey response data) to be entered into a draw to win one of three \$100 gift vouchers. Student participants who took part in an interview were provided with a \$50 gift voucher in recognition of their contribution to the research. Gift vouchers were provided via email and all participants needed to reply by email to confirm that they had received the voucher.

6.5 Data Analysis

To address the research question and objectives, two forms of data analysis were used. To address research objective one, qualitative data from student interviews were

analysed using an IPA approach as outlined in Smith et al. (2009)⁵. Research objectives two and three were addressed through analysis of data gathered from interviews with support network members⁶, as well as analysis of survey responses from family members, and university staff. Data were analysed using an RTA approach as outlined by Braun and Clarke (2022). The following sections provide a detailed overview of the analytic process.

6.5.1 Research Objective One

The steps taken to conduct the analysis are outlined in Figure 6.6 and discussed in more detail in the sections below. Each individual student transcript was analysed following steps 1 – 7; however, the process itself was iterative. After all student transcripts had been individually analysed, themes were developed across all eight student transcripts.

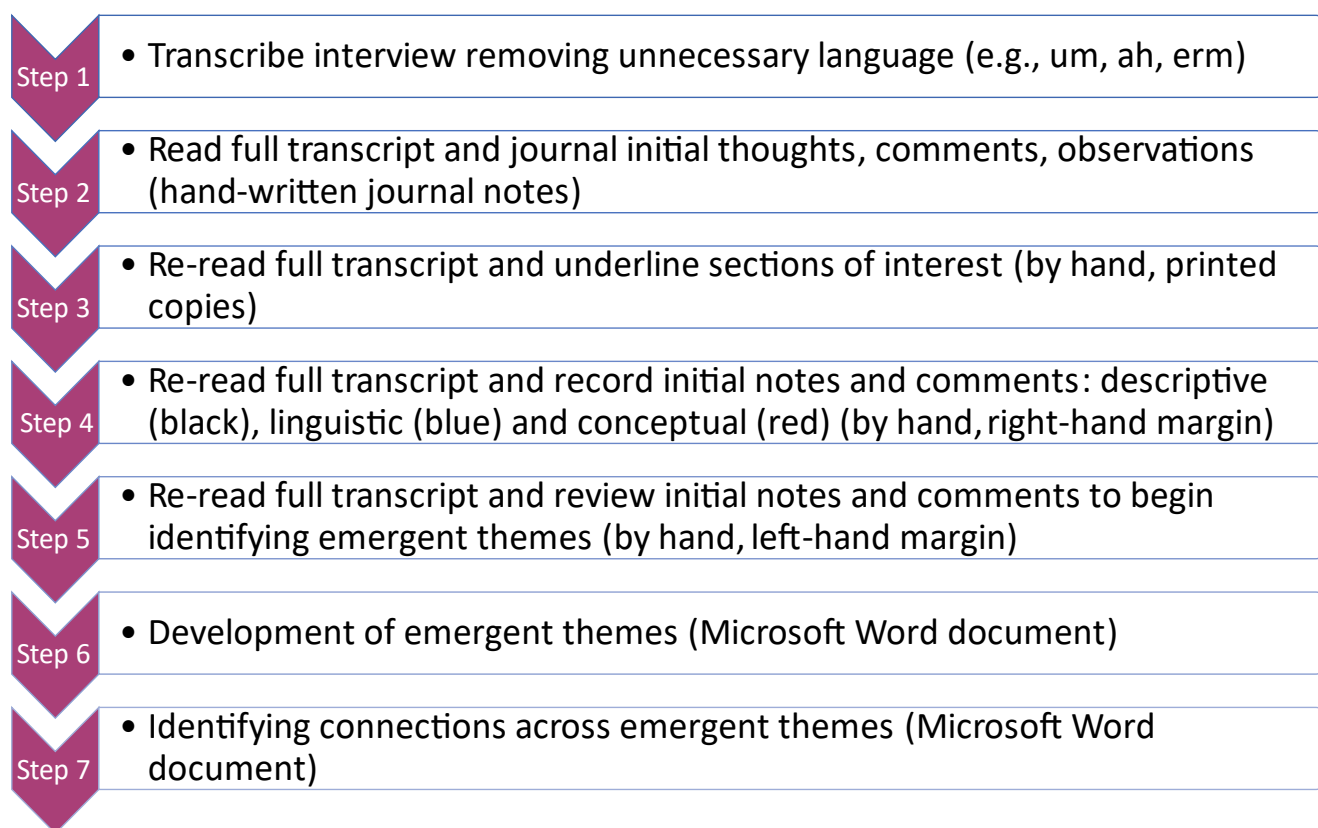


Figure 6.6: Outline of steps undertaken for IPA (adapted from Smith et al., 2009)

⁵ Analysis of interview data commenced in mid-2021. As such, a significant portion of the analysis had been undertaken before the publication of Smith et al.'s second edition of their book, *Interpretative Phenomenological Analysis: Theory, Method and Research* (2022). As per the suggestion in Smith et al., (2022, p. 76) the researcher continued to follow the steps and terminology outlined in Smith et al. (2009), rather than changing to the new terminology midway through the analysis.

⁶ Due to the low number of interview participants from students' support networks, analysis of the data as case studies presented a risk of breaching participant confidentiality. Therefore, data collected through interviews with members of the autistic student participants' support networks were analysed together as one group (support network).

Microsoft Word was utilised for the development of themes as it enabled engagement with the emergent themes in a flexible, visual manner as the analysis progressed. This strategy was also appropriate as it enabled the use of visual tools, which aligned the researcher's strength and preference for manual and visual processing of information.

6.5.1.1 Step 1: Transcription.

All interviews were transcribed by the researcher, which enabled the researcher to familiarise herself with the transcripts from an early stage of the data collection and analysis process. Smith et al. (2009) suggested that IPA aims to focus on interpretation of the "content of the participant's account" (p.74), as such transcription of interview recordings did not include detailed transcription of prosodic aspects of speech, such as lengths of pauses, or non-verbal utterances (e.g., "um", "ah").

6.5.1.2 Step 2 and 3: Reading and Re-reading.

During this stage of the analysis, the researcher spent time immersing herself in the data by reading and re-reading the original transcripts. Initial observations and thoughts about each individual transcript were documented in a reflective journal. The process of reflective journalling can help to reduce feelings of overwhelm by allowing the researcher to document initial ideas and possible connections and put them aside; enabling them to re-focus on the data (Smith et al., 2009).

Reflexivity was also important during this stage of the analysis to ensure that the researcher was looking closely at participants' descriptions of their experiences. Whilst IPA acknowledges the importance of interpretation, it is critical that the participants' voices are "privileged as the source for the interpretive activity of the researcher" (Eatough & Smith, 2017, p. 14). Reflexivity as it was applied throughout the current research project is discussed further in Section 6.6.

Throughout the reading and re-reading of each interview transcript the researcher was also able to become more familiar with the overall structure of the transcript. This enabled her to begin to identify links between various sections of each transcript, where ideas were repeated, or in some cases contradictory statements were made.

6.5.1.3 Step 4: Initial Noting.

Smith et al. (2009) noted that there may in fact be overlap between reading and re-reading and the commencement of initial noting. Initial noting is a process in which the researcher begins making written comments and notes of anything of interest in the right-hand margin of the transcript (Smith et al., 2009). This was undertaken using hard copies of

each original transcript as suggested by Smith et al. (2009). The process of initial noting enabled the researcher to continue to develop familiarity with the transcript and begin to explore the semantic content and the participant's language use (Smith et al., 2009).

Initial noting focused on descriptive, linguistic, and conceptual comments. Descriptive comments were noted in black and were primarily focused on the content of the participants responses. Linguistic comments were noted in blue and focused on specific use of language, particular phrases, or the evidence of emotions or feelings being described. Conceptual comments were noted in red and focused on examination of the data at a more interrogative level, by reflecting on and questioning the data.

6.5.1.4 Step 5 and 6: Identification and Development of Emergent Themes.

Emergent themes were identified and noted in the left-hand margin of the transcript (Smith et al., 2009). Further development and organisation of superordinate themes and subordinate themes was then completed in Microsoft Word for each interview transcript. Figure 6.7 provides an example of initial noting and identification of emergent themes from one of the student interviews. Figure 6.8 provides an example of the early stages of development and organisation of superordinate and subordinate themes.

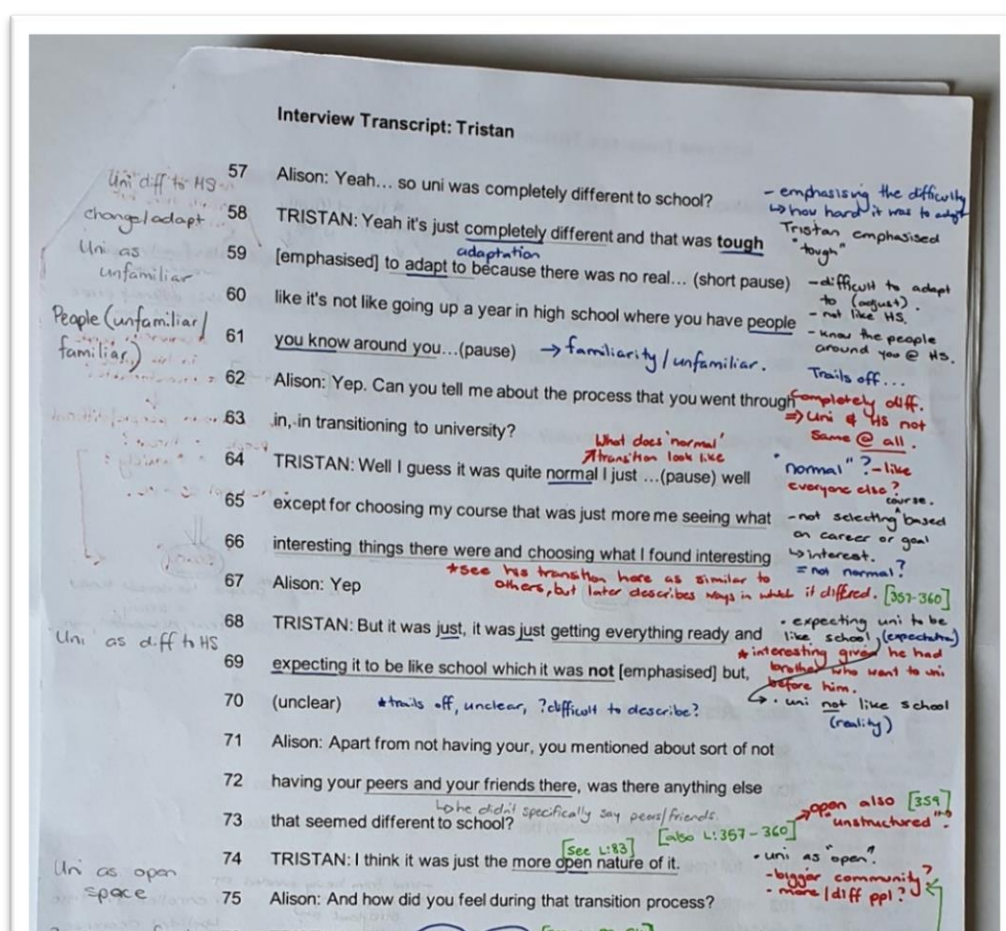


Figure 6.7: Example of initial noting and identification of emergent themes

Tristan		
Theme	Exemplar quote	Initial comments
Uni as occupation	"I came out high school going straight to <u>uni</u> because I had nothing better to do." (L: 51-52) "I guess [I was looking forward to] just learning more things." (L: 79)	"<u>uni</u> as something to do/occupation ~~"had nothing better to do"~~ No particular goal to go to <u>uni</u>? HS → <u>uni</u> as logical next step. <u>Continue on from high school - Continue to learn things</u>
Adapting to university		
Uni is completely different to high school	"<u>it</u> was just completely different to me, it, just because it wasn't like school where you had people you saw almost every day." (L: 54-56) "it's just completely different [to high school] and that was tough [emphasised] to adapt to because there was no real- (short pause) like it's not like going up a year in high school where you have people you know around you- (pause)" (L: 58-61) "<u>it</u> was just getting everything ready and expecting it to be like school which it was not [emphasised]" (L: 68-69) "I think it was just the more open nature of it [was different to school]" (L: 74)	Uni as different to high school <u>Completely</u> = emphasising just how different School you know the people/see the same (familiar) people Consistency/comfort/community (didn't feel this at <u>uni</u>?) <u>Completely</u> = emphasising just how different tough = emphasising just how difficult/hard it was to adapt Uni and HS not similar at all Difficult to adapt to (adjust) Not like high school Don't know the people around you (like you did at HS) Familiar v unfamiliar Expecting <u>uni</u> to be like school (expectation) Interesting given he had brother who went to <u>uni</u> before him. Uni not like school (reality) Uni as "open" Bigger community, more/different people
	"Like, at school at least- (short pause) (...) it's always people you know, like you know, this person passes you in a hallway or something like that, but at <u>uni</u> it is often times many different people at different times and- (pause) yeah" (L: 87-90) "I think there was [a difference between my transition and that of students without autism] because I- (pause) like, a sudden change is just so weird for me and I was so used to a general structure to every day (...) I guess it, it goes back to that thing of not really knowing anyone." (L: 357-360)	"open" also unstructured? HS – familiar people, <u>uni</u> – different people around him. Not talking about friends here, just people in general. People around him. People in his space Unknown people in his space = uncomfortable? Unknown people = threat, increased anxiety (-y&?) He finds it difficult to articulate these points. Uni not the same as HS. HS structure, people you know. Uni not. → Difficult to adapt to
Campus environment – open, noisy, unfamiliar	"<u>it</u> wasn't like school where you had people you saw almost every day." (L: 55-56) "it's just completely different [to high school] and that was tough [emphasised] to adapt to because there was no real- (short pause) like it's not like going up a year in high school where you have people you know around you- (pause)" (L: 58-61) "I think it was just the more open nature of it [was different to school]" (L: 74) "I guess [I felt] unsure, scared? [during the transition process]" (L: 76)	Uni as different to high school School you know the people/see the same (familiar) people Consistency/comfort/community (didn't feel this at <u>uni</u>?) <u>Completely</u> = emphasising just how different tough = emphasising just how difficult/hard it was to adapt Uni and HS not similar at all Difficult to adapt to (adjust) Not like high school Don't know the people around you (like you did at HS) Familiar v unfamiliar Uni as "open" Bigger community, more/different people "open" also unstructured? Transition unsure, scared negatives Fear Uni as larger more public space than high school

Figure 6.8: Development of emergent themes

6.5.1.5 Step 7: Identifying Connections Across Emergent Themes.

To identify connections across themes the researcher used: abstraction (grouping together similar themes under new superordinate themes); subsumption (an emergent theme acquiring a superordinate status); polarisation (focusing on differences between emergent themes, rather than similarities); contextualisation (identifying contextual or narrative elements within an analysis [temporal, cultural or narrative themes]); numeration (noting the frequency of particular themes); and function (examining themes in relation to their function within the transcript) (Smith et al., 2009). The researcher also noted line numbers of similar ideas and concept (in green), to begin identifying theme patterns across each interview.

Superordinate and subordinate themes underwent continued revision until a final set of superordinate and subordinate themes were developed. Revision of superordinate and subordinate themes included consideration of input from the autistic co-analyst (see Section 6.5.2) as well as debriefing, discussion, and feedback from the researcher's supervisors (FR, MB, and AR).

6.5.1.6 Looking for Patterns Across Cases.

After undertaking the analysis steps outlined above, patterns were explored across all eight transcripts. This process of cross-case analysis enabled the researcher to identify connections across cases and develop a table of superordinate and subordinate themes. These themes are presented and described in Chapter 8.

6.5.2 Role of the Co-Analyst

In line with the inclusive research practices described in Sections 5.9 and 6.2 embedded within this research, an autistic co-analyst was employed to analyse a sample of the case study data independently. This provided the opportunity for the co-analyst to provide input and feedback on the initial analysis process and provided the researcher with opportunities to debrief and reflect on her analysis and emerging themes, as well as identify and address potential biases during initial analysis. This also provided a focus for reflection during analysis of the remaining interview transcripts and survey responses.

The co-analyst analysed four interview transcripts (three students and one support person), which provided a representative sample of responses. The co-analyst and the researcher then met on three occasions to discuss and compare the emergent themes identified within these transcripts. Additional discussion of themes was undertaken asynchronously via email in between meetings to promote an open dialogue and discussion of the themes and ideas identified.

Due to the nature of a PhD project, there was limited scope for additional contribution from the co-analyst through the remainder of the data analysis, as the candidate is required to demonstrate independent research skills. However, the inclusion of the co-analyst added a significant strength to this research, as the researcher and co-analyst brought unique perspectives and experiences which enriched the overall project. Whilst acknowledging that there are diverse identities and experiences within the autistic community, this brought an important lens to the work and resulted in the production of rich, autistic-informed findings from the research.

6.5.3 Research Objectives Two and Three

RTA was used to analyse data collected from interviews with support network members, as well as survey data collected from family members, and university staff. Braun and Clarke (2022) outlined six phases which guide the RTA process (see Figure 6.9). Each phase is described in more detail below.

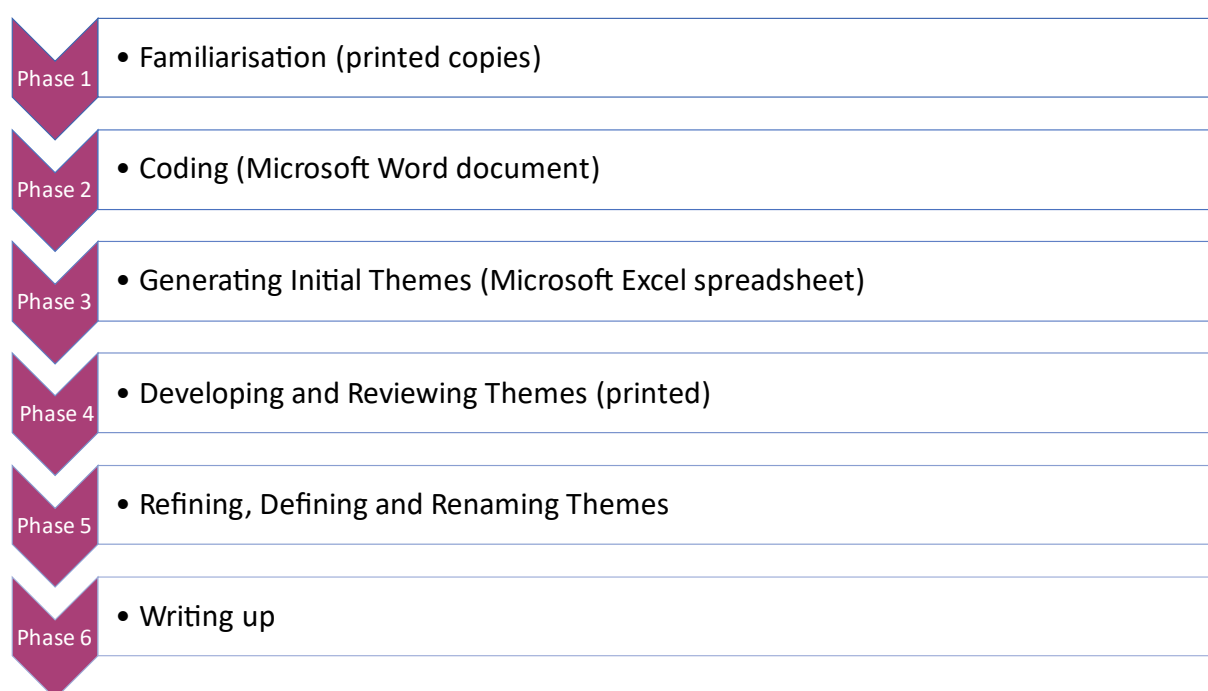


Figure 6.9: Outline of phases undertaken for RTA (adapted from Braun and Clarke, 2022)

6.5.3.1 Phase 1: Familiarisation.

The first phase of RTA requires the researcher to immerse themselves in the dataset, engaging deeply with the data through a process of reading and re-reading the data (e.g., transcripts, survey responses). Familiarisation of interview transcripts and survey responses was undertaken using printed copies.

During this phase the researcher noted initial thoughts, comments and ideas as they related to both an individual data item (e.g., one transcript) and the broader dataset as a whole (e.g., across transcripts) (Braun & Clarke, 2022). This enabled the researcher to become intimately familiar with the dataset as a whole, and to reflect on her own assumptions and perspectives (an example can be seen in Figure 6.10). Reflexive journaling was also undertaken during this phase (see Section 6.5).

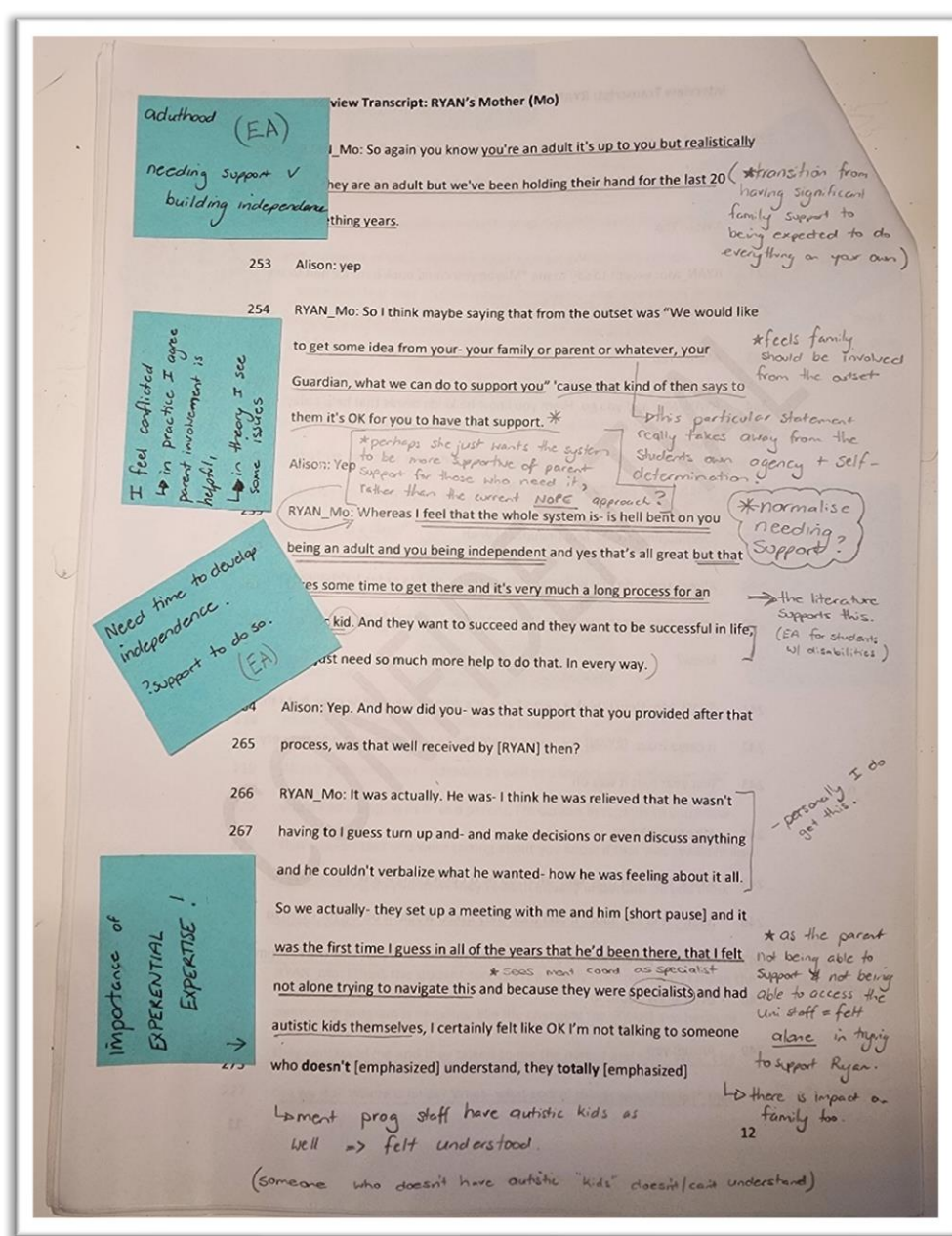


Figure 6.10: Example of notes taken during familiarisation phase of RTA

6.5.3.2 Phase 2: Coding.

Coding is a systematic process which involves the researcher once again reading each data item (transcript) closely and noting sections of the text which appear meaningful in

addressing the research question (Braun & Clarke, 2022). This process of meaning-making is both subjective and interpretive. Braun and Clarke (2022) acknowledged this subjectivity as a strength of RTA, rather than a weakness, resulting in a process of meaning-making which is not about identifying themes that exist within the data, but developing and generating themes through reflexivity and deep engagement with the data.

Coding of interview transcripts and survey responses was undertaken using Microsoft Word. Sections of text, which captured a single idea, concept, or meaning, were tagged using a succinct phrase, known as a code label (Braun & Clarke, 2022). Coding was undertaken using the comment function within word (see Figure 6.11), these comments and associated text were exported to a Microsoft Excel spreadsheet to assist with further phases of analysis (see Figure 6.12).

Interview Transcript: Ryan (DA)

142 Alison: How would you describe personally your own knowledge, |

143 experience and confidence when you're supporting students on the autism

144 spectrum?

145 RYAN_DA: I feel reasonably confident but you know I guess my support- the

146 support I provide is fairly minimal like it's giving them advice, drawing up

147 access plans- working out the adjustments they need, it's- we don't have

148 the capacity to see students regularly and provide that day-to-day support |

149 so for example if they come in they've got lots of issues they've enrolled full

150 time, you'll kind of say "look is that really the best idea? These are your

151 options." but you know that day-to-day kind of work with the students

152 sometimes we get a bit of input when they come in when they're struggling

153 or they need help planning but we really don't have the resources to work

154 intensively with these students, so we're very grateful that the mentors can

155 provide that level of support. Yeah so I feel pretty confident in my

156 knowledge of autism and the kind of support students need but I wouldn't

157 say I'm an expert in providing that day-to-day therapeutic type support that

158 they need yeah.

159 Alison: OK thank you. In your experience, what are some of the things that

160 you feel that other people in your role might need to know about autism

161 spectrum disorder before working with students in their first year?

162 RYAN_DA: [short pause] Probably [pause] just understanding what the key

163 issues are what the key impacts on study are [short pause] I guess it's also

164 very individual. Understanding each student's particular profile | do think an

165 awareness of sexuality and gender's important as well 'cause we get a lot of

166 students now having preferred names and preferred pronouns especially

7

Alison Nuske
Confident in own knowledge of autism
@mention or reply

Alison Nuske
Limitations to disability service support
@mention or reply

Alison Nuske
Limitations to disability service support
@mention or reply

Alison Nuske
Mentor role = bridge support gap
@mention or reply

Alison Nuske
Confident in own knowledge of autism (not an expert)
@mention or reply

Alison Nuske
What disability services staff need to know
@mention or reply

Alison Nuske
Autistic students are all different/individual
@mention or reply

Alison Nuske
Autistic students - LGBTQIA+
@mention or reply

Figure 6.11: Example of coding interview data using RTA (Microsoft Word)

36	Family support - emotional/practical	he'll [RYAN] say to me "I don't really know what to do" so I usually get him in the kitchen 9:00 o'clock at night almost in tears "I don't know what to do" and so I'll say "OK let's write down all the issues that you've got and let's make a plan and what we can do to resolve this" (FM)
37	Family support - emotional/practical	we write everything down, what are all the issues and then we go through all those issues and- and usually it comes out to "well have we talked to this person?" and "can we you know would it help if we go in this direction?" and once I've done all of that planning it'll either be "oh well I'll speak to the mentor and I'll tell him this" or "I'll speak to the professor and I'll ask them that" (FM)
38	Family support - emotional/practical	He always puts in for more work than he knows he can handle Alison: Yep RYAN_Mo: and then halfway through realizes he can't handle it and then falls apart Alison: Yep RYAN_Mo: and then I have to put that jigsaw piece back together again. (FM)
39	Family support - emotional/practical	I sit with him and say "tell me how you're feeling, tell me what the problem is, what's your- what are the hurdles here? What are the roadblocks?" all of those things and we navigate through it, usually what it comes down to is "OK well you're feeling really overwhelmed. Is this really important to do? Is this something we can put off 'til next year?" (FM)
40	Family support - emotional/practical	So I'm still going "well you know what that's great you turn up, you do the exams, you do the- do the work" you know (FM)
41	Family support - emotional/practical	I had to do so little after that person became- 'cause anytime [RYAN] he would come to me and I'd say well you know "let's talk about well what's- what are our options here?" and then we'd always come- "Oh I spose I could ask the mentor" and if it was a- so we had a couple of years where they were shit mentors but this last three have been pretty good, and those people were able to go "OK [RYAN] I'll meet you on this day. We'll talk about your problems, we'll talk about issues and we'll see what we can find out" and if they didn't know they would go find out and then come back to him. (FM)

Figure 6.12: Example of coding interview data using RTA (Microsoft Excel)

6.5.3.3 Phase 3: Generating Initial Themes.

The third phase of RTA involves generating initial themes, by looking for patterns of meaning across the dataset that share a core idea or concept. Themes are constructed by the researcher through an active process of review and analytic exploration (Braun & Clarke, 2022). Theme generation was undertaken manually by reviewing the code labels and relevant extracts and identifying patterns of meaning across each dataset (see Figure 6.13).

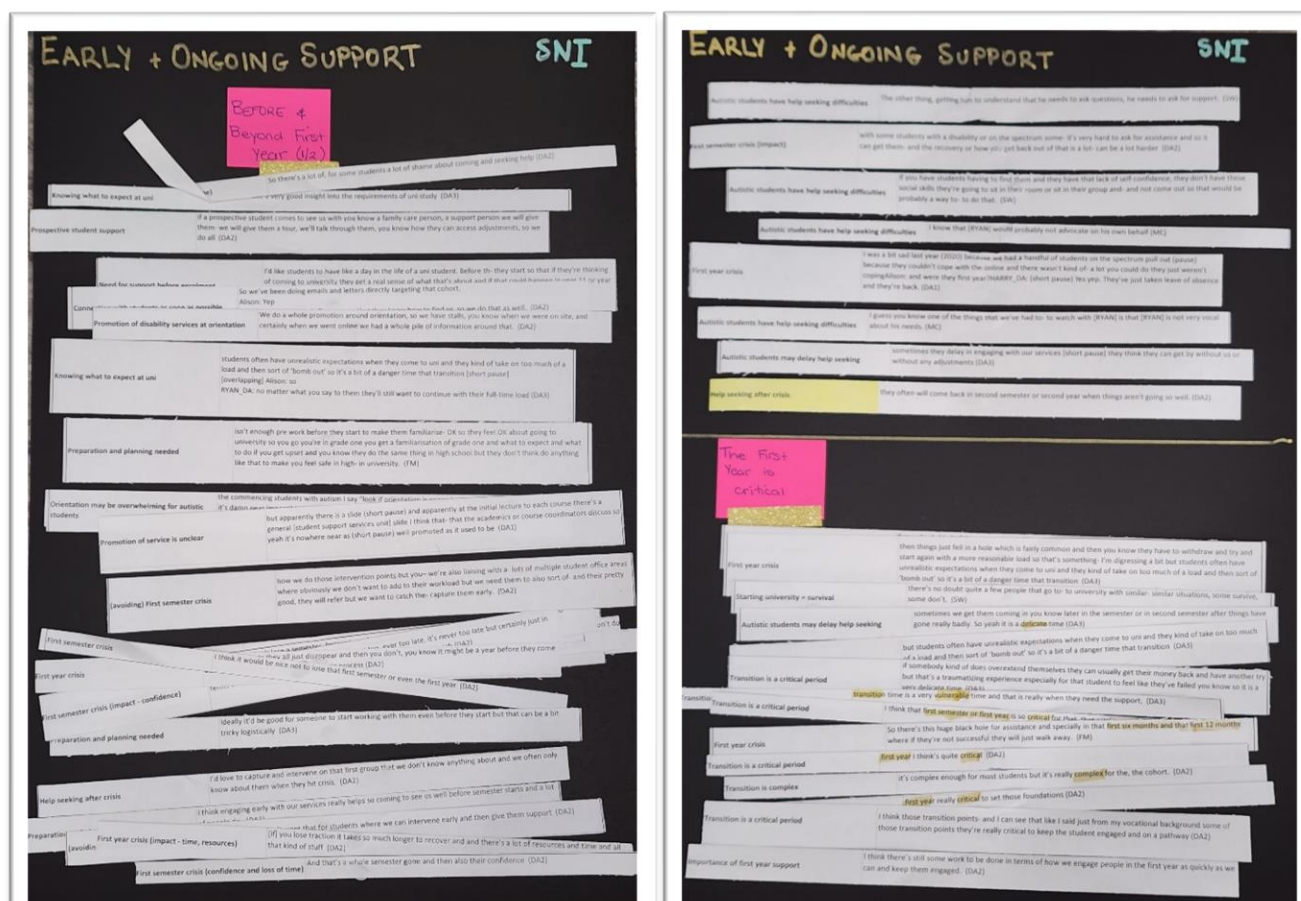


Figure 6.13: Example of theme generation from interview data

6.5.3.4 Phase 4: Developing and Reviewing Themes.

Following generation of initial themes, the researcher continually reviewed the themes against the full dataset to examine whether the themes made sense in relation to both the coded extracts and the dataset as a whole. Development and revision of themes also involved debriefing and discussion with the researcher's primary supervisor (FR). Theme development and revision was undertaken manually.

6.5.3.5 Phase 5: Refining, Defining and Renaming Themes.

Following initial theme development and review, themes were revised further to ensure that each theme was clearly articulated and developed around a strong core concept or idea (Braun & Clarke, 2022).

6.5.3.6 Phase 6: Writing Up.

The final phase of RTA involves writing up the themes. Themes developed during analysis of the support network interviews are described in Chapter 9, while themes developed during analysis of the online survey responses are described in Chapter 10.

6.6 Reflexivity

Reflexivity plays an important role in qualitative research (Braun & Clarke, 2013, 2022) and is a critical component of both IPA and RTA. Reflexivity requires the researcher to critically reflect on their role in the research project and the subsequent production of knowledge (Braun & Clarke, 2022). Reflective journalling enables the researcher to consciously acknowledge their own values and beliefs and reflect on personal assumptions, past experiences, and possible biases they may bring to the research project (Creswell & Poth, 2018; Ortlipp, 2008). In doing so, the researcher can become more consciously aware of these, often implicit, thoughts, perceptions and feelings and recognise how they may influence the research outcomes.

The researcher used reflective journalling throughout all stages of the research project, to record her thoughts, perspectives, and ideas as they emerged. Using a reflective journal enabled the researcher to reflect on what she brings to the research and recognise her own positioning throughout the project as a university disability advisor, an academic, and an autistic person. The researcher undertook reflective journalling during the development of the research project, throughout data collection, and during analysis to continually reflect on her thoughts and ideas as the project progressed. The use of a reflective journal allowed the researcher to document initial thoughts, observations, opinions, and interpretations, which helped her to become cognisant of potential presumptions or biases, and personal perspectives, and reflect on the ways in which they may potentially influence analysis of the data. For example, in the early stages of analysis of the data, the researcher noticed that she reacted negatively to comments from participants about poor communication from university or Disability Services staff. The researcher considered whether this might be a result of her own experience working within university Disability Services and made a note to be conscious of this perspective throughout the remaining analysis. An example of the researcher's reflective journalling, during the development of the theme: *"Deciding to Disclose is Complex"*, is presented in Figure 6.14. The researcher reflected on her previous assumptions that disclosure was a distinct, once-off event. Reflecting on this assumption helped the researcher to recognise the inherent complexity of disclosure. As a result, the researcher was also reminded of the importance of listening carefully to participants' descriptions of their experiences to ensure that such assumptions did not influence the analysis and outcomes of the research.

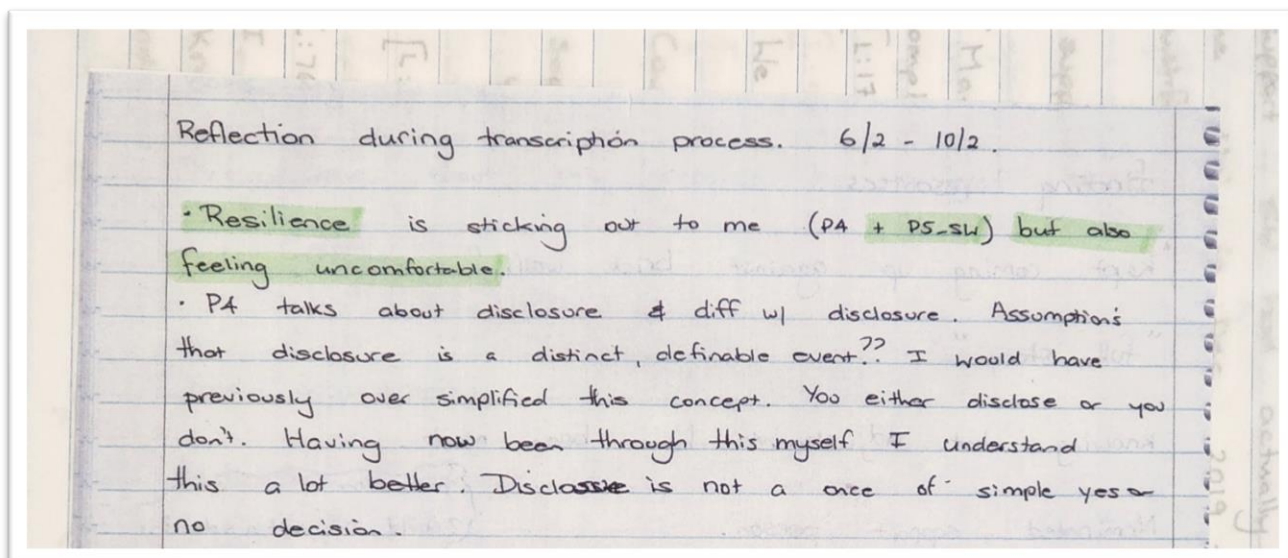


Figure 6.14: Example of reflective journalling

Reflexivity has also been demonstrated within this thesis through the inclusion of a researcher positionality statement (see Section 5.8).

6.7 Quality and Rigour

Yardley (2000) outlined four characteristics for quality in qualitative research: sensitivity to context; commitment and rigour; transparency and coherence; and impact and importance. Sensitivity to context refers to the ways in which the researcher demonstrates a sensitivity to the cultural context within which the study is being undertaken, the existing literature within the field, and the perspectives provided by the participants (Yardley, 2000). Commitment and rigour refer to the ways in which the researcher demonstrates a commitment and thoroughness to the data collection and analysis (Yardley, 2000). Transparency refers to the clarity with which the research is presented and described within the write-up of the study, while coherence refers to whether or not the researcher has presented a coherent and logical argument (Yardley, 2000). Coherence can also be determined by examining the appropriateness of the research in relation to the underlying theoretical assumptions being implemented within the study (Yardley, 2000). She argued that no matter how well a study is conducted, or how thorough the analysis, the “impact and utility” of the study is crucial (p. 223). The impact of the research must also be examined in relation to the context and the intended application of the findings. The ways in which these characteristics have been addressed within the current research are described below.

6.7.1 Sensitivity to Context

The researcher familiarised herself with the existing literature in the field by conducting a systematic literature review (Nuske et al., 2019; Chapter 4) prior to developing

the research question and objectives. This review informed the overall research design and methods. In addition, feedback and input from advisory group members was incorporated to ensure the study was respectful of relevant socio-cultural considerations (e.g., ensuring appropriate use of language and terminology applicable to the autistic and autism communities) (Yardley, 2000).

To ensure that participants felt their contribution was valued and would be represented authentically, time was allowed at the commencement of the interview to develop rapport with the participant. Student participants were provided with the opportunity to select their own pseudonym should they wish to do so; and were also able to inform the researcher of their language preference (identity-first or person-first) in line with recommendations made by Shakes and Cashin (2019). Narratives were then presented in keeping with this language preference for each participant.

Careful and immersive analysis was conducted to ensure that analytic claims were clearly grounded in the raw data. This was demonstrated through the use of verbatim extracts when presenting the raw data, which enables the reader to review the researcher's interpretation of the data (Smith et al., 2009).

6.7.2 Commitment and Rigour

Purposive sampling was used for surveys and case studies as it ensures participants have lived experience of the phenomenon being explored (e.g., transition to university for autistic students/supporting transition to university for autistic students) (Patton, 2002). Participants had the opportunity to share their experience of the phenomenon being explored, either anonymously via online surveys or via a phone or online interview. Interview participants were provided with the opportunity to review and approve the use of their transcripts prior to analysis. They were also able to provide additional information when reviewing their transcript if they felt they had not clearly articulated their perspective on any given topic.

As described in Section 6.5.2, the inclusion of a co-analyst provided a valuable opportunity for discussion and further exploration of the data. The researcher used a reflexive journal to reflect on her own positionality throughout the research, as well as regular debriefing and discussion with her supervisors. Feedback, reflection and debriefing also occurred organically throughout the data collection and data analysis process between the researcher and her supervisors. This provided an opportunity to discuss theme development and reflect on the process of analysis. This debriefing process between researcher and supervisors provides important opportunities for validation and reflection (Creswell & Poth, 2018). Furthermore, debriefing and discussion is not about seeking

approval or agreement on codes or themes, but rather about testing analytic ideas, engaging in critical questioning and scrutiny, and considering new possibilities (Braun & Clarke, 2022).

6.7.3 Transparency and Coherence

To ensure transparency and coherence within this research, a clear outline and overview of participant characteristics and the process undertaken to develop and conduct data collection has been provided, as recommended by Smith et al. (2009). A detailed account of the analytic processes is provided in Section 6.5.

Coherence was also achieved by ensuring there was alignment between the research being conducted and the underlying theoretical assumptions of the research (Smith et al., 2009; Yardley, 2000). Careful consideration of the theoretical framework was undertaken during the development of the research question, objectives, and methods of data collection (including the survey and interview questions). The theoretical framework was considered throughout all stages of development and implementation, to ensure that data collected would be truly representative of the complex bioecological elements which are at play. The inclusion of family members, university staff, and other support staff as participants also ensured that data collected explored the various bioecological elements within this experience. Questions in the online surveys and interviews also took into consideration the bioecological elements that may impact participants' experiences. Therefore, the bioecological theory model provided a coherent theoretical framework threaded throughout this research and resulting thesis.

6.7.4 Impact and Importance

The current research presents an exploration of the experiences of transition to, and first year of university for autistic students in Australia. Thus, the purpose of this research was to provide researchers, disability practitioners, and university staff with a better understanding of the transition experiences of autistic students in Australia. The findings have practical implications for supporting autistic students, and creating a more inclusive university for all students, which will inform future policies, practices, and recommendations both within Australian and internationally.

6.8 Chapter Summary

This chapter has outlined the ways in which participants' experiences of transition to university for autistic students were collected and analysed. The chapter presents the data collection methods, including ethical considerations and inclusive research practices, along with an overview of the process for data analysis. Finally, the chapter addresses the ways in which rigour and quality measures were implemented within this research. The following

chapter presents a narrative overview of autistic students who took part in the case study component of this research project.

7 ANALYSIS: STUDENT NARRATIVES

As part of a series of case studies, autistic students were interviewed to explore their experiences of transition to, and first year of university in Australia. This chapter presents a narrative description of these experiences, using the bioecological theory model (see Chapter 3) as a framework. In keeping with the idiographic approach of IPA, the narrative descriptions presented in this chapter provide a “detailed examination” of each participant’s personal situation (Smith et al., 2009). IPA aims to describe, explore, interpret, and understand a particular phenomenon as it has been understood by those who have experienced it (Cuthbertson et al., 2020; Emery & Anderman, 2020).

Quotations have been presented verbatim throughout this thesis. To improve readability, phrases such as “you know” and “like” have been removed from quotations used. Clarification of terminology is noted in parentheses (), missing words are displayed within square brackets [], and a hyphen has been used to identify an unfinished statement –. Where segments of quotes that did not provide significant meaning have been removed, they have been replaced by three dots within parentheses (...). All participant quotes have been italicised to distinguish them from interpretations and analytical comments, and bold text has been used to indicate words emphasised by participants themselves.

7.1 Student overview

A summary of student participant characteristics is presented in Table 7.1. Four students had received their formal diagnosis of autism spectrum disorder, autism, or Asperger’s syndrome during childhood, while three received their formal diagnosis in adulthood. One student (Harry) who had been diagnosed in childhood, also sought a re-assessment in adulthood to confirm the diagnosis. Two students had transitioned directly from high school to university, four students were returning to university after at least one previous attempt, one student had transitioned to university via a university pathway program (a preparatory program designed to assist students who did not meet direct university entry requirements to gain entry into a bachelor’s degree), and one had transitioned to university through a vocational education pathway. Co-occurring medical or mental health conditions were not asked about specifically during interviews; however, six students mentioned at least one co-occurring condition during their interview (i.e., ADHD or mental health issues such as anxiety or depression).

Table 7.1: Student participant overview

Participant ⁷	Sex	Age (at time of interview) (years)	Age at diagnosis	Pathway to current degree	Additional disability/health/mental health condition (disclosed at interview)
Conrad	M	20	<18	Direct from high school	Mental health issues (anxiety)
Ester	F	30	>18	Previously attempted university TAFE	Mental health issues (anxiety)
Harry	M	25	<18*	2 previous attempts at university	ADHD
Kimberley	F	36	>18	Previously attempted university	ADHD and mental health issues (anxiety)
Ryan	M	26	<18	2 previous attempts at university	ADHD and mental health issues (anxiety, bipolar, depression)
Sean	M	23	<18	Vocational Education pathway (TAFE)	Yes (anxiety)
Taylor	Prefer not to say	21	>18	University pathway program	Mental health issues (depression)
Tristan	M	19	<18	Direct from high school	Anxiety

*Re-assessed as an adult.

7.2 Access Plans

Six students provided copies of their access plans for inclusion in this study. In total, nine access plans were provided as some students had undertaken cross-institutional study. Not all access plans provided were developed during the student's first year of university. However, the access plans provided do offer an overview into the way in which support and reasonable adjustments are communicated. As such, a descriptive summary of access plan characteristics is presented here.

⁷ Pseudonyms have been used to maintain participant confidentiality.

Only one of the access plans provided included the student's diagnosis (Asperger's Syndrome), and most statements outlining support needs within each of the plans were generic in nature. For example: "Student may take longer to complete assessment and study tasks". Although only one of the access plans included specific reference to the student's diagnosis, some included support need statements that may have been seen as more specifically related to the needs of autistic students, such as: "Student may have difficulties with processing large amounts of information", "Student may have difficulty reading social cues, impacting communication", or "Student may have difficulty coping with major changes". However, only one access plan provided suggestions that addressed support needs specific to autistic social-communication difficulties. In this case, information was provided to encourage "clear and concise" communication which avoids "ambiguous language". Two access plans included recommendations for additional time for clarification due to information processing difficulties. One access plan provided detailed guidance for supporting the student with participation in group work activities.

Half of the access plans were ongoing or permanent, while the other half were temporary in nature (approx. 12 months). Additionally, communicating the need for adjustments as outlined in the access plan was predominantly the responsibility of the student themselves. Reasonable adjustments outlined in the access plan included extensions on assignments, the option to negotiate alternatives to oral presentations, breaks from class, and participation/attendance adjustments. Exam accommodations included extra time to complete the exam, rest breaks during the exam, scheduling adjustments (such as only sitting exams in the afternoon), and sitting exams in a smaller or alternative venue. Only one access plan clearly identified referral to mainstream student support services (academic skills support) as a recommended support. The access plan also indicated that contacting the service was the responsibility of the student.

Overall, student access plans were general in nature and did not specify the student's disability, instead describing the impact of their disability on their studies. However, some statements included in access plans did appear to allude to autism, by describing autism specific impacts such as social-communication difficulties. Communication of support needs was most often the responsibility of the student. Accommodations provided generally addressed issues with executive functioning, social-communication, or sensory needs.

7.3 Conrad

Table 7.2 provides an overview of the range of bioecological theory model elements as they apply to Conrad's experience of transition to university. Each of these elements is then discussed in more detail below.

Table 7.2: Overview of bioecological theory model elements – Conrad

Individual	Microsystem	Mesosystem	Exosystem	Macrosystem
Conrad Male 20 years old Looking forward to: career & learning about things of interest to him Diagnosis (Asperger syndrome) in childhood Anxiety Social-communication difficulties – adjusting to new people Executive functioning/cognitive difficulties - time management & organisation Transitioned directly from high school to university First year full-time	Family (parents) - emotional support Friend and cousin – mostly positive interactions Sibling (had already attended university) – no direct support Academic staff – mostly positive interactions Disability Services and university counselling service - Did not access support in his first year Private clinical psychologist - provided insight into university experience	Interactions between Conrad & his family, friend, cousin, academic staff & private psychologist No interactions between microsystem elements	NDIS – not accessing Disability Discrimination Act (DDA) – aware of Disability Standards for Education (DSE) – not aware of	Not discussed

7.3.1 Individual

At the time of his interview (December, 2020) Conrad, a 20-year-old male student, had just completed the second year of his studies in an undergraduate degree in the social sciences. Conrad was looking forward to learning more about things he was interested in and working towards a career. Conrad also described looking forward to studying at university as he: *“did not like [the] high school environment”* and was *“looking forward to interacting with a variety of people”* (Conrad, 197-198)⁸ in a *“more professional”* environment.

⁸ Line numbers have been included in parentheses, which identify the extract within the flow of each interview.

7.3.1.1 Autism/Autistic Identity.

Conrad indicated that he was diagnosed with Asperger syndrome in childhood. At several points during his interview, he used the term *“intellectual disability”* when referring to himself or other people on the autism spectrum. Conrad indicated that he preferred person-first language (person with autism), although throughout his interview Conrad regularly referred to people *“on the autism spectrum”*.

Conrad suggested that autism had impacted on his transition to university. When asked how being on the autism spectrum may have made his transition different to that of other students, he stated: *“being on the spectrum for autism I feel like (...) we tend to experience more anxiety like a high level of anxiety in terms of socialising and in terms of adjusting to new environments”* (Conrad, 593-595).

Individual characteristics associated with autism that may have impacted on his transition to university, discussed by Conrad in his interview, included difficulties with executive functioning and cognitive processing skills, such as time management, motivation and organisation; and social-communication difficulties, particularly adjusting to new people and environments. Conrad also described feelings of anxiety and nervousness in relation to his transition, describing his first few weeks at university as: *“definitely (...) completely full of nerves [laughing] (...) I was just very, very nervous”* (Conrad, 104-106).

7.3.1.2 Pathway to University.

Conrad transitioned to university in 2019, after completing his final year of high school in 2018. Conrad was initially enrolled in a degree in a social science field. At the time of the interview (2020) he had transferred into a double degree in a similar area, which was broader and which he felt would provide him with more *“practical”* experience.

7.3.1.3 Learning Modes.

Conrad initially enrolled in full-time studies; however, in 2020 he enrolled part-time to enable him to explore volunteering opportunities to *“extend [his] resume”*. At the time of the interview, he was planning to return to full-time studies in 2021. Conrad’s initial enrolment was on-campus/face-to-face, although in his second year his classes had transitioned to online due to the COVID-19 pandemic restrictions. Conrad indicated that he had found online learning *“really limited us [peers in class] from being able to interact with one another”* (Conrad, 262-263) and that he hadn’t *“found it as rewarding (...) in terms of how am I [sic] grasping the knowledge well to develop as a professional in terms of working with people and interacting with others”* (Conrad, 259-261). Conrad explained that his preference would be to return to study on-campus/face-to-face in the future.

Conrad indicated that although he preferred to attend his classes on-campus/face-to-face, he would often choose to complete other study-related tasks from home: *“I feel like at home I’m used to everything and I can really focus a bit more and not worry about the environment around me so much”* (Conrad, 272-274).

7.3.2 Microsystem and Mesosystem

At the microsystem level, Conrad reported receiving practical support from his family, in particular his mother who he described as *“definitely very- very supportive”*. His family provided him with a supportive study environment, by making sure *“the environment [was] comfortable enough for us [Conrad and his brother] to really focus on [their] studies”* (Conrad, 412-413) without distractions. Conrad’s parents also helped by providing him with opportunities to talk with them about topic areas he was having difficulty with, to try to understand them better. Conrad also explained that he had regular contact with his clinical psychologist.

During his first year, Conrad had support from a cousin who had previously studied in a similar field to him at the same university. Conrad’s cousin was able to answer questions he had relating to university expectations and policies. Conrad indicated that his brother had also studied at university but did not provide any direct support to him during his first year at university.

Conrad had positive interactions with a friend he had attended high school with who was also enrolled in the same classes, at the same university. However, Conrad noted that he had missed out on opportunities to make new social connections with other peers at university. He explained:

In the first year [at university] (...) I was trying to adjust so much to a university lifestyle and on campus and things like that (...) I really prioritised that over meeting new people and going to certain events and workshops and things like that (Conrad, 531-540)

He reported both positive and negative experiences with academic staff, although these were mostly positive. For example, Conrad reported positive experiences seeking clarification on assessments from one of his course coordinators, but he also noted that some academic staff took a more *“clinical”* approach and were *“very black and white in terms of policies (...) and things like that”* (Conrad, 751-752). Conrad did not access Disability Services in his first year of university, as he was not aware that these supports existed until they were suggested to him by an academic staff member at the end of his first year.

Conrad reported interactions (mesosystem) he had with friends, family members, and staff during his transition to university; however, he did not report any interactions between support networks.

7.3.3 Exosystem

Conrad was aware of the DDA and DSE. Although he was not sure how they may have benefited him during his studies, he did know there “*were laws to protect people who have an intellectual disability [sic]*”. Conrad also stated: “*I didn't know (...) how to go about it and how to apply it to help [me] personally*” (Conrad, 683-685). Conrad had not accessed any supports via the NDIS.

7.3.4 Macrosystem

Conrad did not directly discuss the broader societal or community perception of disability, autism, or social inclusion at the macrosystem level during his interview.

7.4 Ester

Table 7.3 provides an overview of the various bioecological theory model elements as they apply to Ester's experience of transition to university. Each of these elements is then discussed in more detail below.

Table 7.3: Overview of bioecological theory model elements – Ester

Individual	Microsystem	Mesosystem	Exosystem	Macrosystem
Ester Female 30 years old Looking forward to: career change & learning something new No formal ASD diagnosis until after first year Anxiety Social-communication difficulties Executive functioning/cognitive difficulties - time management & organisation Returning to university after previous attempt 10 years prior First year full-time	Peers & friends from same degree – mostly positive Academic staff – mixed University counselling service – positive Disability Services- Did not access support in her first year Family – no support	Ester interacted with her friends/peers, a counsellor, an academic staff member Friends/peers, counsellor, academic staff member did not interact with each other	NDIS – not accessing Disability Discrimination Act (DDA) – aware of Disability Standards for Education (DSE) – not aware of Institutional policies & practices (Orientation program) - positive	Social & cultural understanding of autism – perception that others have “old school” views & (mis)understanding of autism Systemic barriers to accessing a formal autism diagnosis

7.4.1 Individual

At the time of her interview (December, 2020) Ester, a 30-year-old female student, was in her second year of an undergraduate degree in a science field. Ester was looking forward to “*seek[ing] a career change*”. She also stated that she was looking forward to: “*learning something new (...) entering a new field in a field that I thought would be really interesting*” (Ester, 196-197).

7.4.1.1 Autism/Autistic Identity.

Ester did not receive her formal autism diagnosis until after she had completed her first year of university in her current degree. She also did not identify as being autistic during her first year of this degree, or during her prior attempt at university. Ester acknowledged during her interview that her own understanding of autism was still developing, stating: *“I’m not saying that I know everything [about autism] either, I’ve only known (...) the little that I’ve been told and what I’ve read”* (Ester, 694-696). When asked whether she had a preference to be referred to using person-first or identity-first language, Ester stated: *“I have never thought about that before so no [laughing]”* Ester added: *“I don’t identify as autistic anyway (...) if I have to I say I have a neurological condition”* (Ester, 22-23). However, she did refer to *“being autistic”* once during her interview, and also when providing clarification to a statement in her interview during her review of the transcript she referred to fostering *“a more inclusive environment for autistics”*.

Ester described difficulties associated with executive functioning skills, such as time management and organisation. For example, Ester described finding it difficult to *“break stuff down to plan it [and] ascribe some time frame to it”* (Ester, 421-422). She also described verbal and auditory processing difficulties that had impacted her previous attempt at university. Although at the time of her previous attempt at university, 10 years earlier, she had not attributed these difficulties to autism specifically, she reflected in her interview that she had since recognised many of these difficulties as now being related to her autism diagnosis. She explained: *“at the time (...) for lack of a better word to describe it I just thought I was stupid”* (Ester, 130-131). Ester accessed online resources prior to her return to university in 2019, to seek out specific strategies that would assist her to address these challenges.

Ester reported having some concerns about her ability to make and maintain friendships when she returned to university in 2019. Ester also described anxiety as *“probably one of my biggest issues”*, which led to a *“manic sort of feeling”* that *“really drained me”*. She also noted that the anxiety she experienced was perhaps different to the anxiety experienced by non-autistic students.

7.4.1.2 Pathway to University.

Ester completed her secondary schooling in 2008 and subsequently enrolled in an undergraduate degree in the social sciences area in 2009, which she did not complete. After deciding she wanted to pursue a career change, Ester undertook a six-month vocational education course through TAFE in 2018, to see if she may be interested in the science field she was considering. Subsequently, Ester returned to university studies in 2019 to undertake a science degree.

7.4.1.3 Learning Modes.

In her first year of her current degree Ester enrolled full-time. At the time of the interview Ester reported continuing to study full-time, apart from a brief period of part-time studies, coinciding with her diagnostic assessment and other personal difficulties. Ester reported that full-time studies were her original preference as she *“had nothing else to do”* and felt that if things *“got too much [she] could drop out”*.

Ester was enrolled on-campus/face-to-face in 2019, although in 2020 Ester’s classes had transitioned to online study due to the COVID-19 pandemic restrictions. Ester reported that she preferred on-campus studies because it was *“a good way to (pause) get out and do stuff”* (Ester, 245-246), although she also reported that coming to campus created additional stress for her as it required *“preparing mentally for all the interactions that I might have on my way there, while I’m there, and on my way back”* (Ester, 264-266).

7.4.2 Microsystem and Mesosystem

At the microsystem level, Ester sought formal support from a university counsellor during the first year of her current degree in relation to her anxiety and some social interaction difficulties she was experiencing. Ester reported that the university counsellor also assisted her with the process of accessing a diagnostic assessment for autism spectrum disorder.

Even though Ester experienced some social interaction difficulties in the first year of her current degree, she also discussed peer relationships that supported her during this time. She reported close relationships with peers and friends that had developed during her orientation program. Ester discussed these relationships throughout her interview and explained that making friends at orientation *“helped a lot”*, and that she and her peers *“actually helped each other out with a lot of assignments and stuff and that really helped too”* (Ester, 438-439).

Ester reported receiving no supports from her family members; however, the reasons for this were not discussed. When asked about support provided by her family, she noted *“I haven’t told my family or friends at all [about the diagnosis]”* (Ester, 365). Ester reported mixed experiences (positive and negative) with academic staff members. She described some academic staff as *“pretty helpful”*. However, one academic staff member *“made fun of me a fair bit when I couldn’t [do] what she wanted me to do”* (Ester, 659-660). Although Ester interacted with peers, friends, and staff at her university (mesosystem), she did not discuss any ways in which these support networks interacted directly with each other.

7.4.3 Exosystem

At the exosystem level, the elements that impacted Ester's transition and first year were primarily associated with her university's policies and practices. For example, Ester did not try to access the Disability Services, as she did not feel that she would meet the eligibility criteria without a formal diagnosis. It is unknown whether the institutional policy relating to accessing Disability Services would have deemed her ineligible; however, Ester explained that her lack of contact with the services was because she felt she was *"not able to (...) without the (...) diagnosis"*. Thus, it was not until Ester's second year at university, when she received a formal diagnosis, that she was able to access Disability Services.

Ester also discussed her experiences taking part in her degree's orientation program. This institutional practice was discussed at numerous points throughout her interview, and Ester noted the benefits she experienced from taking part in the orientation program, including having the opportunity to meet and make friends with other students in her degree.

Ester indicated that she knew there was some sort of disability discrimination legislation, but that she was unfamiliar with the specific details of the relevant legislation (i.e., DDA, DSE). As Ester had not received a formal diagnosis prior to her first year at university, she had not been able to access NDIS funded support during this time. She did not indicate whether she was considering seeking NDIS funded support in the future.

At this broader exosystem level, Ester also described systemic barriers that impacted on her ability to seek a formal autism diagnosis prior to her return to university, including the length of waitlists and the cost of the diagnostic assessment. Ester explained that she *"was on that waiting list [for an autism diagnostic assessment] for six months (...) needed the money as well to do it (...) so that's another barrier"* (Ester, 557-560). Understanding the process of seeking a diagnostic assessment also proved to be a barrier for Ester:

I had seen a psychiatrist maybe a year or two before I started planning [my return to university], and she made a comment about how I might have Asperger's (...) but I didn't understand enough of it and at the time I didn't have enough money or access to information to— even the know-how to see whether I actually was or not (Ester, 137-142)

After her interview, while reviewing her transcript Ester added:

I think there should be more access to [university counselling etc] for people like me, that haven't yet been diagnosed but think they may be neurologically divergent or are waiting to be diagnosed. Especially during an era when so many of us are falling through the cracks (Ester, 401-405)

7.4.4 Macrosystem

Ester also discussed the impacts of socio-cultural beliefs (macrosystem) on university staff knowledge, understanding, and attitudes towards autism. Ester referred to some staff perceptions as being “*old school*” and suggested that staff should be encouraged to reflect on their own knowledge and understanding of autism. In one reflection, while reviewing her transcript, Ester added:

With the popularity of conspiracy theories and misinformation involving autism, understanding how easy it is for people to fall for common attitudes and mistruths (...) it would be important [for staff] to learn ways to check themselves and being receptive of being checked on possible mistruths [they] may believe (...) a rise in awareness for university staff in these areas should foster a more inclusive environment for autistics
(Ester, 676-682)

7.5 Harry

Table 7.4 provides an overview of the various bioecological theory model elements as they apply to Harry's experience of transition to university. Each of these elements is then discussed in more detail below.

Table 7.4: Overview of bioecological theory model elements – Harry

Individual	Microsystem	Mesosystem	Exosystem	Macrosystem
Harry Male 25 years old Looking forward to: real world experience Diagnosis (Asperger syndrome) in childhood. Re-assessed in adulthood (ASD & ADHD) Executive functioning/cognitive difficulties - time management, organisation, planning, & prioritising Previous attempt at university First year full-time	Family – practical support (living at home) Disability Services – Access Plan (current degree) Study support – peer tutoring	Interactions between Harry & his family, Disability Services staff & study support sessions No interactions between microsystem elements	NDIS – not accessing Disability Discrimination Act (DDA) – aware of Disability Standards for Education (DSE) – not aware of Institutional policies & practices (Study support program) - positive	Social & cultural understanding of autism – societal awareness of autism

7.5.1 Individual

At the time of his interview (December, 2020) Harry, a 25-year-old male student, was completing an undergraduate degree in the social sciences. Harry indicated that in starting his current degree he was looking forward to gaining real-world experience, through placement opportunities in his chosen field. Harry explained however, that he was not able to complete any placements during his degree. Harry stated that his university had been unable to find a suitable placement for him to undertake, even though he had *“tried approaching lots of different places”*. Harry stated that concerns had been raised about his *“safety”* on placement after his initial visit to one of his potential placement settings. However, he did not elaborate as to why this had been the case, so it is unclear whether this was directly related to autism.

7.5.1.1 Autism/Autistic Identity.

Harry was diagnosed with Asperger syndrome in early childhood. He also noted that he was reassessed in his twenties and received a dual diagnosis of ADHD and autism spectrum disorder. When asked, Harry indicated that he did not have a preference between identity-first and person-first language and suggested he would be happy with the term *“person on the autism spectrum”*; this was also consistent with the language Harry used throughout his interview.

Harry had difficulties accessing support during his first attempt at university as he was unable to locate his original formal assessment report for Asperger syndrome, which he had been informed was required to access the Disability Services. He therefore sought an updated diagnostic assessment from a psychologist, prior to commencing his most recent degree. The psychologist diagnosed him with both autism spectrum disorder and ADHD. After receiving the dual diagnosis Harry was prescribed medication, which he described frequently during his interview as improving his concentration and memory.

Harry described difficulties with executive functioning skills such as concentration, planning, time management, organisation, and prioritisation of tasks. Harry indicated that he did not experience any sensory difficulties, nor did he identify any social-communication difficulties.

7.5.1.2 Pathway to University.

A few years prior to his interview, Harry had been accepted into his first preference degree in a medical sciences field but had not been able to complete this degree. Harry returned to university studies at a different university a few years later to study in the social science field. Harry had completed this degree a few weeks prior to his interview.

7.5.1.3 Learning Modes.

Harry indicated that he completed his degree studying full-time throughout. Harry explained this was because he wanted *“to get the degree done as quick as possible 'cause [sic] I'd already dropped out twice”* (Harry, 307-308). Harry indicated that he preferred online study due to its flexibility. He also reported that some of his courses were online from the first year and subsequently all moved online in his final year (2020) due to the COVID-19 pandemic restrictions. Harry explained this *“made life a lot easier”* and had assisted in him remaining in full-time study. Harry preferred to complete other study-related tasks from home as he found it easier than going to campus, but sometimes he would study on-campus if he needed to minimise distractions.

7.5.2 Microsystem and mesosystem

Although Harry noted that he was living with his family at the time of his transition to his current degree, he did not describe any additional study-related supports provided by them during this time. Harry also described accessing support from a disability advisor within the Disability Services team to set up an access plan. Harry felt that some university staff, particularly academic staff came across as *“arrogant”* or *“cocky”*. Harry noted a preference for being able to seek clarification of requirements and tasks directly from the relevant academic staff, rather than in broader general settings such as discussion forums. Staff who enabled this type of direct interaction were identified as being more *“approachable”*.

Harry provided minimal detail about interactions he had with his support networks. He noted that the only interactions he had with a disability advisor were for the purposes of setting up his access plan. Harry also explained that he was aware of the existence of Disability Services at his current university after having had contact with the Disability Services at his first university. Harry had not set up an access plan at his first university as he was informed that he would need a copy of his diagnostic assessment or other supporting documentation to do so, which he reported he could not access.

7.5.3 Exosystem

At the exosystem level Harry noted that he was contacted via email in his first year by a second- or third-year student mentor to see if he required any support. He explained that he did not access any direct support from the mentor. Harry also discussed accessing a peer-based tutoring support group provided by his university. He noted that this study support was *“very helpful”* and *“helped a lot with the exams”*. Harry was aware of the existence of the DDA, but *“not in great detail”*. Harry was not familiar with the DSE and was not accessing NDIS funded support.

7.5.4 Macrosystem

Harry mentioned how society’s awareness and understanding of autism had shifted in recent years. Specifically, Harry noted: *“most people would know something about [autism], there’s all this awareness now. More people getting diagnosed”* (Harry, 24-26). Harry did not comment further on societal or community understanding of autism.

7.6 Kimberley

Table 7.5 provides an overview of the various bioecological theory model elements as they apply to Kimberley's experience of transition to university. Each of these elements is then discussed in more detail below.

Table 7.5: Overview of bioecological theory model elements – Kimberley

Individual	Microsystem	Mesosystem	Exosystem	Macrosystem
Kimberley Female 36 years old Looking forward to: having purpose, working towards something No formal ASD diagnosis until after first year Additional diagnoses: mental health (generalised anxiety disorder), ADHD Social-communication difficulties Executive functioning/cognitive difficulties - time management & organisation Sensory processing difficulties & auditory processing difficulties Previous attempt at university First year part-time	Family – emotional support Disability Services (due to ADHD diagnosis) – positive University counselling service – mixed Therapist – CBT Peer friendship (fellow mature aged student) - positive Other students with disability – positive Academic staff member (lecturer) – positive Academic staff (tutors) – mixed	Interactions between Kimberley & her family, friends, peer, university staff & therapist No interactions between microsystem elements	NDIS – not accessing Disability Discrimination Act (DDA) – aware of Disability Standards for Education (DSE) – not aware of Institutional policies and practices (Orientation program) - mixed Institutional policies and practices (Mentoring program) – chose not to engage	Social & cultural understanding of autism – impact on institutional disability awareness

7.6.1 Individual

At the time of her interview (September, 2020) Kimberley, a 36-year-old female student, was enrolled in an undergraduate arts degree in a social sciences field. Kimberley had previously attended university “*in her twenties*” and disclosed that prior to returning to university in 2017, she had experienced a period of depression. She reported that returning

to university had contributed to a feeling of “*having a purpose*” and explained: “*doing something working towards something (...) having the choice and the ability to learn things all of that meant a lot*” (Kimberley, 248-250).

7.6.1.1 Autism/Autistic Identity.

At the time of the interview Kimberley had only recently undergone an assessment for autism spectrum disorder, had received verbal confirmation of the diagnosis, and was awaiting her formal diagnostic report. Therefore, she did not have a formal diagnosis of autism during her first year at university in her current degree, nor during her initial attempt at university. Kimberley had experienced difficulties during her initial attempt at university in her 20s and explained that she had attributed these difficulties to “*mental health related problems*”. She also has ADHD, which was diagnosed in childhood, and has experienced mental health issues (e.g., anxiety). Kimberley’s identity reflected multiple aspects of her experience: as she described: “*I’m a mature age student I have mental health problems and I have a disability, autism*” (Kimberley, 411-412). When talking about her experiences of disclosing her support needs prior to her autism diagnosis, Kimberley explained:

I occasionally talked to people as needed I’ve got[ten] a little bit more open about it (...) that I have a disability this is my needs and that I have ADHD and mental health issues I’ve gotten a little bit more open about that as I go on (Kimberley, 1016-1020)

When asked whether she had a preference to be referred to using person-first or identity-first language, Kimberley stated: “*I’m not worried at all*”, although she also noted that many people in the autism related Facebook groups she had joined “*prefer to use the [sic] autistic person*”. Kimberley predominantly used identity-first language throughout her interview.

Kimberley suggested that being on the autism spectrum had made her transition to university “*massively*” different to that of other students. Kimberley stated:

I hear things differently (...) learn things in a different way and have to take an entirely different approach (...) have to ask a lot more questions (...) maybe just because of the communication styles that people are teaching [the material] to me, [and] I have to do a lot around stress and anxiety management (Kimberley, 814-820)

Individual characteristics that impacted on Kimberley’s studies included difficulties with executive functioning, which she described as “*memory and cognitive issues*”; social-communication difficulties, such as interpreting body language or facial expressions; sensory

processing difficulties, including difficulties with loud noises and temperature; auditory processing difficulties; and high levels of stress and anxiety. Kimberley explained that she had only recently started reflecting on how these difficulties may also be related to her autism diagnosis.

7.6.1.2 Pathway to University.

Kimberley reported that she left high school part way through her final year. Prior to her current enrolment, she had enrolled in an arts degree at university but had not completed it. Kimberley stated that she had *“dropped out because [she] had autism related problems”* (Kimberley, 69), although at the time she was not diagnosed as autistic.

7.6.1.3 Learning Modes.

In her first semester returning to university in 2017, Kimberley enrolled part-time. She indicated that her decision to do so was influenced by her previous attempt at university: *“I could be easily overwhelmed and it was very very sensible for me to just test the waters”* (Kimberley, 280-281). Kimberley also noted *“stress wise I don’t think I could cope with a full-time load”* (Kimberley, 285-286). At the time of the interview, although Kimberley had intended to increase her study load, she was still undertaking her studies part-time.

Kimberley reported that she was enrolled in a combination of online and on-campus/face-to-face studies. She had found that lectures were easier for her to engage with online as she could watch the recording and pause when needed. Kimberley stated: *“If I’m having trouble processing something I just pause it. I’ve got all the time in the world (...) it works much better for me”* (Kimberley, 306-308). Kimberley chose to complete other study-related tasks at home, as well as in the *“disability room in the library”* of her university campus. Kimberley suggested that if the university didn’t have this room, she would most likely have completed her study-related tasks at home.

7.6.2 Microsystem and Mesosystem

At the microsystem level, Kimberley received emotional support from her family. Although she did not provide any specific details about what this emotional support involved, she did state that *“emotional support is very important for someone with a disability especially when there’s autism because I have [a] harder time sort of building those networks elsewhere”* (Kimberley, 507-510). Kimberley also accessed a therapist external to the university. Kimberley’s therapist provided individual Cognitive Behavioural Therapy (CBT).

As a result of her existing ADHD diagnosis Kimberley had already been able to access her university’s Disability Services and develop an access plan prior to receiving her

formal autism diagnosis. Kimberley also reported that she had engaged with the university's counselling services, describing the experience as *"hit and miss"*. Kimberley also felt the university counsellors *"appeared to just have no idea what to do with me (...) they appear[ed] to be confused and even a bit (pause) stressed communicating and dealing with me which is a concern because my problems aren't unusual or that extreme"* (Kimberley, 843-848). Kimberley attributed this to her university employing *"a lot of provisional psychologists in that department"* (Kimberley, 840).

While Kimberley described examples of positive interactions with some academic staff, she also described concerns regarding her experiences with some of her tutors. She described some tutors as not understanding the needs of students with disabilities, in particular their need for additional support and/or clarification. Kimberley stated:

sometimes the tutors were less than helpful (...) sometimes they can have negative reactions when you ask for support or ask for your special considerations (...) I found lots of them are good but I found a few that are less than accommodating and annoyed to be approached (Kimberley, 584-592)

In addition to these formal support networks, Kimberley described connections she developed with fellow students with disability as well as another mature-aged student she had met at university.

Kimberley reported that she interacted with her family members, university staff, and her therapist during her transition to university. However, she did not discuss any examples of her support networks interacting directly with each other.

7.6.3 Exosystem

Kimberley had heard of the DDA but not the DSE. She was not aware of the details of the DD; however, she did state: *"I know vaguely that there are some sort of rules and laws in place but as far as I know implementing them can be a bit complicated"* (Kimberley, 983-985). Kimberley was not accessing NDIS funded support during her first year at university.

Kimberley's university had an orientation program in her first year; however, Kimberley described difficulties accessing this program including difficulties navigating the campus. Kimberley also described experiencing difficulties with administrative aspects of participating in relevant activities (e.g., not being able to work out which group she needed to engage with). She also described the orientation sessions as *"pretty overwhelming"* and indicated that she chose not to participate in her university's mentoring program, as she did not feel it would be appropriate for her personal situation. Kimberley stated: *"I'm a mature-*

age student, I have mental health problems and I have a disability– autism and as far as I could tell they weren't going to make (...) any considerations in terms of the mentorship program for those things” (Kimberley, 411-414).

Kimberley was able to attend orientation sessions specifically designed for mature-aged students, which appeared to be more positive experiences for Kimberley than the standard orientation activities: *“they had a specific talk for mature-age students in which they had previous mature-age students get up and give advice and that was really helpful”* (Kimberley, 398-400).

7.6.4 Macrosystem

At the macrosystem level, Kimberley briefly mentioned an awareness of systemic issues that had potentially impacted on tutors’ ability to develop disability awareness, and the workload pressures that she felt academic staff were experiencing. Kimberley stated: *“[tutors are] under a lot of stress (...) I presume they’re not given any training on how to deal with people with disabilities”* (Kimberley, 586-588). She later added: *“I don’t blame the tutors for being undertrained and overstressed that’s not their fault, and that’s one way the university system has been very unfair to them”* (Kimberley, 1106-1108).

7.7 Ryan

Table 7.6 provides an overview of the various bioecological theory model elements as they apply to Ryan's experience of transition to university. Each of these elements is then discussed in more detail below.

Table 7.6: Overview of bioecological theory model elements – Ryan

Individual	Microsystem	Mesosystem	Exosystem	Macrosystem
Ryan Male 26 years old Looking forward to: social life, having a sense of purpose Diagnosis (High-functioning autism) in childhood Additional diagnoses: mental health (anxiety, bipolar, depression), ADHD Sensory processing difficulties Executive functioning/cognitive difficulties - time management & organisation Difficulties making social connections Did not receive high school certificate Two previous attempts at university (2012, 2013) First year part-time	Family (mother) – practical & emotional support Disability Services – practical, procedural University counselling service – did not find useful Peer mentor/s – mixed	Interactions between Ryan & his mother, mentors, Disability Services staff, counselling staff, academic staff Interactions between mother & mentoring program coordinator* Interactions between Disability Services staff & mentoring program staff (referral)	NDIS – not accessing Disability Discrimination Act (DDA) – not aware of Disability Standards for Education (DSE) – not aware of Institutional policies & practices (University mentoring program) – mixed Institutional policies & practices (census date, alternative exam arrangements)	Social & cultural understanding of autism – Broader perceptions & understanding of autism

*as noted in interview with mother

7.7.1 Individual

At the time of his interview (January, 2021) Ryan, a 26-year-old male student, was enrolled in an undergraduate degree in maths and science. Ryan indicated that he had two

goals for returning to university studies in 2016; the first was academic, and the second was to increase his social connections. When asked what he was most looking forward to about commencing his studies Ryan replied, *"I really wanted to try and get better at the social side of stuff (...) and that was what I was really looking forward to"* (Ryan, 222-226). Ryan also reported an additional motivation for returning to university, to provide a *"sense of purpose"*.

7.7.1.1 Autism/Autistic Identity.

Ryan received a diagnosis of high functioning autism in childhood. In addition to autism, Ryan also disclosed diagnoses of bipolar disorder, depression, and ADHD. Ryan also has dysgraphia. Ryan indicated he did not have a preference as to whether he was referred to using person-first or identity-first language; however, during the interview he most frequently referred to himself as *"autistic"* and to *"autistic people"*.

Ryan mentioned that he was not sure whether the difficulties he experienced during his first year at university were directly associated with autism, his other diagnosed conditions, or are *"just me"*. Ryan stated: *"I can't really point to necessarily what comes from autism and what comes from other things"* (Ryan, 573-575). Later in his interview he also noted: *"it is very hard for me to say what is specifically because I'm autistic and what is just because I'm me (...) I can't really separate what comes from autism and what is just hard for me"* (Ryan, 854-857).

Even though Ryan found it difficult to identify which of his difficulties were specifically associated with being autistic he did suggest that his transition was *"a lot more difficult than it has been for other people (...) particularly the social transition (...) and just being able to transition into such a high workload (...) is very hard"* (Ryan, 849-854).

Individual challenges Ryan experienced during his transition to university included difficulties with executive functioning, such as time management and organisation; sensory processing difficulties associated with noise and temperature; and difficulties developing social connections with his university peers. Ryan's executive functioning difficulties impacted his ability to plan and manage his study related tasks, although he noted that these issues were likely a combination of his autism and his ADHD. Ryan noted: *"The time management and organisation is really difficult for me, knowing how long it might take me to do something"* (Ryan, 562-564) adding *"I find it very hard to motivate myself to do work or to get something done"* (Ryan, 575-577).

Ryan also experienced *"sensory overwhelm"*, which impacted on his ability to engage in classes, he explained:

the classroom being huge was another problem (...) I found it very noisy, very sensory overwhelming [sic] (...) whenever [classes are] quite large I get very overwhelmed even if it's not loud (...) I don't feel comfortable with that many people in the room (Ryan, 442-446)

In addition to sensory issues associated with noise and crowds, Ryan also described difficulties he had participating in his studies in warmer weather stating:

I find myself quite sensitive to [the heat] (...) it's just very uncomfortable (...) it makes it physically difficult to get to classes (...) if I'm sitting in a classroom that is very hot it's gonna be very hard for me to concentrate (Ryan, 667-675)

In relation to social-communication difficulties Ryan identified that he had difficulty with forming social connections, although this was one of his primary goals for attending university. Ryan explained:

one of my goals going into university was not just the academic things but also to try and meet people and get involved in the social life of university and what I found was that I felt very excluded from that (...) I didn't really know how to be included (...) I kind of felt a bit helpless about that, about not knowing how to be involved with any of that (...) that affected my mood quite a lot and affected how I performed at university as well. So that wasn't helpful (Ryan, 133-143)

7.7.1.2 Pathway to University.

Ryan had previously attempted undergraduate degrees in computer science and in engineering in 2012 and 2013 respectively. His previous attempts at university were at the same university he was enrolled in at the time of his interview.

7.7.1.3 Learning Modes.

In the first year of his current degree Ryan enrolled part-time. Ryan reported he was already aware that a full-time study load would “*not [be] feasible for me*” as a result of having attempted full-time study in 2012. Ryan was enrolled on-campus/face-to-face in the first year of his current degree. Ryan reported that he found online classes difficult because he would “*never get around to watching [the lectures]*” or he would “*get distracted while trying to watch them*” (Ryan, 285-286). He also found the opportunity for face-to-face discussion in on-campus/face-to-face classes “*really valuable*”. Ryan indicated that he preferred to undertake other study-related tasks at home because of the “*familiarity*”, and the fact that studying at home was less distracting than on campus.

7.7.2 Microsystem and Mesosystem

At the microsystem level, Ryan described receiving practical (e.g., helping with daily living tasks) and emotional support from his mother, which he reported as being helpful. Ryan also received support from the Disability Services at his university. He had prior contact with the service from his previous attempts at university and had previously developed an access plan. Ryan was therefore already aware of the services and supports available for students with disability before returning to study in 2016. Although Ryan explained that it can be difficult to get an initial appointment with the Disability Services staff at his university, he described the process of accessing the service and setting up his access plan as *“fairly easy”*.

Ryan had contact with the counselling services at university; however, he did not find this useful because he did not feel the university counselling services were suitable for someone with his mental health difficulties. He stated: *“[the counsellors are] very inexperienced generally is what I’ve found and they’re not very specialist (...) I’m sure they’re good for people with kind of more minor concerns but it’s not been very helpful for me”* (Ryan, 1073-1076).

Ryan had both positive and negative interactions with academic staff. He described positive experiences with lecturers who were *“engaging”* and *“passionate”*. He also described a negative experience with one of his lecturers who asked him about his access plan in front of his classmates. Ryan explained that this made him *“very uncomfortable”* and was *“really not OK”*.

The interactions Ryan described between himself and his support networks (mesosystem) were mostly practical and procedural in nature. Ryan’s access plan was a key tool for interactions and communicating his support needs to relevant academic staff. He did not discuss interactions between members of his support networks. However, during the interview undertaken with the coordinator of the university’s mentoring program, it was noted that mechanisms had been in place that enabled the coordinator to communicate directly with Ryan’s mother as his nominated support person.

7.7.3 Exosystem

At the exosystem level, Ryan accessed mentoring support through the university’s autism specific mentoring program, which he reported was somewhat helpful, although he felt one of his mentors *“did not really understand [him]”*. Ryan was not aware of the DDA or the DSE and was not accessing NDIS funded support.

7.7.4 Macrosystem

Ryan mentioned broader community (mis)understanding of autism, describing ways in which he felt others perceived autistic people as potentially “*rude or odd*”. Ryan explained:

*I think in general certain body language things like avoiding eye contact
(...) I can't really think of anything else other than that but I'm sure there are
other things that make— make autistic people seem like they're being rude
or odd (Ryan, 1236-1239)*

7.8 Sean

Table 7.7 provides an overview of the various bioecological theory model elements as they apply to Sean's experience of transition to university. Each of these elements is then discussed in more detail below.

Table 7.7: Overview of bioecological theory model elements – Sean

Individual	Microsystem	Mesosystem	Exosystem	Macrosystem
Sean Male 23 years old Looking forward to: study/work in an area he enjoys, meeting new people/friends Diagnosis (autism) in early childhood Anxiety Executive functioning/cognitive difficulties - time management & organisation Transitioned via TAFE pathway First year part-time	Family (father & stepmother) – practical support NDIS provider/NDIS funded support worker – mostly positive, some difficulties exacerbated due to COVID-19 Disability Services – mixed Academic staff – seeking adjustments Peer mentoring group – positive (before COVID-19) Peers & friends – positive	Interactions between Sean & his family, friends & peers, mentors, NDIS support worker (some difficulties due to COVID-19) Interactions between NDIS support worker & Disability Services staff (impacted by legislation & policy at the exosystem level)*	NDIS – Accessing funded support Disability Discrimination Act (DDA) – not aware of Disability Standards for Education (DSE) – not aware of Legislation and institutional policies on privacy & confidentiality	Not discussed

*as also noted in interview with support worker

7.8.1 Individual

At the time of his interview (December, 2020) Sean, a 23-year-old male student, was on leave from his undergraduate degree in science. Sean had commenced his degree in February of 2020 and was planning to return to his first-year studies again in 2021. Sean's transition to university occurred during a very complex year; he was impacted by a significant bushfire event that took place in his hometown in early 2020, and after moving to on-campus living, returned to his hometown in early 2020, due to the implementation of the COVID-19 pandemic restrictions put in place at the time. Sean discussed the impacts of

these challenges throughout his interview. Sean was looking forward to studying in an area he enjoys and meeting new people.

7.8.1.1 Autism/Autistic Identity.

Sean indicated that his diagnosis of autism occurred in early childhood. When asked whether he would prefer person-first or identity-first language, Sean indicated that he would prefer “*person with autism*”. Sean consistently referred to autism as something he “*has*” or “*always had*” throughout his interview, which also aligns with his stated language preference.

Sean suggested that it was difficult for him to know what transition would be like for someone who did not have autism. When asked if he felt autism may have made his transition different to that of students who did not have autism, Sean explained: “*I don’t really know how to answer that question because I’ve always had autism and I don’t know what it’s like to not be on the spectrum*” (Sean, 764-766). He also went on to state:

I can’t really tell the difference between myself and what a neurotypical person would be like (...) I really don’t understand to be honest, I go by what other people tell me, and other people tell me that I’m pretty normal so I— I really don’t know [laughing] how to answer (Sean, 768-773)

Sean described how his individual characteristics had impacted on his transition to university but was often unsure whether these were related to having autism or not. Sean described some difficulties with executive functioning skills such as organisation and finding a balance between university expectations and maintaining a social life. Sean suggested these difficulties “*may have been affected by autism*”. When describing difficulties that he experienced in trying to study on campus Sean also stated: “*I’m not sure if that’s related to autism or not or it’s just part of learning how to adapt to uni [sic]*” (Sean, 692-693). Sean experienced anxiety and nervousness during his transition to university, particularly in relation to university expectations and living independently:

I did have a bit of anxiety [starting at university]. Moving back to [region] again, living by myself, having to look after myself (...) There was a bit of anxiety there, a bit of nervousness (...) the expectations for uni [sic], I was quite anxious about that (Sean, 732-740)

7.8.1.2 Pathway to University.

Sean completed his final year of high school in 2015. As he did not receive an ATAR (Australian Tertiary Admission Rank) after completing his final year of high school, Sean undertook two vocational education courses through TAFE in 2019, in preparation for university in 2020.

Sean completed one of his first-year subjects in semester one of 2020; however, he took leave from his studies in semester two of 2020. Sean spent this time preparing to return to university in semester one of 2021. When reflecting on his progress in preparing to return to university Sean stated: *“I’m feeling really confident and optimistic about 2021 (...) I’m much more better prepared [sic] (...) I’m quite happy at this point, optimistic”* (Sean, 216-219).

7.8.1.3 Learning Modes.

Initially, Sean enrolled in three subjects (75% study load) in his first semester; however, he withdrew from two subjects during the semester, completing the remaining subject. At the time of his interview Sean was planning to enrol in one subject when he returned to his studies in semester one, 2021.

Sean had hoped to undertake his studies on-campus/face-to-face; however, due to the COVID-19 pandemic restrictions teaching was moved to online. Sean indicated that his preference would have been to be *“doing things like lectures and workshops and all those kinds of things in person”* (Sean, 368-369) and hoped that he could return to on-campus learning again in 2021. Sean indicated that he was happy doing other study-related tasks on-campus or at home, providing it was somewhere quiet with minimal distractions.

7.8.2 Microsystem and Mesosystem

At the microsystem level, Sean reported receiving support from his father and stepmother who assisted him with developing independent living skills in preparation for his transition to on-campus living. Sean also received support from a local Australian Disability Enterprise (ADE) via his NDIS funding to assist him in preparing for his transition to university. Staff from the ADE assisted Sean with identifying an appropriate pathway into university, enrolling in the relevant TAFE courses, navigating supports while at TAFE, and preparing Sean for his first year at university. Sean’s NDIS funded support worker also continued to provide support to Sean throughout his first year at university, although Sean’s ability to make use of these supports was limited by external factors including the impact of bushfires on his community, and the COVID-19 pandemic restrictions. Sean stated:

“they’re a registered NDIS provider and they couldn’t help me very well in [university region] because A) it was more distant [from his hometown where the NDIS provider is based] and B) so I couldn’t like meet them face-to-face (...) I couldn’t talk to them in person it would just be via email, phone (...) it was quite complicated (...) with the COVID [sic], (...) they [the NDIS provider] just weren’t able to provide the support that I believe I should have received because (...) everyone was going through quite a

bit of grief at the time (...) it was very hard to really get the support I needed basically 'cause [sic] [the NDIS provider] had a lot of different things on their plate, including the fires, [and] recovery from it (Sean, 253-264)

Interactions Sean described with his academic staff were limited, such as talking with them *“about implementing my educational access plan”*, and general discussions about coursework. He accessed the Disability Services, and set up an access plan, which he reported provided him with *“extensions on assignments and exams”*. Sean explained that he had requested content-based tuition support from the Disability Services but was disappointed to find that this was not available. Efforts to access content-specific tutoring using his NDIS funding were also unsuccessful in his first year.

Sean was part of a mentoring program in his first year at university and reported that this group was beneficial as it enabled him to meet other students with disabilities and develop social connections. He stated that this social interaction was *“really helpful (...) Really enhanced my uni [sic] experience”* (Sean, 460-461); however, contact with the mentoring group appears to have been limited after the COVID-19 pandemic required students to move away from on-campus living.

Sean interacted directly with each microsystem element; however, he did not discuss any interactions that took place between these elements during his interview. Interactions between microsystem elements became apparent during the interview with Sean's support worker. Sean's support worker described ways in which he attempted to engage with the university Disability Services to support Sean.

7.8.3 Exosystem

Sean's NDIS funding enabled him to engage a support worker who provided support during his preparation for and transition to university. His support worker indicated that he had attempted to make direct contact with university staff (academic and professional), but these attempts were at times hindered by legislation and university policy (exosystem), as well as external factors including the bushfires and the COVID-19 pandemic restrictions. For example, Sean's support worker was not able to make contact with university staff directly to discuss Sean's progress with his studies, which he attributed to privacy legislation and university policies. NDIS funding also enabled Sean to return to his NDIS funded vocational support service while he was on leave from his studies in his second semester and access support to prepare for his return to university. Sean indicated that he was not familiar with the DDA or the DSE.

7.8.4 Macrosystem

Sean did not directly discuss the broader societal or community perception of disability, autism, or social inclusion at the macrosystem level during his interview.

7.9 Taylor

Table 7.8 provides an overview of the various bioecological theory model elements as they apply to Taylor's experience of transition to university. Each of these elements is then discussed in more detail below.

Table 7.8: Overview of bioecological theory model elements – Taylor

Individual	Microsystem	Mesosystem	Exosystem	Macrosystem
Taylor Prefer not to disclose gender identity 21 years old Looking forward to: meeting new people with similar interests, developing social connections Formal diagnosis in adulthood Previous suggestion of autism in childhood Social-communication difficulties Executive functioning/cognitive difficulties - time management and organisation Transitioned directly from high school to university University pathway program into current degree (same university) First year part-time	Family (parents) – emotional, practical, financial support Disability Services - positive Peers (fellow students in residence) – social, positive Academic staff – mixed	Interactions between Taylor & parents, peers, Disability Services staff, academic staff No interactions between microsystem elements	NDIS – not accessing Disability Discrimination Act (DDA) – not aware of Disability Standards for Education (DSE) – not aware of	Autism stigma - autism in “hushed tones” or as a “slur on the internet”

7.9.1 Individual

At the time of their⁹ interview (December, 2020) Taylor was a 21-year-old student enrolled in a science degree. Taylor was looking forward to *“the social life”* at university, meeting *“like-minded people”*, and developing new social connections.

7.9.1.1 Autism/Autistic Identity.

Taylor’s formal diagnosis did not occur until the end of their first year in their current undergraduate degree, although they reported that the possibility of autism had been mentioned in childhood and again in the final years of high school. Taylor referred to the delay in formal diagnosis on several occasions throughout the interview, and this appeared to have played a significant role in relation to their sense-making of various experiences, in particular their social difficulties. Taylor chose to identify using identity-first language (autistic), stating *“I’m just fine being called autistic ‘cause [sic] (...) it is what it is”* (Taylor, 11-12). Taylor did however refer to *“having”* autism when they talked about the formal diagnostic process.

Individual difficulties Taylor experienced during their transition to university included executive functioning difficulties, and social challenges. Taylor suggested being on the autism spectrum had made their transition different to that of other students, in particular relating to the social experience, stating *“being on the spectrum (...) you don’t really have that initiative to (...) make those social connections (...) get involved”* (Taylor, 584-587). Taylor explained that one of their goals for attending university had been to develop new social connections but described having difficulties knowing how to make and maintain these connections. They stated: *“I kind of wanted to use [university] as (...) a chance to (...) get out there, be more social, be around people I actually like. (pause) despite my best intentions I had no idea **how**”* (Taylor, 145-149).

Taylor also noted having some difficulties with decision making, prioritising, and managing their workload, attributing some of these difficulties to what they termed *“gifted kid burnout”*, which they described as:

when I was a kid, things were easy, I just got by coasting, and I didn’t realise that things were getting harder and harder and (...) by the time I was— reached university I already built my identity as the smart one
(Taylor, 95-99)

⁹ As Taylor preferred not to identify with a specific gender, the pronouns ‘they/them’ have been used throughout the thesis when discussing Taylor’s experiences.

7.9.1.2 Pathway to University.

Taylor transitioned directly from high school into university, initially undertaking a university pathway program before transitioning to a bachelor's degree at the same university. Taylor's experience of enrolling and transitioning to university was complicated by what they described as a *"paperwork kerfuffle"*. Taylor had been offered a place in a science degree which they accepted. In Taylor's first week at university, they were informed that due to not having the minimum entry requirements they would need to undertake a pathway program before being able to enrol in the science degree. This required Taylor to re-enrol in a different selection of classes before they could transfer into their bachelor's degree. Taylor referred to this administrative mix-up on several occasions during the interview, at one point describing it as *"a large debacle"*. At the time of the interview Taylor was formally enrolled in, and completing, a bachelor's degree in science.

7.9.1.3 Learning Modes.

Taylor initially enrolled full-time, but due to the administrative mix-up and changing subject choices they were mostly part-time from the early stages of their studies. While Taylor was enrolled on-campus/face-to-face, they indicated that where they would undertake other study-related tasks depended on the specific task they were undertaking. Taylor stated: *"Most of the time I [undertake other study-related tasks] at home (...) and occasionally when I need to refer to a textbook I often use the [University Name] libraries"* (Taylor, 247-255).

7.9.2 Microsystem and Mesosystem

Taylor reported receiving practical, emotional and financial support from their family. Taylor also reported receiving some support from peers, such as other students also living in the on-campus accommodation where they resided in their first year. Taylor stated: *"I found the community at the residence [on-campus accommodation] for the most part pretty welcoming"* (Taylor, 431-432). In Taylor's second year they were no longer able to reside in the on-campus accommodation and they reported the friendships they made there did not continue once they had moved out. Taylor attempted to make social connections with students on campus through one of their university's clubs; however, they eventually left the club and joined a similar social group outside of the university instead.

Taylor accessed support from the Disability Services. Taylor explained that finding the service was a little difficult at first, but once they had located them, the process of accessing it was *"straightforward"*. Taylor found access to a disability specific space on campus useful. They also developed an access plan which was used to document the adjustments Taylor required such as extensions on assessments. They noted: *"I generally*

avoid using those [extensions] but I find it's very relieving to have that lifeline" (Taylor, 651-652).

Taylor also described both positive and negative experience with academic staff. They described interacting with one of their lecturers as speaking with someone who *"spoke only in riddles"* and explained that they *"didn't give a straight answer"* when asked questions about assignments. Taylor acknowledged that some of their initial interactions on the online forums were potentially not *"constructive"*, but they noted that although they tried to address this issue, they continued to have difficulty and *"couldn't figure out what [they were] doing wrong"*. Taylor described other academic staff as *"reasonably accepting"*.

Taylor only reported interactions (mesosystem) between themselves and family, peers, Disability Services staff, and academic staff. They did not describe any interactions occurring between their support networks.

7.9.3 Exosystem

At the exosystem level, Taylor had not heard of the DDA or the DSE. Taylor also indicated that they had not heard of the NDIS.

7.9.4 Macrosystem

Taylor described their personal experiences with the terms *"autism"* and *"Asperger syndrome"* prior to their formal diagnosis. Taylor stated that their own family *"never discussed [autism]"*, even though it had been suggested as a possible diagnosis for Taylor during their primary school years. Outside of their family home the only time Taylor heard the terms autism or Asperger syndrome was in *"hushed tones"* or as a *"slur on the internet"*. They described one example of this experience from their primary school years:

one time I was doing some extracurricular activities (...) I still remember it, we were all sitting around this classroom (...) and the topic of another student came up (...) and the teacher kind of got all hushed and quietly said that "you know she has Asperger's" in a tone like it was some great secret (...) I didn't know much about it at the time I kind of if a student was a bit odd but I just generally didn't really make that connection and yeah that was the only time I heard for word autistic used in like a serious context for years (Taylor, 396-407)

7.10 Tristan

Table 7.9 provides an overview of the various bioecological theory model elements as they apply to Tristan's experience of transition to university. Each of these elements is then discussed in more detail below.

Table 7.9: Overview of bioecological theory model elements – Tristan

Individual	Microsystem	Mesosystem	Exosystem	Macrosystem
Tristan Male 19 years old Looking forward to: learning new things Diagnosis in childhood Sensory processing difficulties Anxiety (associated with sensory processing difficulties) Transitioned directly from high school to university – then took leave from May the following year Enrolled first year full-time	Family (mother) - practical support Sibling (brother) - content/study support Disability Services – policy/procedure University student services – policy/procedure	Interactions between Tristan & family, Disability Services staff, & student services No interactions between microsystem elements	NDIS – not accessing Disability Discrimination Act (DDA) – aware of Disability Standards for Education (DSE) – not aware of Institutional policies – for taking leave	Not discussed

7.10.1 Individual

At the time of his interview (September, 2020) Tristan, a 19-year-old male student was studying a degree in medical sciences. Tristan was looking forward to attending university to learn more things.

7.10.1.1 *Autism/Autistic Identity.*

Tristan reported that his autism diagnosis occurred in childhood. He indicated a preference for person-first language; this was consistent with the language he used throughout his interview. In some instances, Tristan also referred to “*my autism spectrum*”

when referring to himself as having autism, although specific references to autism during his interview were limited.

Tristan suggested that his autism may have meant his transition was different to that of other students. He described his experience, stating: *“a sudden change is just so weird for me and I was so used to a general structure to every day (...) it goes back to that thing of not really knowing anyone”* (Tristan, 357-360).

Tristan identified sensory and anxiety-related individual difficulties that he experienced during his transition to university. His sensory difficulties were mainly related to the busyness and noise associated with being on a campus in a central business district. Tristan noted: *“it’s not generally the loudness (...) just how much noise there is in general (...) the city’s a bit louder than what I’m generally used to”* (Tristan, 297-299), he also explained: *“I get a bit anxious around people just passing by”* (Tristan, 314-315).

Tristan reported that it was anxiety-related difficulties which ultimately led to him needing to take leave from his studies in his first year and return the following year: *“basically my anxiety took over and I needed to (pause) take a leave [sic], because it was too much for me”* (Tristan, 108-109). Although Tristan did not identify any specific social-communication difficulties, he did report having few friends at the university he attended.

7.10.1.2 Pathway to University.

Tristan transitioned to university in 2019, after completing year 12 in 2018. He took a leave of absence mid-way through his first semester and returned to university in 2020. At the time of the interview Tristan had completed one semester of undergraduate studies and was undertaking his second semester.

7.10.1.3 Learning Modes.

Tristan initially enrolled in full-time studies in 2019. When he returned to his studies in 2020 Tristan again enrolled full-time. Tristan reported that he preferred to enrol in on-campus/face-to-face classes. However, he often chose to complete other study-related tasks from home because his home is *“a bit far away from the campus”*. He reported only attending the university campus for classes when required. Tristan also reported that he had chosen to enrol on-campus/face-to-face because he had *“heard some less than good things about online courses”* (Tristan, 138-139) and his older brother also had positive experiences studying on-campus at university.

7.10.2 Microsystem and Mesosystem

At the microsystem level, Tristan reported receiving support from his family, particularly from his mother who assisted him in making the decision to take leave during his

first year and helped him to access the support required to do so. Tristan also reported receiving topic/content-based support from his brother who had previously completed some of the same classes as Tristan.

Tristan reported one interaction with student services staff at his university when searching for information about taking leave from his studies. The student services staff also referred Tristan to Disability Services. His interactions with both student services and Disability Services staff were positive, with Tristan reporting staff were *“helpful”*.

Tristan reported interactions with his mother and brother, as well as staff from the student services and Disability Services. The only interaction Tristan described between his support networks was his mother assisting him with his interactions with student services, and the referral he received from student services to access Disability Services.

7.10.3 Exosystem

Tristan’s interactions with Disability Services were only initiated due to his search for information on university policies relating to taking leave from his studies. Tristan indicated that he was aware of the DDA stating, *“basically it just says that (...) you have to try and provide good support for people with disabilities”* (Tristan, 466-467); however, he had not heard of the DSE. Tristan had not accessed any NDIS support.

7.10.4 Macrosystem

Tristan did not directly discuss any broader societal or community perceptions of disability, autism, or social inclusion at the macrosystem level during his interview.

7.11 Participant Summary

Eight autistic students took part in semi-structured interviews to explore their experiences of transition to, and first year of university. Students used varying terms when describing their autistic characteristics and identity. The terminology and language students used to describe themselves, and autism more generally, was often framed in terms of seeing themselves as different to others. For example, both Conrad and Sean referred to themselves and other autistic students as having an *“intellectual disability”* (Conrad, 330, 637, 646, 818, 865; Sean, 829) even though, from their description of their diagnosis, it did not appear that either participant had an intellectual disability. Two participants, Harry and Ryan, referred to their identity in terms of a *“problem”*, or something that was different to others. For example, when discussing the benefits of his diagnostic re-assessment Harry stated: *“I guess not knowing what the problem is you can’t really do anything about it”* (Harry, 135-136). Harry later explained: *“getting a dual diagnosis then you can get treatment for that disorder (...) you usually can’t do anything if you don’t know what the problem is, don’t have*

a *diagnosis*” (Harry, 550-552). In contrast, Ryan used comparative language that situated himself in contrast to “*normal*” or “*regular*” people: “*normal people tend to be a lot shy [laughing] than I am sometimes*” (Ryan, 822-823) and “*even a regular person- I don't know how anyone [laughing] manages to get through [timed assessments]*” (Ryan, 925-927). Before Ester received her formal diagnosis, she saw herself as “*stupid*” (Ester, 131), while Kimberley saw her previous difficulties as related to “*mental health problems*” (Kimberley, 69-70). Taylor labelled the difficulties they experienced as being associated with what they called “*gifted kid burnout*” (Taylor, 95, 228).

Table 7.10 provides an overview of the bioecological elements discussed by each of the student participants during their interview, which are summarised below.

7.11.1 Individual

Participants described a range of individual characteristics associated with an autism diagnosis that impacted on their transition, including social-communication difficulties, sensory processing difficulties, and executive functioning and cognitive processing difficulties. Some participants discussed sensory processing difficulties as being related to their experiences of associated anxiety, stress, or distraction.

7.11.2 Microsystem and Mesosystem

Participants reported accessing support from family members, Disability Services staff, academic staff, friends, and peers. Family support was most often described as emotional or practical. Some participants were unable to access Disability Services due to a lack of formal diagnosis of autism when they first enrolled at university, which was required to access the services and develop an access plan. Only two participants, Conrad and Kimberley, discussed accessing mental health supports external to their university. Experiences of interactions with academic staff were mixed, with some students describing positive and supportive interactions and others describing situations that were unhelpful or negative in nature. The experience of interactions with academic staff appeared to be influenced by individual staff members’ understanding of autism or their willingness to provide additional supports to the student.

7.11.3 Exosystem and Macrosystem

Some participants also discussed their experiences of institutional policies and programs, such as mentoring or orientation. Participants’ experiences of these programs were varied. Five of the students were aware of the existence of disability discrimination legislation, although this they were not necessarily aware of the DDA or DSE specifically. Sean was the only participant who was accessing NDIS funded support.

At a broader societal and cultural level students discussed stigma associated with autism, systemic barriers to accessing diagnosis and other supports, as well as the broader socio-cultural understanding of autism.

Table 7.10: Summary of bioecological elements discussed by each student

		Conrad	Ester	Harry	Kimberley	Ryan	Sean	Taylor	Tristan
Individual	Social-communication	X	X		X	X		X	
	Executive functioning	X	X	X	X	X	X	X	
	Sensory processing				X	X			X
	Anxiety		X		X		X		X
Microsystem and Mesosystem	Family (parent)	X		X	X	X	X	X	X
	Family (other)	X							X
	Friends/Peers	X	X		X		X	X	
	Disability Services			X	X	X	X	X	X
	University counselling service		X		X	X			
	External (mental health)	X			X				
	External (support worker)						X		
	Academic	X	X		X		X	X	
	Other			X		X	X		X
	NDIS						X		
Exosystem	Institutional policies – orientation program		X		X				
	Institutional policies – mentoring program					X			
	Institutional policies - other			X		X	X		X
Macrosystem	Stigma							X	
	Systemic barriers		X		X				
	Social-cultural understanding of autism		X	X		X			

7.12 Chapter Summary

The narrative descriptions presented in this chapter have provided an overview of the lived experiences, perspectives, and bioecological context for the eight student participants

who took part in this research. It is important to highlight the individual experiences of each of these participants and ensure the heterogenous nature of autistic students is represented within each of these narratives. The narratives demonstrate the various people and services students interacted with during their transition to university. Students described experiences across the individual, microsystem, mesosystem, exosystem and macrosystem level. The following chapter presents an interpretative phenomenological analysis of the data collected through semi-structured interviews with each of these students.

8 ANALYSIS: PARTICIPANT THEMES (STUDENTS)

This chapter presents the analysis and subsequent identification of themes generated from interviews undertaken with eight autistic student participants introduced in the previous chapter (from here onwards referred to as students) about their experiences of transition to, and first year of university (research objective one). The lived experience of students was analysed using IPA as described in detail in Chapter 6. Data from semi-structured interviews with eight autistic students were analysed manually. Idiographic analysis of each individual participant interview was conducted, with themes generated at the individual level, before undertaking a cross-case analysis (see Section 6.5.1). The superordinate themes and associated subordinate themes are described in this chapter, along with quotes from the participants to illustrate each theme.

8.1 Summary of Themes

Three superordinate themes were developed: *sense of self and identity*; *persistence and resilience*; and *accessing and receiving support from others*. Table 8.1 provides an overview of these themes and their relevant subordinate themes. The superordinate and subordinate themes are discussed in more detail in the following sections.

Table 8.1: Superordinate and subordinate themes developed from student interviews

Superordinate theme	Subordinate theme
Sense of self and identity	Importance of understanding oneself
	Deciding to disclose is complex
	Self-awareness or internalised ableism
	Camouflaging and masking to overcome difficulties
Persistence and resilience	Anxiety: “Enormously stressed but very determined”
	Transition and first year as a period of adjustment
	The journey to and through first year at university
Accessing and receiving support	Family support: Emotional, practical, financial
	Peer support: Seeking social connection, but not always finding it
	University supports: Programs and people
	Genuine understanding of autism

8.2 Sense of Self and Identity

Following analysis four subordinate themes that included elements of students' perspectives of themselves, their identity, and their experiences as an autistic university student were generated under the superordinate theme *sense of self and identity*:

1. *Importance of understanding oneself*: where students discussed their identity, the impact of late diagnosis, and the role diagnosis plays in enabling students to identify and access relevant and appropriate supports and strategies.
2. *Deciding to disclose is complex*: including who to disclose to, and when and how to disclose, as well as the need to consider a range of factors before disclosing.
3. *Self-awareness or internalised ableism*: reflecting some students' awareness of their difficulties that demonstrated aspects of internalised ableism and resulted in students feeling as though it was up to them to change or resolve their challenges independently.
4. *Camouflaging and masking to overcome difficulties*: where students described the mechanisms used to overcome individual difficulties, which appeared to reflect attempts to camouflage or mask the difficulties they were having.

8.2.1 Importance of Understanding Oneself

Students highlighted the need for a “*full understanding*” (Taylor) of oneself in supporting positive transition experiences for autistic students. This was especially evident for students who had not received their formal diagnosis prior to commencing their university studies. Upon receiving a formal diagnosis, students were able to reflect on their current and past experiences and difficulties using this new information as a lens for self-understanding.

Taylor, Kimberley, and Ester all received their formal diagnosis as adults, having already commenced their university studies. For these students the process of self-understanding reflected the challenges they had experienced prior to their formal diagnosis. For example, Kimberley reflected on her previous difficulties and the fact that in the past she had difficulty understanding them or identifying the reasons behind these challenges.

I knew I had social problems and executive functioning problems but the sensory issues and the restricted and repetitive behaviour, always had them didn't really notice and categorise them as what they are until fairly recently (Kimberley, 662-665)

Similarly, Ester reflected on her previous difficulties stating: *“I didn’t know all this [what these difficulties were] at the time (...) for lack of a better word to describe it I just thought I was stupid.”* (Ester, 130-131).

For Taylor, having a formal diagnosis played an important role in the process of self-understanding. Taylor had not received a formal diagnosis of autism prior to commencing university, despite the fact that their parents had suspected they may have had autism in primary school. Additionally, the possibility that Taylor was autistic had been suggested to them at a doctor’s appointment during their final years of high school. During their first year of university, Taylor sought out a diagnostic assessment and received their formal diagnosis of autism. The belief that Taylor was possibly autistic and that this had not been shared with them during their childhood was central to Taylor’s account of their experiences of transition. Taylor felt that this had impacted on their social skills, ability to make social connections, and self-understanding. Taylor explained:

“when I think back I find a lot of the problems I’ve kind of encountered because of my autism could all have been (...) resolved a lot more easily if I had gotten my diagnosis earlier and actually had an earlier and like full understanding of what autism is, how it affects someone” (Taylor, 281-285)

While Harry had received a diagnosis of autism in childhood, he had been unable to locate his diagnostic report and had sought an updated diagnostic assessment to confirm his diagnosis. Harry reflected on receiving confirmation of his autism diagnosis and the additional diagnosis of ADHD as like *“the puzzle coming together”* (Harry, 131). Similarly, Taylor related their experience of receiving a formal autism diagnosis to being like *“building a puzzle”* (Taylor, 621). Taylor added:

*[the diagnosis] gives you a greater context and then you just see how more and more pieces fit together and it reaches this kind of critical mass where everything just (...) kind of slots together easily and (...) it’s incredibly relieving to finally understand **yourself*** (Taylor, 622-626)

In summary, it was evident students who had recently received their autism diagnosis were still processing this information. The diagnosis appeared to enable them to better understand themselves, as well as their past challenges and experiences. This appeared to contrast with students who had received their diagnosis in childhood and described autism as something that had always been a part of them. Students who received their diagnosis in childhood also appeared to reflect on autism as something they found difficult to separate from their other characteristics or experiences.

8.2.2 Deciding to Disclose is Complex

Decisions about disclosure were complex and multifaceted. Students needed to decide whether or not to disclose their autism diagnosis to university staff or peers, while also considering the potential biases and risks associated with disclosure. Some students chose to disclose on an 'as-needs' basis, describing this in terms of a transactional experience (e.g., disclosing in order to receive support). Students also expressed that they were not intentionally trying to hide their diagnosis, but instead found it difficult to identify the right time or process to disclose.

Students' views varied as to whether they felt disclosing their autism diagnosis was necessary or not. While some students were comfortable disclosing their autism diagnosis, others preferred to request support using their access plan. The access plan appeared to be a mechanism for disclosing support needs, without specifically stating or disclosing their diagnosis. For example, Harry explained: *"so if you need a time allowance [in your exam] you just have to send the access plan to a lecturer and in the access plan there's just (...) broad and general comments, it doesn't mention the diagnoses"* (Harry, 576-578).

Similarly, Ryan did not feel the need to disclose his specific diagnoses, but instead preferred to use his access plan to communicate his support needs:

I don't really see what the benefit would be [of disclosing my autism diagnosis] (...) I mean the access plan itself doesn't disclose, it just says this is what this person needs it doesn't actually say what the diagnosis is or why they need it (Ryan, 1117-1120)

Disclosure was sometimes described in ways that appeared transactional in nature, with some students choosing to only disclose when requesting support, adjustments, or accommodations. Some students opted not to disclose unless it was necessary, for example Tristan explained their preference not to disclose to *"anyone else that just doesn't really need to know"*, only disclosing on a *"need-to-know"* basis:

I just don't really mention it [my diagnosis] at all unless I really need to for example when I send [Disability Services] plans to lecturers (...) I sort of need to disclose that, but other than that I don't really disclose it to anyone (Tristan, 483-486)

Taylor explained that they only disclosed their diagnosis when they felt it was relevant, particularly if they felt there may be potential communication difficulties:

when I think it's kind of (...) relevant to the conversation when I need to kind of mention I do have a bit of trouble communicating (pause) at least sometimes I do (...) [if] the subject comes up (...) of communication or I start to struggle with communication or (...) going to a social event I might disclose it straight-up to kind of pre-empt any issues (Taylor, 725-737)

Similarly, Sean described disclosing to friends if he felt it would allow them to “*get to know me basically as a person, as a friend, as a peer*” (Sean, 896-897). Sean also highlighted that he did not have specific concerns about disclosing, as long as he was able to access the support he needed: “*I really don't mind [disclosing] to be honest as long as I'm getting the supports I need (...) I don't really mind how it's [my diagnosis] being disclosed*” (Sean, 887-889).

Kimberley and Ester reported positive experiences disclosing to pre-empt potential difficulties in the future. For example, Kimberley explained:

I have been disclosing to my more supportive tutors (...) because I've had some negative experiences with tutors in the past (...) I think possibly they see me just as needy and not have been put[ing] the work in, so now early on I say “I've got these issues. I work very hard. They manifest in this way, and so I will occasionally need to contact you to talk about this or I might need a little bit more support in terms of the report” (...) that's gone really really well (Kimberley, 1034-1042)

Similarly, Ester disclosed her autism to inform her lecturer about concerns regarding the shift to online learning resulting from the introduction of COVID-19 pandemic restrictions:

before we went online [due to COVID-19] (...) I was (...) worried about what that's going to do 'cause I'm on the spectrum. And then after I got my diagnosis (...) I told him [the lecturer] that I was diagnosed and just sort of asked him little bits about how that would work and stuff and he was really nice (Ester, 383-388)

Students also highlighted the potential risks or biases that may result from disclosure of their autism diagnosis or co-occurring condition. For example, while Ester felt that “*being open and honest with coordinators about your needs is important*” (Ester, 532-533), she also acknowledged that this can be “*a lot harder than it seems and opens you up to the possibility of discrimination or just casual bias*” (Ester, 533-534). Tristan and Sean had similar concerns about the consequences of disclosing: “*it's just that worry that I'll be treated differently*”

(Tristan, 507-508). Similarly, Sean explained: *“I’d never disclose to someone who I thought would take advantage of me or something like that”* (Sean, 893-894).

While some students chose not to disclose, they also clarified that they were not actively trying to “hide” their diagnosis. For example, Taylor explained: *“I don’t really make a fuss about it but I don’t really have any interest in hiding it either”* (Taylor, 728-729). Ryan similarly stated: *“it’s not something that I hide from people, it’s not something that I don’t want people to know but it’s also not something I just tell people unprompted”* (Ryan, 1145-1147). Students indicated that it was not necessarily a conscious choice to withhold their diagnosis, but instead they expressed difficulties identifying the right time, place or situation to disclose. Ryan and Conrad explained:

“it kind of just seemed weird to go up to someone and say “oh by the way I have autism” It just kind of seems unnecessary and a bit strange” (Ryan, 1137-1139)

“I didn’t really feel like there was really an appropriate opportunity to really bring it up [autism diagnosis]” (Conrad, 701-702)

Overall, it was evident that deciding to disclose was complex, and required students to consider a range of factors, such as when to disclose, how to disclose and who to disclose to. In addition, students reflected on the outcome of disclosure, which could be both positive and negative. Students also explained that they were not seeking to hide their autism or actively trying not to disclose but explained that disclosing was not always a straightforward process.

8.2.3 Self-awareness or Internalised Ableism

The theme of self-awareness or internalised ableism was developed after debriefing between the researcher and co-analyst regarding student description of individual difficulties. While the researcher noted the self-awareness evident in the students’ descriptions, the co-analyst also highlighted the negative self-concept and internalised ableism that some of these descriptions also reflected. Internalised ableism refers to a person with disability expressing prejudice, or discrimination against themselves (Campbell, 2009). The theme therefore encompasses students’ descriptions of the individual difficulties they experienced and their internalisation of both the difficulties and the potential solutions and strategies. Several students described difficulties they had experienced during their transition to university in terms of things they personally *“struggled with”* or *“were not good at”*. For example, both Kimberley and Ester reflected on previous difficulties by internalising these challenges:

“I’m not very good at that [time management, planning] normally” (Ester, 106)

“I don’t have very good social skills and communication skills long-term so they [the friends made at orientation] may get sick of me one day we’ll see” (Ester, 482-483)

“I had a really really big problem writing reports” (Kimberley, 757-758)

“I can’t read body language, I have problems with facial expressions and voice tone and everything like that” (Kimberley, 717-719)

Similarly, Conrad reflected on some of his previous communication difficulties, noting concerns that he felt he *“might not make sense”* because *“I speak in too much detail which confuses a lot of people”* (Conrad, 152). As a result, Conrad felt people may dismiss his input and seek someone else’s instead. This made him wonder if his opinion or understanding was *“valid”*.

In addition, Conrad and Kimberley reflected on their difficulties as something they themselves would need to work on. For example, Conrad explained:

I always felt like I needed to adjust personally to a lot of things in terms of assessments and things like that (...) I just felt like I needed to adjust myself and really change how- how I study and (...) really I don’t know just get used to how– how they apply certain assessments for neurotypical students (Conrad, 712-720)

Similarly, Kimberley felt it was up to her to *“build up skills and have various sort of tools as ways of dealing with [her executive functioning difficulties]”* (Kimberley, 603-605).

Overall, it was evident in several students’ descriptions of their difficulties, that they demonstrated self-awareness. However, for both Kimberley and Ester these descriptions at times appeared to reflect a sense of internalised ableism, by focusing on their difficulties as internal problems, and things they were personally responsible to resolve or address.

8.2.4 Camouflaging and Masking to Overcome Difficulties

Students described various experiences that demonstrated attempts to camouflage or “mask” the difficulties they were having. Camouflaging and masking appeared evident in ways that students tried to hide or conceal the difficulties they experienced. Ester and Ryan described efforts to fit-in socially by *“pretending”* (Ryan) or *“putting on a personality”* (Ester):

“I can put on– (pause) a personality or an attitude that gets people to talk to me I can joke around and people will– people will talk to me” (Ester, 205-207)

“I mean people don't necessarily know if I'm autistic or not (...) I have gotten better at pretending to make eye contact, I have a strategy where I look at someone's forehead instead of their eyes and usually people can't tell the difference” (Ryan, 1232-1236)

While Ester used these strategies to engage socially, she also reflected that it often did not lead to the creation of long-term or ongoing friendships. Ester also described these strategies as a mechanism for overcoming difficulties associated with executive functioning and auditory processing difficulties:

what I usually do in those situations (...) I don't bother asking questions because rarely ever is [it] explained to me in a way that I understand, but what I do is I just watch what other people are doing (...) and gauge what I'm meant to be doing from that (Ester, 187-192)

95% of what I do is just piece things together from what everyone else is doing and saying [laugh] (Ester, 474-475)

Masking and camouflaging also appeared to have negative consequences for Ester, as at times it led to people making assumptions about her abilities and challenges. Ester explained:

the people who do know have seen me as high functioning they haven't really understood that (...) as much as they've tried to help the attitude has been quite dismissive 'cause their conceptualisation is that it's not that bad for me (Ester, 704-708)

In summary, it appeared that some students utilised masking or camouflaging as mechanisms to overcome some of their difficulties. While this appeared to be an effective way of overcoming some difficulties, students also reflected on experiences where masking their difficulties had resulted in negative experiences of assumptions or resulted in misunderstanding.

8.3 Persistence and Resilience

This superordinate theme was derived from students' descriptions of persisting despite challenges and setbacks. Under the superordinate theme of *persistence and*

resilience, three subordinate themes were developed that reflected elements of students' experiences of overcoming anxiety and adjusting to university, as well as their journey to and through university. These subordinate themes included:

1. *Anxiety: "Enormously stressed but very determined"*: reflecting students' descriptions of anxiety as an overarching challenge that impacted across various elements of their transition experience.
2. *Transition and first year as a period of adjustment*: where students described their experience of transition as a period of adjustment, which required reflection on past experiences, and adapting to changes in environment and expectations.
3. *The journey to and through first year university*: where students described the ways in which they had arrived at their university studies, with many having previously attempted university studies, or having transitioned through alternative pathway programs.

8.3.1 Anxiety: "Enormously stressed but very determined"

Most students highlighted experiences of anxiety, nervousness, stress, or worry during their transition to university. Persistence and resilience were evident in the way these students had recognised their anxiety but continued with their studies despite these challenges. Kimberley summarised this experience when asked how she felt about transitioning to university: *"I felt enormously stressed about it but I was also very determined"* (Kimberley, 220-221)

Some students experienced anxiety as the result of social interactions, sensory difficulties and difficulties with executive functioning. For example, Kimberley explained: *"I didn't think I would fit in, (...) or be able to cope with other students"* (Kimberley, 255-261). While Ester noted:

*it's definitely the engaging (...) who I might see and who I might not see
[on campus] (...) it's preparing mentally for all the interactions that I might
have on my way there, while I'm there, and on my way back [home]*
(Ester, 263-266)

Sensory difficulties had made it challenging for Ryan to engage in some of his classes. He explained: *"Sometimes it [anxiety] has been triggered by often large classrooms, like I was saying with sensory– (...) which is kind of not really separable from just the sensory issues themselves"* (Ryan, 793-798). Conrad expressed difficulties with time management which resulted in him feeling: *"very nervous and constantly anxious about how each week would come"* (Conrad, 112-113). Conrad also experienced anxiety when engaging in class:

before I'd walk into the door for tutorials there would be butterflies in my stomach I'd always be very anxious to really— share and participate so (...) it was very nerve-wracking to really have all the eyes on me 'cause I don't really like it when a lot of attention's on me and people are listening to my input (Conrad, 573-579)

Yet, despite these challenges, all three of these students had continued to engage and participate in their studies.

When asked how they saw their experience of transition as different to that of non-autistic students, Conrad, Ester, and Kimberley highlighted anxiety as a key factor. During her transition to university, Kimberley felt that she had to do *“a lot around stress and anxiety management”* (Kimberley, 820) than non-autistic students. Similarly, Conrad felt that students on the autism spectrum experienced *“more anxiety, like a high level of anxiety in terms of socialising and in terms of adjusting to new environments”* (Conrad, 594-595). Ester acknowledged that most students feel some anxiety about their transition to university; however, she felt this differed for autistic students:

everyone's anxious about starting uni [sic], they don't know what to expect (...) but being autistic just added another layer that you needed to plan for so I— I say it definitely does make it a bit harder if you're on the spectrum (Ester, 524-527)

Overall, anxiety appeared to play a significant factor in the transition experiences of autistic students. Despite this anxiety, most students were able to continue with their studies or work on strategies to address these challenges in the future, demonstrating their ability to persist and overcome these barriers.

8.3.2 Transition and First Year as a Period of Adjustment

Transition was described by some students as a period of adjustment, and adaptation to change. Students expressed the need to adjust to university environments and lifestyle, as well as social and academic expectations. They also spoke about ways in which they adjusted to the experience by monitoring their progress, reflecting on past experiences, and decreasing their study load.

Conrad and Tristan described the experience of transitioning to university as something they had to *“adjust to”, “adapt to”, and “get used to”*. Both felt that there were differences between high school and university which took them time to adjust to:

[university] was just completely different to me (...) just because it wasn't like school where you had people you saw almost every day (...) it's just completely different [to high school] and that was tough [emphasised] to adapt to because there was no real– (short pause) like it's not like going up a year in high school where you have people you know around you (Tristan, 58-61)

in the first couple of weeks [first year university] it was completely different than my experience in high school (...) with like assessments (...) and referencing it's all completely different and so that was– that was definitely a big shock (Conrad, 90-95)

While adapting and adjusting to university expectations may not be an autism-specific experience, Conrad and Sean both saw autism as a key factor in how they experienced this adjustment differently to their non-autistic peers. Conrad felt the need to adjust to the change in environment from high school to university contributed to autistic students' experiences of increased anxiety:

being on the spectrum for autism I feel like– (...) we tend to experience more anxiety like a high level of anxiety in terms of socialising and in terms of adjusting to new environments (...) adjusting to new rules and policies and to new– new assessments (...) I think it takes more time for people who are on the spectrum to adjust to that. At least that's what happened- that's what happens in my experience I need to take more time to really feel like I can balance it out and really get- get control of it. So I feel like in that sense I think time plays a big role in the difference with neurotypical students (Conrad, 593-604)

Similarly, Sean expressed difficulties adjusting to the social aspects of university, including finding an appropriate study/life balance which he identified as potentially associated with his autism:

[when] I started at uni I found that (...) there's a lot more to just studying, studying, studying (...) there's a social aspect, there's a health aspect, I need to find that balance (...) the main problem I found which may have been affected by autism is I just couldn't understand, and I couldn't find that balance which is something that I've learnt to adapt to in the latter half of this year basically (Sean , 636-644)

For Taylor, Conrad, Sean, and Ryan adjusting and adapting to university also meant reviewing and decreasing their overall study load. Ryan had undertaken full-time study in his first attempt at university and consequently chose to enrol in a decreased study load in the first year of his current degree. Ryan reflected on his previous attempt at university as informing this decision: *“I had tried doing full-time (...) the very first time I started university (...) and I found that that was just not feasible for me (...) I am still at a point where that’s just not feasible”* (Ryan, 157-161). He was also concerned about becoming overwhelmed with the workload, which he reported had happened in previous years: *“I was worried that basically the same thing that had happened in the last two degrees would happen again”* (Ryan, 239-241).

Ryan also explained:

I knew that I wouldn't be able to handle a four-unit workload [full-time] so that's why I started with three and then dropping down to two (...) ever since I've only done two units [part-time] because [short pause] mostly just– (...) just that I don't think I can handle more than that (Ryan, 252-267)

Similarly, Taylor reduced their study load and by the time they commenced their current degree they were studying part-time. For Sean, the reduction in study load resulted from his difficulties with specific courses and content areas. Sean explained:

I started with the three courses (...) the courses were quite difficult I was doing (...) and it just got to the point where (...) I just had to drop [one] course, drop [another] course and by the time exams came along I was just doing the maths course (Sean, 153-161)

In summary, students reflected on the experience of adjusting to the social, academic, and environmental aspects of university. Both Conrad and Sean saw the experience of adjustment to university as being potentially related to autism. For some students, adjusting to academic expectations at university was challenging, with several students reducing their study load during their first year to adapt to these challenges.

8.3.3 The Journey to and Through First Year at University

This theme reflected students' descriptions of their various pathways into and through their first year of university. The pathway to students' current degree was often non-traditional or disrupted. However, the descriptions students provided about their educational pathways into university, their previous attempts at university, and their strategies for continuing to study despite setbacks, reflected resilience, persistence, and determination.

Only two students (Tristan and Conrad) transitioned directly from high school into their current university degree. While Tristan had initially transitioned directly from high school to university, he reported finding his first semester “*overwhelming*”, and ultimately took a leave of absence in his first semester, before returning to recommence his studies again the following year. The remaining students either transitioned via a university or TAFE preparation program (Taylor and Sean), or had attempted university previously (Ryan, Harry, Ester, and Kimberley).

The language used by Ryan, Harry, Ester, and Kimberley to reflect on their previous attempts at university was often neutral and framed in the context of their journey to university. For example, Ester described having ‘*tried*’ university previously, while Harry, Kimberley, and Ryan described having previously ‘*been*’ to university. Similarly, while some students used the phrase ‘*dropped-out*’ of university, none referred to ‘*failing*’ their previous attempt at university.

Taylor and Sean undertook additional courses to gain entry into their university degrees. For Taylor this was via a university pathway program, although this had been complicated by an academic mix-up and presented as an unexpected setback for Taylor. Taylor reflected on the experience of undertaking the university pathway program as “*a blow to my ego*” (303-304), and the overall experience of the enrolment mix-up as “*a large debacle*” which they still seemed frustrated by at the time of their interview. However, despite this setback, Taylor completed the pathway program and therefore gained entry into their chosen degree.

Sean gained entry to university via a VET pathway undertaking additional TAFE courses, which he described as a useful and necessary process that would enable him to meet his goals. Sean explained: “*I got into uni [sic] via a TAFE course*” (Sean, 54-55). These courses provided him with the entry requirements to apply for university which he had been unable to do at the end of high school as, he had not received an ATAR score at the end of his high school studies. Sean explained that the process of locating, enrolling in, and completing the TAFE courses had been supported by his NDIS provider:

I expressed to them [NDIS provider] that I wanted to go to uni [sic] and study the things I am trying to study now (...) and they essentially looked for (...) pathways that I could go to get into that position (...) so they essentially found the Cert [certificate] III and Cert [certificate] IV for me (...) so essentially I had this goal (...) the NDIS people showed me what I needed to do to get towards that goal, I worked– I studied towards that goal, and I eventually got there (Sean, 606-618)

For Ester, completing a six-month lab course via TAFE enabled her to explore new career options. Ester described this as *“starting small”*. After completing the TAFE course, she spent six months *“looking for things [studies] that I wanted to do”* (99), before enrolling in a degree which *“covered a fair few different topics which gave me the opportunity to try out different things and see what I liked”* (Ester, 101-103).

The pathway through university was also varied for most students. Sean and Tristan both took leave during the first year of their current degree, and most students undertook part-time studies or reduced their study load in their first year. As a result of these enrolment variations, most participants did not complete all their first-year subjects in one calendar year. Tristan took a leave of absence enabling him to take *“a break from study”* and return to his studies the following year. In preparation for his return to studies, Sean used his leave to focus on familiarising himself with the mathematical content that he was having difficulties with. Sean felt this time off allowed him to *“have a reset”* so that he could *“do some background work”* to be *“better prepared, so I’m not going to feel overwhelmed and stressed basically”* (Sean, 211-212). Sean reflected on taking this leave as a positive impact on his studies: *“I took semester two off (...) for the self-study (...) I’m feeling really confident and optimistic about 2021 (...) I’m much better prepared (...) I’m quite happy at this point, optimistic”* (Sean, 216-219). He later added *“because I took a breather and I was able to communicate with my NDIS provider (...) I’ve been trying to get myself into a position where I’m a lot better prepared for study (...) in semester one 2021 basically”* (Sean, 242-245).

Overall, students demonstrated varied pathways to university. Students also adapted their study-load during their first year, which resulted in varied pathways through their first year of university and beyond. These varied experiences were not reflected as negatives but instead appeared to demonstrate students’ sense of persistence and resilience.

8.4 Accessing and Receiving Support

All students shared experiences of accessing and receiving support during their first year of university studies. This superordinate theme highlights the types of support students received during their transition. The following four subordinate themes were developed under this superordinate theme:

1. *Family support: Emotional, practical, financial:* where students described the various types of support provided by their family members.
2. *Peer support: Seeking social connection, but not always finding it:* reflecting students’ descriptions of peer support and social connections, and the benefits and challenges of these supports.

3. *University supports: Programs and people:* encompassing the range of university programs and supports students accessed during their transition to university, including orientation programs, peer mentoring programs, Disability Services and academic support.
4. *Genuine understanding of autism:* reflecting students' desire for university staff to develop an understanding of autism which moves beyond myths and misconceptions and helps them to understand the autistic student experience, and hence provide better support for autistic students.

8.4.1 Family Support: Emotional, Practical, Financial

Family members provided emotional, practical, or financial support to students during their transition to university. The most common type of family support described by students was practical support. Conrad felt the practical support provided by his parents created a quiet and comfortable space to study without distractions. Conrad reflected that it was this “stability” that enabled him to study effectively at home. Conrad also explained that his parents also supported him by helping him to break down study tasks to “*understand more about what the week's topic is*” (Conrad, 395).

Students also felt that family members provided support by helping them with tasks of daily living, such as washing, cleaning, and cooking. Some students explained that their parents undertook these tasks for them, which allowed them to focus on their studies. Support with daily living activities also included teaching the student skills to live independently. For example, Sean received support from his dad and stepmother to develop skills like preparing food and “*just basic living skills (...) that I needed to live independently*” (Sean, 548-550). Similarly, Taylor received support from their mother to learn cooking skills:

when I was first moving into my flat (...) beforehand my mum had made sure to give me a couple of crash courses in cooking very simple meals like getting a salad, making French toast, cooking a steak, the simple things like that, how to use an oven without burning the place down that sort of thing (Taylor, 345-350)

Practical support was also evident in the way family members supported the student to navigate university life. For example, Tristan's mother helped him to navigate the university policies and services to apply for leave of absence. Conrad received support from his cousin who was able to answer questions he had about assessment requirements, expectations, and referencing.

In addition to practical support, several students described receiving emotional support from family members. Conrad and Ryan reported receiving emotional support from their mothers, while Taylor reported that their parents provided emotional support by *“sticking around for the first week [of university] to make sure I didn’t have any problems”* (Taylor, 130-131). Taylor’s parents also let them know that *“if I ever needed anything they could pop down for the day”* (Taylor, 359-360). Similarly, Kimberley described her family as being *“on call for emotional support”* (Kimberley, 506).

Taylor was the only student to explicitly identify their parents as having provided financial support. Taylor reported that their family members provided assistance with the costs of *“renting me a flat out in the city”* (Taylor, 250-251) and providing *“a reasonable allowance”* (Taylor, 365).

In summary, students shared their experiences of support from family members, primarily in terms of practical or emotional support. Support from family members was reported in positive terms, with support typically focused on assisting the student to effectively engage with their studies or live independently.

8.4.2 Peer Support: Seeking Social Connection, But Not Always Finding It

Support from friends and peers appeared to be a positive factor for some students during the transition to university. However, friendships and social connections were not always easily made. For students who found social connections difficult to make, this was reported as impacting negatively on their overall university experience and wellbeing.

Ester, Conrad, and Sean reported friendships and peer connections supported them to navigate the university experience. Ester felt that her degree’s orientation program was a significant factor that assisted her to develop friendships with peers in her degree:

one thing at this degree that they did is they did a very elaborate orientation day (...) I actually made some friends (...) which helped a lot after that. I don’t think I would have made any friends if it wasn’t for that orientation day (Ester, 161-171)

The friendships Ester made during the orientation program were central to Ester’s description of her transition experience, identifying these friends as a significant support for her during her first year at university.

Similarly, Sean expressed that having friends *“really enhanced my uni [sic] experience”* (Sean, 461), while Conrad highlighted the benefits of having someone *“to lean on”* (667) when reflecting on his relationship with a friend from high school who was doing

the same degree as him. Having this friendship provided Conrad with *“a familiar face to really help me get through any challenges or any questions I might have”* (Conrad, 426-428), describing the relationship as a reciprocal friendship, stating: *“both of us helped each other out and clarifying [sic] certain things”* (Conrad, 435-436).

For some students, social connections had been difficult to develop, even though this was something they were actively looking forward to when starting university. For example, Taylor had seen university as *“a chance to get out there, be more social, be around people I actually like”* (Taylor, 146-147). However, they observed that making social connections had been quite difficult, stating: *“despite my best intentions I had no idea how [emphasised] [to be more social]”* (Taylor, 148-149). Ryan had been similarly, eager to make new friends at university but instead found himself feeling socially *“excluded”*. Ryan reflected on his difficulties making social connections as something that had a negative impact on his mood and his performance at university. He also noted that he found it *“very difficult and very disheartening that my expectations of what socialization would be like weren’t really being met”* (Ryan, 419-421). In contrast, Sean spoke about initially positive experiences making new friends at university, stating: *“[university] was going really well for a while, [I] made a lot of friends”* (Sean, 108). However, due to the COVID-19 pandemic restrictions Sean had to leave his on-campus accommodation and return home, making it difficult for him to maintain the friendships and connections he had made.

Kimberley also found it difficult to connect socially with her peers, although she mostly attributed this to her being a mature-age student rather than to being autistic. She observed: *“I suppose I had trouble kind of connecting to my peers and building the friendships because (...) I’m not the same age as most of them”* (Kimberley, 533-535). However, Kimberley also felt there could be more opportunities to support *“people with autism to meet and connect”* (Kimberley, 536-537) at university. Additionally, Kimberley mentioned the disability study room on her campus as a helpful place to meet other students:

I used the disability room to study. I did meet quite a lot of other disabled students and regardless of the disability I did get on and connect with them and that was really nice (...) I found lots of them really really lovely and really approachable (Kimberley, 539-543)

Taylor and Ryan both attributed their difficulties making social connections directly to being autistic. Taylor reflected this as particularly challenging before they received their formal diagnosis:

since I hadn't received a fully formal diagnosis [of autism] I still didn't have that much education on what autism means. I still found it quite difficult to socialize and I couldn't really (...) make the best of it (Taylor, 152-155)

Taylor also explained: *"being on the spectrum it's (...) you don't really have that initiative to get— go out [and] make those social connections, really get involved"* (Taylor, 584-587). Similarly, Ryan saw his difficulties making social connections as potentially related to being autistic, stating:

I suspect being autistic (...) I just don't understand how people suddenly just form these groups of people and suddenly just become friends with each other and suddenly get involved with all this stuff I just— I don't understand how it even happens (...) Like it's so opaque to me that I can't even tell you what I'm not doing because it's just [short pause] it's something that I just don't understand at all (Ryan, 733-741)

Overall, it appeared that social connections and friendships were not always easy for students to make. However, for students who did develop such connections, they played an important role in their overall transition experience.

8.4.3 University Supports: Programs and People

Students' experiences accessing university support programs and personnel were mixed. They described benefits from accessing support; however, they also described the challenges they experienced in being able to locate or access these support services. The key programs described by students included: orientation and mentoring, while key staff members included academic and Disability Services.

8.4.3.1 Orientation.

Students described mixed experiences related to their university's orientation program. Ester for example participated in a specific orientation program for her degree, which she found beneficial. The program provided her with a *"sense of stability"*, and enabled her to learn more about the *"things that we might be doing during the degree"* (Ester, 274-275). In addition, it provided her with the opportunity to develop social connections and meet *"most of our lecturers and coordinators"* (Ester, 276-277). Ester felt that this program impacted positively on her social experience at university, attributing her ability to develop peer relationships to having attended the orientation program: *"I think honestly if it wasn't for that orientation I would have struggled a lot more with the social and communication aspects of things"* (Ester, 486-488).

In contrast to Ester's experience, orientation programs were not reflected positively by most students. Taylor thought orientation activities were *"for the most part quite entertaining"* but found the sessions on academic skills *"a little on the dry side"*. Sean also expressed that the orientation sessions available at his university seemed to be predominantly related to essay and report writing which he reported were *"quite general"* and *"didn't really apply a great deal to the study that I was doing in semester one"* (Sean, 406-407). Sean also explained that orientation programs which were more specific to his degree area would have been more helpful.

Kimberley and Taylor's orientation experiences reflected their challenges navigating the university campus and engaging in the activities. Kimberley found orientation very difficult to attend:

I tried to go along for the open days [orientation] and the activities and things like that too (...) I found those too hard and I kept getting lost and unsure about which group I was meant to join and had to go home right away, basically it didn't work out well (Kimberley, 154-158)

Kimberley described being unable to attend *"more intense"* orientation sessions, and the sessions Kimberley was able to attend she described as *"overwhelming"*. She explained: *"I did manage to get to campus but I didn't get much further than that"* (Kimberley, 162-163). Both Kimberley and Taylor found it difficult to find their way around their university campus. Kimberley explained: *"I also couldn't find the locations [for orientation activities] (...) I just I can't work out where to go half the time"* (Kimberley, 373-376). Similarly, Taylor reported that they *"blissfully missed one or two [orientation sessions] because I (...) struggled to find my way around campus"* (Taylor, 272-273).

Ryan and Harry did not attend any orientation programs. Ryan did not elaborate as to why he had not attended; however, Harry explained that he was unaware of any orientation programs provided by his university.

Overall, experiences of orientation programs varied. Attending orientation programs appeared to be challenging for some students, while for others, orientation did not appear to provide them with any specific benefits. However, for one student, attendance at a degree-specific orientation program appeared to provide an effective opportunity for the development of social connections which was a positive outcome for the student throughout their transition.

8.4.3.2 Peer Mentoring.

Several students accessed peer mentoring or similar supports during their first year at university. Experiences of peer mentoring support were varied. For example, Sean found being part of a mentoring group for students with disabilities provided opportunities to socialise and ask questions about university life. However, he also explained: *“there was only so much the senior student [mentor] was able to tell me”* (Sean, 494-495). He also felt this support was *“quite general”*, noting that the senior student mentor was responsible for supporting a small group of first year students, who all had different disabilities and support needs.

Ryan had a similarly mixed experience as a participant in a peer mentoring program specifically for autistic students at his university. He described the mentoring program as *“fairly helpful”* in his first year, with the mentors helping to ensure students were *“staying on top of things”*. Ryan also felt that he had positive relationships with some of his mentors. However, he also reflected on his experience with one specific mentor, explaining: *“she didn’t really get autistic people at all and didn’t really understand me at all and I didn’t really get on that well with her”* (Ryan, 382-384). Ryan further explained:

She [the mentor] would try and recommend that I do things like plan out my day (...) make a study plan and write things down and use an app to plan things and it was sort of like her trying to give me these organisational tools but (...) I feel personally (...) my brain just doesn't work in a way that I can just write down what I'm gonna [sic] do and then do it. I— I don't know if that's autism or just me (...) I feel like a lot of the things she [the mentor] was suggesting are the very things that I'm not well suited to doing (Ryan, 389-397)

Ryan noted that the mentors in his program were mostly students from disciplines other than the one he was studying, and therefore unable to provide content specific support, but they could assist him with more general problems.

Concerns were also highlighted by some students that peer mentors may not have the knowledge or skills to support students with disability, including autistic students, effectively. For example, while Kimberley had been offered peer mentoring support through her university, she did not feel her specific support needs and situation would be taken into consideration:

[the uni] did make the offers [of mentoring support] but I'm a mature age student I have mental health problems and I have a disability, autism, and

as far as I could tell they weren't going to make, do any considerations in terms of the mentorship program for those things (Kimberley, 410-414)

According to Kimberley, the peer mentoring program was “*just pairing third year psych students with first year students who identify as having autism*” (Kimberley, 423-424), which she didn’t see as an appealing option. She explained:

just because someone is in psych doesn't mean they have much of an idea or [are] particularly sensitive. I've met lots of students (...) who are in psych who don't have a good grasp or a good approach to mental illness or disabilities so that's a bit off-putting (Kimberley, 426-430)

Kimberley chose not to engage in the peer mentoring support program: “*I felt weird about having a mentor who was much younger than me and had no idea about any of those issues [mental health, disability, autism] so I didn't go for it*” (Kimberley, 416-418).

Harry did not see peer mentoring support as an appropriate option for him. He noted that there were students who were responsible for contacting new students to offer support. However, he did not opt to engage with their support at the time. Harry explained:

they just send you a couple of emails and just say 'get back to me if you've got any concerns, any questions' (...) so yeah she just sent me some emails and I just replied and just said thanks for the email I don't have any questions at this point (Harry, 345-352)

Overall, students’ experiences of peer mentoring support suggested that some found it to be a useful mechanism for accessing support and navigating their transition. They also had concerns and reservations about the quality of the support and the expertise of the mentors.

8.4.3.3 Academic staff.

Students’ experiences of interactions with academic staff were mixed, with some describing ways in which academic staff supported or motivated them, while others described difficulties they experienced engaging with academic staff.

Students reflected positively on academic staff who were “*approachable*”, able to be contacted by a variety of methods, and who took the time to listen and support all students (not just autistic students). Harry and Ryan both described the characteristics of academic staff who had a positive influence on their studies. Harry for example, found staff who were “*on a first name basis*” with students, and dressed in a more “*casual*” style to be more

approachable, which was very important to him. Ryan felt motivated by academic staff who were “*passionate*” and “*enthusiastic*”. He reflected:

I had that very enthusiastic lecturer (...) it just made me more interested in the class in general and I just found that unit everything about that unit was just really fantastic and made me feel really passionate about what I was doing (Ryan, 214-219)

Conrad and Kimberley described positive experiences with academic staff who provided supports which were beyond academic content delivery alone, such as taking the time to check in on students, their progress, and their wellbeing. For example, Conrad described the support he received from one of his academic staff:

the course coordinator for my psychology course. She was very good in terms of really supporting the students like on a level where you don't just refer the students to the support services (...) she took the initiative to (...) send us emails and (...) check in on us (...) she would set (...) certain times in a— in a certain week for us to all catch up and have any questions in a smaller group setting so we don't feel so uncomfortable when there's a lot of people around (...) when I attended that for further support on assessments and exams that was very, very beneficial and she was very understanding and very professional about everything and very— very, very friendly and welcoming (Conrad, 802-816)

Similarly, Kimberley described one of her experiences with an academic staff member who had supported her during a difficult time:

I remember I went up and talked to him for an hour when I was having a panic attack and was having a really hard time (...) I didn't even tell him what was going on but he just stayed with me and talked to me (Kimberley, 555-558)

She commented that this staff member provided this type of support to all students, not just to her, and explained that this support had made a significant difference to her transition experience: “*just his whole approach to students, to all of us it wasn't me in particular, was really really good and made a big difference, if he'd been horrible I might have left uni [sic] and never returned*” (Kimberley, 549-552). These positive interactions appeared to provide Kimberley with more confidence to seek support in the future:

I just– felt like it would be possible for me to do [university] (...) just the fact that he [the lecturer] reacted positively rather than negatively to me (...) so he was really good about that and that made me feel like I could approach lecturers and some (...) would respond positively and support me (Kimberley, 568-581)

While Kimberley reported positive experiences with academic staff members supporting her during her transition, at times she reflected these experiences as “*lucky*”. For example, “*I was lucky in that the lecturer I had for the very first unit I took– just by coincidence (...) just about one of the loveliest people I’ve ever met, and was just incredibly supportive*” (Kimberley, 548-550).

Not all students had positive experiences with academic staff members. Difficulties engaging with academic staff were reported by students who saw some academic staff members as “*arrogant or quite cocky*”, “*clinical*”, or “*black and white in terms of policies*”. Several students also described experiences where academic staff were “*difficult to contact*”, or slow to respond to their queries, resulting in the student experiencing increased stress and anxiety.

Ryan and Ester both observed negative experiences with academic staff, resulting from staff responses and reactions to their disability and support needs. For example, Ryan recalled one staff member asking him about his support needs in front of his classmates:

I did have one negative kind of interaction with one professor (...) so my access plan lets the lecturer know that I’m going to have extra time on the exam and this lecturer just basically said in front of the class ‘Oh why do you get extra time in the class what makes you so special?’ and that was just very uncomfortable and putting me on the spot and really not OK (...) [laughs] [pause] (...) I just kind of muttered something and just said ‘oh you know I just have some disability stuff’ or something like that and then they left it alone after that so I didn’t do anything about that. But that was a fairly negative interaction like being called-out in front of a class is not great [laugh] (Ryan, 1183-1196)

Similarly, Ester felt one lecturer had “*ridiculed*” and “*made fun of*” her.

For Conrad and Kimberley, difficulties with academic staff were experienced when engaging with tutors. Conrad felt that some tutors came across as “*a bit too full-on*”, and potentially not open to discussion or clarification. As a result, he felt “*a bit too nervous to really go up to her and ask further clarification for certain assessments or things like that (...)*

it was a lot to take on in my first year I must admit" (Conrad, 795-798). Kimberley reported similar anxieties about engaging with tutors:

sometimes they can have negative reactions when you ask for support, or ask for your special considerations or things like that, I found lots of them are good but I found a few that are less than accommodating and annoyed to be approached (Kimberley, 588-592)

As a result, Kimberley felt tutors saw her as *"needy and [to] not have been put[ting] the work in"* (1037-1038). She felt these difficulties may have been due to her tutor's own stress and potential lack of training or awareness of disability. As Kimberley explained: *"they're [tutors] under a lot of stress and they're not given any training, or at least I presume they're not given any training on how to deal with people with disabilities"* (Kimberley, 586-588). She also noted systemic issues that may have contributed to these difficulties:

I don't blame the tutors for being undertrained and overstressed that's not their fault, and that's one way the university system has been very unfair to them [pause] but yeah just generally it appears that a lot of people don't know that autistic and disabled students require extra support (...) [and] what sort of supports those might be (Kimberley, 1106-1111)

Conrad observed one positive experience with a tutor who assisted students to engage with their studies, explaining that the tutor would *"pick out and choose (...) the main relevant sections of the textbook (...) in a PowerPoint for every tutorial so that (...) we can grasp the topic really well every week"* (Conrad, 124-127). He felt this *"took a lot of pressure off"* and *"helped me tremendously"*.

In summary, students described various experiences with academic staff members with both positive and negative outcomes. Positive experiences with academic staff were often associated with students feeling motivated or supported to engage with their studies, while negative experiences appeared to be associated with difficulties being able to seek and access support.

8.4.3.4 Disability Services.

Several participants had successfully accessed support through their university's Disability Services during their first year of studies, describing access to the service as *"straightforward"*, or *"easy enough"*. Challenges accessing Disability Services were also highlighted, with some students finding it difficult to locate the services or access them when needed. For example, Ryan found the process of accessing Disability Services reasonably easy, but noted the delay between seeking support and being able to access it:

it can be hard to get an appointment in the first place (...) But I found it (...) fairly easy to access (...) It can take a little while to get an appointment, but it's— it's easy enough to just call them and ask for one, it just takes a little while before you can actually get in and speak to someone (Ryan, 1008-1016)

Similarly, Taylor found accessing Disability Services was “*helpful*” and “*straightforward*”, but also noted: “*firstly it did take a bit for me to find it [Disability Services]*” (Taylor, 660).

Accessing Disability Services was reasonably straightforward for Kimberley also; however, this was primarily due to the fact she had engaged with them during her previous attempt at university. Previous access to the service also meant that Kimberley was already aware that she would be able to develop an access plan and access support based on her existing ADHD diagnosis.

Most students described Disability Services staff in terms of the practical support they provided, such as developing an access plan. Access plans documented academic adjustments students were eligible for, most commonly extra time in exams and extensions on assignments. In addition, some students spoke about the accommodations and adjustments implemented via Disability Services such as the use of a laptop for completing written exams. Access plans were generally provided to students, who were then responsible for passing this information on to their academic staff.

Kimberley provided a more detailed description of her experiences with Disability Services, highlighting that it was a disability advisor who suggested to Kimberley that she may be autistic. Kimberley explained that the disability advisor herself was autistic and had experiences and training in autism, describing her as “*insightful*”. She also spoke about the experience of accessing an advisor who was autistic and had this level of background knowledge and experience as: “*pure luck*”, “*pot-luck*”, and “*coincidence*”, noting that “*generally they [disability advisors] don't have that level of training*” (Kimberley, 479-481). Kimberley also explained that the disability advisor she saw provided her with extra support “*out of the goodness of her own heart*” (496), which she reported “*made a huge difference*” to her transition experience.

Accessing Disability Services was also made more difficult for some students as they were unaware of the services and supports available at their university. For example, Tristan had been unaware of Disability Services until he was referred to them when looking for advice about taking leave from his studies. Taylor was also unaware of the services available at his university until one of their parents suggested they seek additional support.

Conrad had also been unaware of the services and support available until he was referred to Disability Services by an academic staff member after disclosing concerns about sitting his end of year exam:

I had no idea (...) that Disability Services (...) even existed at the time I didn't know (...) what they could do to provide extra support for people who've got intellectual disabilities [sic]. It only came to my attention (...) at the end of the year when I emailed my course coordinator and I asked her 'is there anything for a supplementary venue where people who are on the spectrum can go to another environment with a less amount of students and get given maybe an extra few minutes (...)?' (...) then she referred me to developing an access plan (Taylor, 634-644)

Access to Disability Services was also dependent on having a formal diagnosis and the necessary documentation. Ester did not feel she could access her university Disability Services without a formal diagnosis. When asked if she had any contact with Disability Services during her first year she stated: *"No I didn't think I was able to [access the Disability Service]. Not without the— the diagnosis"* (Ester, 563). Harry also had difficulty accessing Disability Services because, although he had received a diagnosis of Asperger syndrome in childhood, he was unable to locate an official diagnostic report. He explained:

I also saw a disability advisor and she said that we need evidence from a psychologist, she said 'if we don't have a psych report then we don't really know what the problem is' [pause] she also said 'if you've got a letter from a GP [General Practitioner] or something that mentions a diagnosis then we might be able to do something' but I couldn't find anything at home (Harry, 164-172)

Kimberley expressed concern about students' ability to access Disability Services if they weren't aware of the support available and did not have access to supportive health practitioners or a formal diagnostic report. She explained that without these she *"would probably find it [the process of accessing Disability Services] pretty distressing"* (Kimberley, 941).

Overall, students described mixed experiences engaging with the university Disability Services. Students who had been able to access Disability Services described the process as reasonably straightforward, although they highlighted delays in access to support as one concern. Not accessing Disability Services was associated with being unaware of the support available or being unable to access the support due to a lack of formal diagnosis or access to their diagnostic report.

8.4.4 Genuine Understanding of Autism

This theme reflected students' descriptions of what they wished university staff knew and understood about autism. Students identified the need for university staff to have a genuine understanding of autism and the way that it impacts each person individually. They highlighted issues that staff may need to be aware of when providing support for autistic students, such as needing to allow extra time for information processing and task completion, communication difficulties, as well as potentially needing additional clarification of expectations or course specific content.

Ester, Taylor, and Ryan highlighted the importance of university staff having a genuine understanding of the communication difficulties autistic students might experience, such as *"misunderstanding"* information (Ester), a tendency to *"take things at face value"* (Taylor) or having difficulties with *"subtext or implications"* (Taylor). Similarly, Ryan suggested that it was important for staff to understand *"how an autistic person's body language might be different"* (Ryan, 1229-1230). He expressed concern that students who do not make eye contact may be interpreted as *"rude or odd"* (1239) and suggested it was important for staff to understand *"that autistic people aren't meaning to be rude by avoiding eye contact or aren't meaning to seem strange"* (Ryan, 1241-1242).

For Conrad, it was important that staff were aware of the difficulties autistic students may experience and the impact this might have on a student's learning and ability to engage or participate at university. He felt knowledge of these challenges and using appropriate strategies would enable staff to provide autistic students with extra support without needing to single them out from other students. As a result, Conrad felt this would help to make autistic students feel less *"marginalised"*. Similarly, Kimberley thought that staff needed to be aware that autistic students may need extra support, additional clarification or explanations, and that this may in turn mean they *"require more time than other students"* (Kimberley, 1090). Ryan however, felt that all students, not just autistic students, would benefit from being able to access someone, other than the lecturer, who could support them with understanding and clarifying academic content.

Ester and Sean highlighted the need for university staff to be aware of the potential diversity of autistic experiences, and to recognise that all autistic students are different and have different support needs. Ester felt it was important:

for coordinators/lecturers especially, [to have] a better understanding of the complexities that come with ASD [sic] and how that affects those of different demographics, like gender and race, for things like symptoms [sic] and struggles (Ester, 672-675)

Sean felt that staff understanding of diversity and difference would provide a positive and supportive university environment:

*if university staff has– has that knowledge that everyone's different (...)
and people with autism they are– they're treated with respect, dignity (...)
and if they have a question in relation to their ability, what they think they
can do, or what they– they believe they can do they can talk to the
university staff about it in an open, supportive manner and– and can
create a positive academic, social environment basically (Sean, 972-978)*

To address the difficulties experienced by autistic students, and ensure they are supported to succeed in their first year, Ester suggested universities needed to increase awareness of autism for university staff to *“foster a more inclusive environment for autistics”* (Ester, 682). Similarly, Taylor felt it was important that university staff *“learn about autism at the very least the basics”* (Taylor, 610-611). Ester also felt it was important for staff to understand ways in which they can interact positively with autistic students, although she did not elaborate on what strategies this might require. Kimberley on the other hand explained that she would like to see more *“autism-specific programs”* at university, run by a designated staff member with expertise and experience in autism who could develop these programs, work with students, and provide guidance and advice to university staff.

In summary, students talked about the importance of staff knowledge and understanding of autism, in particular the communication challenges experienced by autistic students. They also highlighted the importance of understanding how these experiences impact on autistic students' university experience and transition to university. Staff education was suggested as one potential strategy to support staff understanding.

8.5 Chapter Summary

This chapter has presented superordinate and subordinate themes generated from analysis of semi-structured interviews with eight autistic students. Three superordinate themes were generated: *sense of self and identity*, *persistence and resilience*, and *accessing and receiving support*.

Students described their experiences relating to their sense of self and autistic identity, including the importance of formal diagnosis, as well as understanding autism and their support needs. They also described the difficulties they experienced in deciding whether to disclose their autism diagnosis. In addition, students discussed strategies they used to address the difficulties they experienced during their transition. Experiences of anxiety and adjustment demonstrated students' persistence and resilience to continue with

their studies despite setbacks. It was also evident that students' pathways to and through their first year of university were varied.

Finally, students also discussed the types of supports they accessed during their first year of university including support from family members, peers, and university staff. Family members provided emotional, practical, and financial support; while peers and friends often provided academic, practical, and social support. However, not all students had been able to develop social connections during their first year of university. Students also described their experiences of university programs and support; however, access and experiences of these supports varied. To enable access to support and create an inclusive university environment, students highlighted the importance of staff understanding and knowledge of autism. The following chapter presents an analysis of data collected through semi-structured interviews with six members of students' support networks.

9 ANALYSIS: PARTICIPANT THEMES (SUPPORT NETWORKS)

This chapter presents the findings from reflexive thematic analysis of interviews with six people who provided support to autistic students during their transition to, and first year of university, addressing research objectives two and three. As described in Chapter 6, due to low numbers of participants from students' support networks, analysis of these data as individual student-based case studies presented a risk of breaching participant confidentiality. Instead, data collected from semi-structured interviews with members of the students' support network were analysed together as a single support network group, using RTA.

The chapter begins by presenting an overview of the support network participants' roles and relationships with autistic students as they exist within the bioecological context of student experiences during transition to university. Four themes and twelve sub-themes were developed, and are described in this chapter, along with quotes from participants to illustrate each theme.

9.1 Participant Summary

Six support network members (from this point onwards referred to as participants) took part in semi-structured interviews, including: three disability advisors employed by universities (DA1, DA2, DA3), one external NDIS funded support worker (SW), one family member (FM), and one professional staff member who was responsible for coordinating a university-wide mentoring program for autistic students (MC). Participants were asked about both their broader experiences of supporting autistic students during the transition to, and first year of university, as well as their experience of providing support to the student who had referred them to this study.

Some student participants were unable to refer a disability advisor or similar professional staff member to the research project as they had not had contact with a disability advisor during their first year. Similarly, some students indicated that the staff member they had engaged with had since left the university. In these situations, some students chose to refer an alternative professional staff member or disability advisor that they had since been in contact with. Consequently, not all professional university staff members were able to provide detailed responses regarding the support provided to the student who had referred them. Instead, these participants provided broader insight into the university's relevant transition supports and services to support autistic students during the transition period.

In the context of autistic students' experiences of transition to university, participants were all situated within the microsystem level of the bioecological theory model. Two participants were external to the university and provided emotional and practical support directly to the autistic student who referred them (SW and FM). The remaining participants were employed in professional roles within the university (DA1, DA2, DA3, MC). Participants described interactions or attempted interactions between themselves and other people in various support network roles (mesosystem). Participants also described their experiences of other elements of the bioecological theory model, such as institutional policies and expectations (exosystem).

9.2 Summary of Themes

Four themes were developed, representing the experiences of participants supporting autistic students during their transition to university. The first three themes relate to transition to, and first year of university specifically, while the final theme outlines participants' experiences of providing support to autistic university students more broadly. Although the final theme addresses broader experiences associated with supporting autistic students at university and does not address transition specifically, it has been included as it highlights important considerations for supporting autistic students in university more generally, including during their first year. Reflecting on broader support experiences and perspectives also provides insight into strategies and mechanisms that can be implemented to support autistic students during the crucial transition and first year period. An overview of these themes and their associated sub-themes is provided in Table 9.1.

Table 9.1: Themes and sub-themes developed from Support Network member interviews

Theme	Sub-theme
Early and ongoing support	The first year of university is a critical period
	Delays and difficulties with help seeking impact support provision
	Transition support is needed before, during, and beyond the first year
Peer-to-peer support	Benefits and challenges associated with autism-specific peer mentoring programs
	Facilitated social groups also provide peer-to-peer support
Support networks outside of the university	External supports: Emotional and practical
	External support networks: Barriers to providing support
	The challenges of balancing support need and autonomy
Supporting autistic university students	Recognising the diversity and individuality of autistic students
	Providing appropriate support requires time and resourcing
	Developing a university wide understanding of autism
	Autistic students would benefit from a safe space on campus

9.3 Early and Ongoing Support

This theme illustrates participants' views and experiences regarding the importance of *early and ongoing support* for enabling a successful university transition experience. Three sub-themes were developed which reflect the importance participants placed on the first year of university, the consequences of delayed access to support, and the need for supports which extend beyond the first 12 months of university. These sub-themes included:

1. *The first year of university is a critical period*: participants highlighted the transition period as crucial to ongoing engagement, participation, and student retention.
2. *Delays and difficulties with help seeking impact support provision*: highlighting the importance of early access to support such as the university Disability Services, and the impacts of delayed access to supports and services.
3. *Transition support is needed before, during, and beyond the first year*: participants described the importance of engaging with autistic students before commencing their first year of studies, and the potential for support to continue beyond the traditional 'first year' of university.

9.3.1 The First Year of University is a Critical Period

Participants depicted the first year of university as one of importance, but also risk, describing the period as: *“critical”* and *“complex”* (DA2); *“vulnerable”* and *“delicate”* (DA3); and *“a bit of a danger time”* (DA3). One participant suggested the first year was one of survival, stating: *“there’s no doubt quite a few people that go to (...) university (...) some survive, some don’t”* (SW, 126-127). Similarly, the first year was noted as important for student success and engagement: *“in that first six months (...) 12 months (...) if they’re not successful they will just walk away”* (FM, 151-152). These reflections highlighted the significance and risk participants associated with the first year of university.

9.3.2 Delays and Difficulties with Help-Seeking Impact on Support Provision

Delays in seeking and accessing support at university were noted as challenges which impacted successful transition. Participants described these delays as resulting from help-seeking difficulties experienced by autistic students, or the student’s desire to undertake university without accessing support. For example, one disability advisor (DA2) stated: *“with some students with a disability or on the spectrum (...) it’s very hard [for them] to ask for assistance”* (DA2, 807-808). The same participant also explained: *“for some students [there’s] a lot of shame about coming and seeking help”* (497-498). Another disability advisor (DA3) saw the delay or lack of help-seeking as potentially related to students not wishing to access support or engage with support services at university, stating: *“sometimes they [autistic students] delay engaging with our services they think they can get by without us or without any adjustments”* (DA3, 475-477).

Autistic students were seen by some participants as being unlikely to voice their own needs or ask for support. For example, MC felt the student they supported was *“not very vocal about his needs”* (MC, 319) and suggested that he would not be likely to *“advocate on his own behalf”* (MC, 331-332). Similarly, SW explained that the student they supported was not likely to *“ask questions”* or *“ask for support”* (SW, 97).

It was also noted that sometimes students who delayed seeking supports in their first semester would present to Disability Services *“later in the semester or in second semester after things have gone really badly”* (DA3, 478-479). In situations where students sought help only after a crisis had occurred, participants noted that this could lead to both positive and negative impacts on the autistic student. One disability advisor (DA2) noted that autistic students who were not *“linked-in”* with support services and experienced difficulties with their studies may become *“overwhelmed”*, and unlikely to contact Disability Services. The same participant added that overwhelmed students would often *“disappear”*, with some only returning after a period of leave, describing this as *“quite a disruptive academic process”*

(DA2, 892) that may also impact on students' confidence in their abilities. Consequently, DA2 expressed concern that students who take leave from their studies may become "*disengaged*" and potentially withdraw entirely. In contrast, two participants (SW, DA3) reported experiences where students taking leave and subsequently returning to studying after a period of crisis, had resulted in them being able to access the supports they had not accessed previously. For example, DA3 stated: "*when things fell in a hole there was more support. When he [the student] came back [to university]*" (DA3, 383-384). Similarly, SW explained:

[Disability Services] gave him [the autistic student SW supported] some links, some people to talk to, and some access [to adjustments] too that he didn't have before, so that (...) [was] positive and that came about only because he struggled (...) if he hadn't of struggled and just got through he may not have had access to this support that he's getting now (SW, 141-146)

In summary, participants saw delays in help-seeking as resulting from students' difficulties asking for support or avoiding asking for help altogether. Participants also noted the negative consequences that delayed access can have for autistic students during their first year of university.

9.3.3 Transition Support is Needed Before, During, and Beyond the First Year

Participants discussed the need for support prior to, and early in the first year of university, as well as the need for support that extends beyond the first 12 months of university. This was highlighted as particularly important when students were unable to complete their first semester or year, withdrew from their studies, and recommenced their studies after a period of leave.

One participant (FM) noted that transition support prior to starting university was lacking, explaining that there "*isn't enough pre-work before they [students] start, to make them familiarise- [sic] (...) to make you feel safe (...) in university*" (FM, 613-618). However, one university staff member (DA3) noted the need for students to connect with Disability Services prior to commencing their studies. She suggested that while it "*can be a bit tricky logistically*" (DA3, 431), autistic students would benefit from "*engaging early with our services [Disability Services] (...) coming to see us [disability advisors] well before the semester starts*" (DA3, 432-434).

Participants described ways that their universities attempted to inform students of the support services available in the early stages of their studies through promotion at

orientation programs, direct communication via email or letters, and via university mentoring programs. For example, DA2 explained: *“we do a whole promotion around orientation, so we have stalls, when we were on site [before the COVID-19 pandemic restrictions] (...) we had a whole pile of information around [support]”* (DA2, 249-251). In contrast, DA1 noted that as a disability advisor they had limited engagement with the university’s orientation program and were unsure of how or whether Disability Services and relevant supports were promoted to students during this time. They also highlighted the challenges for autistic students engaging with orientation activities, describing the orientation program as *“overwhelming”*, with information about the program *“near impossible to find on our website”* (DA1, 107-108). Two disability advisors (DA2, DA3) also described using more direct methods to promote their support services, including email or letters sent directly to students who identify on enrolment as having a disability. As one disability advisor (DA2) explained: *“we’ve been doing emails and letters directly targeting that cohort [autistic students] (...) in their first year so that they know how to find us”* (DA2, 342-345).

Participants also reported that some autistic students experienced significant difficulties in their first semester or year, such as missing deadlines or becoming overwhelmed with their study load. These difficulties may result in students withdrawing or taking leave from their studies. As a result, participants noted that autistic students would often require transition-related support, beyond the first 12 months of their studies. Participants also acknowledged that the provision of support during the first year of university, did not negate the need for further support in second and subsequent years of university. One participant (MC) reflected on the difficulties this can pose at a systemic level, particularly in relation to funding of support. MC explained:

one of the difficulties we’ve had is trying to educate the university (...) to understand that autism does not disappear after the first year, because there was some suggestion that they wanted to just stop the mentoring during that first year (MC, 101-105)

Overall, participants highlighted the importance of early access to support, as well as the need for ongoing support throughout the student’s university studies. Participants also noted that autistic students may end up taking leave during their first year or reduce to part-time studies, which may result in students requiring additional transition support beyond their first year.

9.4 Peer-to-Peer Support

Peer-to-peer support was seen to have significant benefits for autistic students, through both mentoring and social group connection. Two sub-themes were developed within this theme and are described in more detail in the following sections:

1. *Benefits and challenges associated with autism-specific mentoring programs:* where participants described the ways in which peer mentoring programs supported student engagement at university and the complexities associated with establishing and maintaining an autism-specific mentoring program.
2. *Facilitated social groups also provide peer-to-peer support:* reflecting participants descriptions of social groups as an alternative to peer mentoring.

9.4.1 Benefits and Challenges Associated with Autism-specific Peer Mentoring Programs

Autism-specific mentoring programs were aimed at supporting autistic students but were also available for students currently seeking an autism diagnosis or who had social anxiety or similar difficulties. For example, the autism-specific mentoring program coordinated by MC, facilitated peer mentoring support for autistic students, as well as students with “*autistic traits*” or social anxiety. One disability advisor (DA3), who worked at the same university as MC, described the autism-specific mentoring program as also being available for students who had an “*autism-like condition*”. However, DA3 did not clarify what was meant by the term. Similarly, DA2 described the autism-specific program at their university as being available for students “*on the spectrum or (...) like conditions*” (DA2, 124-125). It was noted that not all autistic students wanted to be connected to an autism-specific mentoring program, DA2 explained that their university also provided a broader disability mentoring program that autistic students could participate in if they did not want to join the autism-specific program:

So we don't just channel everyone into the specialist [autism-specific] mentoring program like it's a factory (...) we've got that other (...) option as well for students who might just need something that's not associated with a broader group [autistic students] (DA2, 89-93)

Later during her interview, DA2 added:

I'm actually very careful as well about whether I refer them [autistic students] off to the specialist [autism-specific] mentoring program, where they're not ready (...) Because they don't want it, they see it as a label, whereas maybe the [Disability Services] mentor [is] fine. It's individual,

there's no label attached to that [the disability mentoring program] (DA2, 405-411)

Participants spoke about the benefits they had observed for autistic students who had engaged in an autism-specific mentoring program. One disability advisor (DA3) explained *"the level of support they get in the mentoring program is fantastic"* (DA3, 447), and *"an absolute key factor in keeping the students engaged"* (DA3, 15). She also noted that the program had *"proven to make a huge difference to the retention and success of students on the spectrum"* (DA3, 11-12). Another disability advisor (DA2) saw the autism-specific mentoring program at their university as *"a critical part of (...) keeping students engaged and helping them navigate [university] (...) with people often closer to their own age as well"* (DA2, 905-907). Similarly, MC described their observations of the impact of autism-specific mentoring programs on autistic students' engagement at university, stating: *"I have seen the difference between students when they come into our program [autism-specific mentoring program] initially to how they develop over time (...) absolutely amazing"* (MC, 509-511). In describing the impact of the autism-specific mentoring program on her son's university experience, FM explained: *"it's only because of that mentoring system that he's been at all successful"* (FM, 72-73), also describing the program as *"life changing"* (FM, 225). She felt that once her son was a part of the program *"he didn't feel alone"* and *"he had someone he could contact"* (FM, 104-106), although she also felt that her son's *"ability to be successful [at university] varied depending on that mentor"* (FM, 106-107).

The roles of autism-specific mentors were practical in nature. Mentors could assist autistic students with *"navigating university"* (DA2; 29), *"how to study"*, *"how to engage with services"*, *"how to navigate the study environment"* (DA3; 63-66), and how to *"manage their work schedule"* (MC; 336). Participants noted that autism-specific mentors did not provide mental health support, nor did they provide tutoring or support with academic content.

Participants did not discuss how or whether the support provided by mentors in autism-specific programs differed from the support that was provided by general mentoring programs. However, MC did suggest that general mentoring programs were less accountable for the student's success and functioned more *"at arm's length"* from the student. MC also noted that general mentors had limited training and less supervision than those within the autism-specific program she facilitated. The general mentoring support described by MC was also only provided for a period of six months. MC explained:

their mentors [in general mentoring programs] they get limited training and limited supervision. They have a 1 to 15 ratio. If their students don't

engage it doesn't really matter because they're just offering that support if they need it. It's only for six months (MC, 280-283)

In contrast, mentors from the autism-specific mentoring program facilitated by MC were able to provide support for students throughout and beyond their first year.

Recruitment, training, and ongoing support of suitable mentors required adequate resourcing. One participant (DA2) explained that their mentoring program involved a process of induction and training, with a specific focus on autistic characteristics. Similarly, DA1 noted that mentors within their autism-specific mentoring program had undergone training, although specific details of the training content and delivery were not provided. Autism-specific mentors also required ongoing guidance and support from university staff to ensure they maintained personal and professional boundaries (DA2). Staff also needed to provide suggestions as to how mentors can effectively engage with their mentee and overcome potential communication difficulties. For example, when discussing the support provided to a mentor to engage with one autistic student, MC stated: *"we've had to word up [prepare] successive mentors to make sure that they make contact with him on a regular basis"* (MC, 319-321). She also explained: *"we do try to direct the mentor to try other ways to get them [mentee] to open up (...) and maybe [be] more (...) direct in their communication style"* (MC, 362-365).

Funding and resourcing were highlighted as a potential challenge to effectively establishing and maintaining an autism-specific mentoring program. As the coordinator of such a program, MC highlighted the complexity of her role, identifying it as *"a very unusual role"* (MC, 249), which requires *"time and emotional energy"* (MC, 440) to ensure its success. She also noted that coordinating the program required dealing with difficult situations and managing the wellbeing of both mentors and mentees. As such, MC felt it was important for autism-specific mentoring program coordinators to have access to relevant support services and resources themselves (e.g., counselling and supervision).

Adequate resourcing and funding to maintain autism-specific mentoring programs was highlighted by several participants (MC, DA2, DA3). For example, MC explained: *"I guess the biggest barrier is the lack of resourcing and time"* (MC, 436-437), adding that taking on additional autistic students within the program had a negative impact on the *"quality of the program"* (438). Similarly, DA3 stated: *"the mentoring program is lucky to be still going, our services are just hugely under-resourced"* (DA3, 445-446). Another disability advisor (DA2) also indicated that accessing funding to continue the autism-specific mentoring program each year was *"a bit of a struggle"* (DA2, 939). Both MC and DA3 highlighted the challenges facing autism-specific mentoring programs, particularly as they

become more recognised, and more students seek to access them. For MC this has resulted in their program being *“overloaded and oversubscribed”* (MC, 177), while DA3 indicated that there was now a waitlist for access to their university’s autism-specific mentoring program, describing it as: *“a victim of its own success”* (DA3, 14). Concerns regarding the lack of ongoing resourcing were discussed by MC, who noted that a lack of resources could result in students not being able to access the program in a timely manner. MC also highlighted that this could be seen as an equity issue that could potentially put the university at risk of facing a complaint via the Equal Opportunity Commission, from students who are unable to access the program.

In summary, participants described the benefits they saw for autistic students who took part in autism-specific peer mentoring programs, including promoting social connection, and improving the retention and engagement of students. Participants also highlighted the role of mentors as providing support to navigate university, as well as helping students to manage their studies. Finally, participants reflected on the challenges of implementing and maintaining autism-specific mentoring programs, specifically related to funding and resourcing, noting that this resulted in some students missing out on accessing the support.

9.4.2 Facilitated Social Groups Also Provide Peer-to-Peer Support

Social groups were described by participants as providing an alternative or additional support network for autistic students. Social groups were sometimes implemented as an addition to autism-specific mentoring programs or as an alternative while students waited to be matched with a suitable mentor or where autism-specific mentoring programs were already at capacity and unable to take on additional mentees. For example, MC explained that the social group at their university provided an opportunity for autistic students new to the university to connect with their peers while they were on the waiting list for an autism-specific mentor. Autism-specific mentoring programs also provided autistic students with opportunities to meet monthly as a group. One participant described the social group as *“a safe social platform”* for autistic students (DA2, 52-53). Some social groups also involved formal meetings, workshops, or events where guest speakers would attend to present information on different issues, such as employability skills or study strategies. Social groups also provided peer-to-peer support for autistic students where they could connect with other autistic students and hear from them about their experiences at university. Being supported by autistic peers were seen to provide autistic students with opportunities to hear *“neurodiverse ideas about ways that they can navigate their university life”* (MC, 42-43) and be *“encouraged by their autism cohort”* (MC, 63-64).

Social groups were implemented through Disability Services or as part of existing autism-specific mentoring programs. However, both DA3 and MC highlighted that, once

established, these groups were often facilitated or led by one or more autistic students. For example, MC explained that some of the former mentees from their university's autism-specific program had taken on the role of leading and facilitating the social group. MC explained that participating in the social group also provided some autistic students with the opportunity to develop new skills and build leadership capacity:

we've seen a sort of a step-by-step process in that social group whereby new members will audit the social group and then they'll become members and then they'll become part of the committee and then if they feel they want to really push the envelope in terms of their own skill development they will offer to become a coordinator and that's actually worked out really well (MC, 56-61)

Overall, three participants discussed the potential of social groups to provide an alternative or additional support as peer mentoring programs. They also highlighted the potential for these social groups to be peer-led and facilitated by autistic students with support from the university.

9.5 Support Networks Outside of the University

Participants indicated that autistic students often received support from family members (e.g., parents) during their transition to university. External support workers were less commonly mentioned; however, some participants noted that, with the roll out of the NDIS, they expected to see more students accessing support from external, NDIS funded support workers in the future. Three sub-themes were developed within this theme:

1. *External supports: Emotional and practical:* where participants reflected on the emotional and practical supports provided by external supports.
2. *External Support Networks: Barriers to providing support:* reflecting experiences of the two external support network participants, and the challenges they faced in providing support.
3. *The challenges of balancing support need and autonomy:* where participants reflected the importance of balancing students' support needs with their right to autonomy and self-determination.

9.5.1 External Supports: Emotional and Practical

Participants noted that autistic students were sometimes supported by people external to the university (e.g., family members or paid support workers). Two disability advisors (DA1, DA3) noted that family support was commonly provided by mothers. For

example, “*you usually get to know them [autistic students] and their parents (...) usually the mums*” (DA1, 265-268). Other than attending meetings, disability advisors did not provide any further details of the role played by parents or other family members supporting autistic students during their transition to university.

Two members of students’ external support networks participated in the current research (FM: Family member and SW: Support worker). The types of support provided by FM and SW were similar, and commonly emotional and practical in nature. SW described his experiences supporting one student during their first year of university. As part of his role, SW saw himself as someone who could monitor the student’s progress, and who the student could contact when they experienced difficulties. SW explained:

so I’ve been meeting with him [the student] once a week, once a fortnight just for a general chit-chat. So he has my phone number, he has my email, he’s promised that he’s going to talk to me when things are good, as well as when they’re bad (SW, 109-112)

SW also provided emotional support and reinforcement:

the counsellor [from NDIS provider] and I’ve put our heads together and we promote the same sort of stuff (...) being positive about using the support you have, being confident (...) reinforcing how well he’s done (...) how good things are going (SW, 300-306)

Practical support provided by SW included finding mobile applications to assist this student with learning new content. In addition, the service provider SW worked for provided a study space for the student, and this enabled SW to monitor the student’s progress and check in with him to see how he was going.

Emotional and practical support was also provided by FM. Emotional support focused on reinforcement of her son’s progress and providing someone he could talk to when things became difficult. Practical support involved spending time with her son, writing down the issues he was having, and planning how they could be resolved. She also explained that she helped her son to prioritise important tasks, or potentially delay things that were less important. FM reflected that parent support provided her son with a “*middle ground*” and someone who could prompt him to seek university support. Similarly, SW felt that a support person, such as a family member or NDIS funded support worker, particularly someone who was familiar with the university system, would make the transition a lot easier for autistic students.

In summary, the experiences of both the family member (FM) and support worker (SW) were similar, with both providing emotional and practical support. Both also saw their support role as being beneficial for the student.

9.5.2 External Support Networks: Barriers to Providing Support

The two external support network participants (FM, SW) also highlighted barriers they experienced in providing support, specifically related to interacting with university staff (academic staff and disability advisors). They described being unable to communicate directly with university staff, and university expectations that students should engage with university support services independently. FM reflected that it was difficult for her son to contact academic staff or student services without support. However, she experienced barriers which prevented her from assisting him with these tasks and was told her son would need to contact the service directly himself. FM explained: *“anytime I rang it was very much considered the wrong thing to do”* (FM, 64-65). Similarly, she found organising an appointment for her son to meet with an academic staff member was difficult. When asked about how the appointment was organised, FM explained that it was *“very hard to get because I was the parent (...) it [was] really very anti that, and he [the academic] looked at me like ‘why are you here?’”* (FM, 452-456). She also explained that trying to access any information to support her son with his studies was difficult: *“because (...) [he] was in his 20s and considered an adult (...) you have no say in anything, you get no feedback, you can’t ring, you can’t talk to anyone”* (FM, 47-49). FM also noted university expectations that students would function independently within an adult learning environment. However, she felt that this expectation presented challenges for her son in accessing support, explaining:

I feel that the whole system is– is hell bent on you [the student] being an adult and you being independent and yes that’s all great but that takes some time to get there and it’s very much a long process for an autistic kid (FM, 259-262)

Similar difficulties were observed by SW, in his role as an external (NDIS funded) support worker. He found it difficult to contact university staff directly: *“because he’s– of his age (...) they didn’t allow any access, they wouldn’t talk to me about his academic progress”* (SW, 325-326), later explaining that he felt like he was *“coming up against brick walls because (...) I didn’t have the legal right to access the information”* (SW, 348-349). As a result, SW found it difficult to provide the student with support, describing it as *“a bit of an issue because I don’t know exactly where he’s at”* (SW, 327). He explained:

I didn’t want to talk to him about issues before I knew what the issues were because I was worried [that] I wasn’t getting the full story, where I

could have got [sic] the full story from the uni [sic]. Like he was doing a couple subjects and he dropped one and didn't tell us (...) if when he dropped the subject I got an email– I got a phone call (...) we could've jumped in then and probably stopped the next problem happening (SW, 353-363)

Participants did not clarify whether student permission had been provided for interaction between university staff and external support providers, although FM's son had provided written consent for her to communicate with staff from the mentoring program. For FM the difficulties connecting and communicating with university staff reduced when her son joined the university's autism-specific peer mentoring program. For students to participate in the program, they were required to provide contact details of a family member or other support person. As such, FM was able to communicate directly with the mentoring coordinator and a meeting was set up to discuss her son's support needs. She described the meeting as: *"the first time (...) in all of the years that he'd [her son] been there [at university], that I felt not alone trying to navigate this"* (FM, 270-271). FM found having direct communication with the mentoring program a positive experience, stating: *"because they [the mentoring staff] contacted me and they talked to me, the parent, and said 'What else can we do? Where is he at?'" (...) that sort of emotional support was so much better than ringing student services"* (FM, 225-228). Being able to communicate directly with someone from the university was seen as an important and positive factor in supporting her son. When asked whether she felt that the support provided was positively received by her son, FM explained: *"I think he was relieved that he wasn't having to I guess turn up and– and make decisions or even discuss anything and he couldn't verbalise what he wanted– how he was feeling about it all"* (FM, 266-268). FM also highlighted the need for universities to normalise communicating directly with an external support person or family member with the student's permission:

I think maybe saying that from the outset (...) "We would like to get some idea from your– your family or parent (...) your guardian, [about] what we can do to support you" (...) that then says to them [the student] it's OK for you to have that support (FM, 254-257)

Overall, external support network members highlighted the challenges they experienced interacting with university staff. While it was unclear whether students had provided permission for communication between support network members and staff, it appeared that there was an expectation that the student would engage with staff independently and autonomously.

9.5.3 The challenges of balancing support need and autonomy

Participants' perspectives on parental and external support for autistic students varied. While one disability advisor (DA1) recognised the benefits of parental support for autistic students during their transition to university, another disability advisor (DA3) noted that there was also a need for students to develop their skills as independent adult learners. DA1 spoke positively about his experiences working with family members to support autistic students during their transition to university, explaining that parents *"understand their kids' needs"* (DA1, 314). DA3 however, expressed concerns that autistic students may be *"used to having parents (...) push them along to different things and although they [parents] can still come to our appointments with them the parents really can't do their uni [sic] work for them"* (DA3, 435-437), describing the change in parental support as a big *"parental role change"* which has a *"big impact"* on students.

Participants recognised that parents were aware of and supported the need for students to exercise their autonomy and develop independence as an adult learner. DA1 noted that parents who provided support to autistic students during their first year at university seemed generally aware of university requirements and expectations. In addition, he suggested that parents also wanted the student to have the opportunity to develop their independence, explaining: *"most of the time the parents are there but they want (short pause) their kid to become independent in things"* (DA1, 308-309). As a parent, FM discussed the difficulties she experienced in providing transition support, while also acknowledging the fact that her son was now enrolled in an adult learning environment. One disability advisor (DA3) also discussed the impact of students accessing external NDIS funded support workers, suggesting this support as potentially *"bridging that transition gap"*, by providing students with *"an external support worker (...) that's not a parent (...) someone who can hopefully foster their independence"* (DA3, 480-482).

In summary, participants appeared to recognise the role of family support, yet also noted the importance of promoting independent adult learning. They also reflected on the importance of balancing the students' need for support with their right to self-determination and autonomy.

9.6 Supporting Autistic University Students

Participants described ways in which they provided transition support to autistic students and the challenges associated with effectively providing this support. In addition, participants highlighted strategies to support autistic students' experiences on campus in general. While the perspectives and experiences discussed within the following sub-themes were not necessarily specific to transition, they were still recognised as important factors

which may contribute to the transition and first year experiences of autistic students. Four sub-themes were developed and are described in more detail in the following sections:

1. *Recognising the diversity and individuality of autistic students*: participants reflected on the various areas of knowledge and understanding that are required to effectively support autistic students at university.
2. *Providing appropriate support requires time and resourcing*: reflecting participants observations that developing the knowledge and skills across a diverse range of areas requires adequate time and resourcing.
3. *Developing a university wide understanding of autism*: participants highlighted the importance of all university staff having knowledge and understanding of autism, and the need for a university-wide approach to developing this.
4. *Autistic students would benefit from a safe space on campus*: where participants discussed the need for safe spaces on campus to support the inclusion and participation of autistic university students.

9.6.1 Recognising the Diversity and Individuality of Autistic Students

University staff members highlighted the importance of recognising and understanding the diverse and individual needs and experiences of each autistic student; and the subsequent need to develop knowledge and skills around a range of issues, including co-occurring conditions, and gender and sexuality.

For disability advisors specifically, having a broader understanding of the diversity of autistic experiences not only enabled them to provide effective transition support, but also enabled them to assist other staff to better understanding autistic students and their support needs. One disability advisor (DA2) noted that there are some “*commonalities*” in autistic characteristics that both academic and professional staff working with autistic students should be aware of. However, she also noted that each autistic student is “*different*”. Two disability advisors (DA1, DA2) described autistic students as a “*diverse cohort*”, with one disability advisor stating:

they're [autistic students] not all the same. You know don't go in like “oh she's got autism so this is what we need to do” you treat ‘em like every other student (...) they're individuals– with their individual strengths and skills (...) and weaknesses as well (DA1, 195-200)

Similarly, DA2 stated: “*you need to treat people with the diversity that that presents and understand their [the student's] perspective*” (DA2, 514-516). The importance of

recognising the individuality of each autistic student was also recognised by MC who stated: *“well every person on the spectrum is different, so I mean we just go in with the understanding that the person on the spectrum knows [their support needs] best”* (MC, 182-184). The importance of understanding students’ past study experiences and their age at diagnosis when providing support to autistic students during their transition to university was also highlighted by DA2:

you need to really understand the background for that student, and what scaffolding they might have had in the past (...) you’ve got students going “Oh, I never got anything at school” (...) so you do need to understand, I guess just understanding where they’re coming from (...) I think when they got their diagnosis is always helpful [to know], I do think that makes a big difference to understand where they are on their journey (DA2, 493-502)

Two participants noted the importance of awareness, understanding, and knowledge around frequently co-occurring conditions, such as ADHD, anxiety, or other mental health conditions. Co-occurring conditions were referred to as adding complexity, because it was seen as an added layer of support needs. For example, one disability advisor (DA2) referred to co-occurring conditions as *“complex”* (DA2, 357), stating that they *“really do impact differently for every different student”* (DA2, 364-365). Similarly, MC felt that students with co-occurring conditions presented with *“more complicated profiles than others where we’ve had a layering up of other comorbid conditions”* (MC, 186-187).

One disability advisor (DA3) highlighted the need for those working with autistic students to have *“an understanding and sensitivity to issues around gender and sexuality (...) because there is a higher frequency of identification with diverse genders and sexualities in this group [autistic students]”* (DA3, 188-191). DA3 described this as a *“body of knowledge you need to have under your belt”* (170-171). Similarly, MC suggested that many autistic students who participated in the mentoring program were *“exploring their gender, their sexuality”* (MC, 108).

Overall, participants recognised the diverse experiences of autistic students, and the importance of respecting individual differences. They also reflected on the need to develop and maintain a diverse range of knowledge and skills to work effectively with autistic students, the impact of which is discussed further in the following sub-theme.

9.6.2 Providing Appropriate Support Requires Time and Resourcing

Participants reflected on a range of strategies used to provide effective support to autistic university students during their first year, including relationship and rapport building, providing additional appointments and meetings for autistic students, and maintaining up-to-date knowledge and skills for supporting autistic students. These strategies, while identified as important, are also strategies that require adequate time and resourcing to enable them to occur.

One participant (DA2) reflected that the diversity of individual student experiences, required Disability Services staff to develop a broad range of professional knowledge and expertise, explaining: *“regularly making sure that you’re on top of current research and evidence-based information [is important]”* (DA2, 503-504), but added *“trying to keep on top of that can be quite difficult”* (DA2, 505-506). DA2 recommended that staff consider engaging with webinars, team-based case reviews, and communities of practice as mechanisms for developing, maintaining, and sharing this professional knowledge and expertise.

Rapport and relationship building was also noted by several participants as important when working with autistic university students (DA3, SW, DA1). For example, DA1 described working with one autistic student *“over the process of the year”* supporting the student to decrease his study load and identifying relevant exam accommodations the student needed. While DA1 explained that this *“took me a while”*, he reflected that the student was now *“doing much better”* and *“getting credits and distinctions”* in his studies. When asked whether there were any barriers or difficulties that impacted on his ability to provide this support DA1 replied *“I think it’s more [the] time factor”* (DA1, 356). Similarly, SW felt that developing a relationship and rapport with the student he supported was important in building trust and providing ongoing support, explaining: *“it all comes back to that relationship, rapport (...) like he knows he can text me whenever, he knows you [he] can ring (...) So again it’s that relationship building”* (SW, 473-480). Having the opportunity for the student to build similar relationships and rapport with university staff was also noted as important:

when a student will go from high school to university it’s that transfer of that relationship so if it’s the [high school] careers advisor, the [high school] special Ed teacher, [high school] head teacher, whoever and that can be transferred to someone in the [Disability Services] and develop that relationship so that’s on site that would make it so much easier and better (SW, 481-485)

Disability advisors identified the need to provide extra time and appointments, outside of what is typically provided to students with other disabilities, to effectively support autistic students during and beyond their first year of university. For example, DA1 stated: *“most of the students with autism spectrum disorder I’d meet with a lot more frequently (...) at the beginning of the year than I would most other students”* (DA1, 260-264). Similarly, DA3 noted that autism is *“a significant group that we have an increased demand to see”* (DA3, 181-182) and *“a group that tend to need high support”* (DA3, 183-184). When asked about any limitations to the support they had provided to one autistic student she replied: *“I guess I did as much as I could. Bit more than we normally offer but within the limits of my capacity as well”* (DA3, 355-356). Resourcing issues were also noted by MC who stated: *“universities are forever reducing services to the students”* (MC, 467).

One disability advisor (DA3) noted that students with more complex situations may benefit from a meeting between Disability Services staff and academic staff to discuss their support needs in more detail; however, she also explained that coordinating these opportunities could be very challenging. The same disability advisor also noted that the *“time and resourcing”* required to implement academic adjustments also posed a challenge for academic staff, given the demands that are already placed on them, explaining:

if we send them [academic staff] a lot of detailed information they just get stressed about ‘How am I supposed to know all this and do all this for this student when I’ve got thousands of students in my unit?’ (DA3, 223-226)

The challenges of academic workload were also reflected by DA2 who stated: *“I really appreciate the difficulties the academic staff– they can have 300 – 400 students (...) it’s a tough gig”* (DA2, 649-6510). While acknowledging the challenges posed by class numbers and workload, DA2 also explained that many strategies used to support autistic university students were not unique or extraordinary. Instead, strategies such as clear and concise communication, clear expectations, minimising unnecessary changes, and clear subject outlines, were identified as potentially supporting all students, including those who are autistic. She explained:

I think sometimes maybe some academics think that they’ve got to go (...) some amazing extra mile, they don’t actually, they’ve just got to be clear, concise, don’t change things too much unnecessarily (...) that helps all students (...) it’s not rocket science actually, I think it’s pretty straight forward (DA2, 669-677)

While the type of support autistic students required was not seen as unique or special, the time required to adequately provide this support was highlighted as a

challenge when supporting autistic students during their transition to, and first year of university.

Overall, participants reflected on the resourcing required to effectively support autistic university students. They acknowledged the need for skill development in specific areas, as well as the need to allow time to develop rapport with autistic students. Participants also suggested that autistic students may at times require more time and resourcing, from both professional and academic staff, than students with other disabilities.

9.6.3 Developing a University-Wide Understanding of Autism

Participants noted the need for those working with autistic students to understand the autistic experience beyond the textbook definition, common misconceptions, and broad stereotypes. Reflections on the importance of all staff understanding highlighted the need for a whole of university approach to knowledge and understanding of autism and autistic experiences.

Participants recognised that academic staff may not always be informed when an autistic student was enrolled in their classes. Disability advisors explained that access plans or similar documentation were used to communicate information about a student's support needs to academic staff. However, access plans were not likely to include specific reference to the student's diagnosis, instead including *"impact statements"* (DA3) which outlined the students' support needs. These impact statements would provide broader information such as: the student's communication requirements (DA2, DA3); the need for the student to take breaks from classes if needed (DA2, DA3); the need for clear instructions and opportunities to seek clarification (DA3); and support or adjustments for oral presentations/group work (DA2).

Difficulties engaging directly with staff were also highlighted by participants, citing staff workloads as one factor impacting on these experiences. All three disability advisors had experienced challenges when trying to seek adjustments, accommodations, or support for an autistic student from other university staff. One disability advisor (DA1) noted: *"sometimes you might get a bit of kickback from academic staff"* (DA1, 371-372) when provided with a student's access plan. Two disability advisors described these challenges in relation to staff assumptions and understanding of autism, and the need for reasonable adjustments. For example: *"you get that 'well he's not acting like I understand someone with- on the autism spectrum to act, because my cousin or my somebody else I know [is autistic]'"* (DA2, 561-563). Similarly, DA3 noted that some academic staff had expressed concerns about *"unfairly advantaging the [autistic] student by giving them advice that they're not giving to the whole group"* (DA3, 242-243).

Disability advisors also discussed the importance of increasing knowledge, understanding and awareness of the needs of autistic students for all staff, and suggested disability awareness training as an important tool to achieve this. Two disability advisors (DA2, DA3) indicated that their university provided general disability awareness training; however, each noted that completing these training modules was not compulsory. In addition, they both suggested that getting staff to complete the training modules was challenging. Both disability advisors also noted that autism was only a small part of these awareness training programs. One disability advisor (DA2) spoke about more targeted autism-specific training they provided for some of the university's professional staff, such as those in the library, security, or other *"front-facing"* roles. This training was intended to support interactions with autistic students and provide staff with information about referral pathways, services and support that was available for students. The third disability advisor (DA1) noted there was no current autism awareness training program within their university, although this was something that had been identified previously as needed. They also highlighted the importance of ensuring this training was university-wide and provided to all staff.

One challenge identified by DA1 in developing and delivering an autism awareness training program was the need to find a staff member who would commit to and had the time to develop and deliver the awareness training to other university staff. Similarly, DA3 stated: *"we haven't got the capacity to train everybody (...) we haven't got the capacity to train the whole university"* (DA3, 205-209). Only one participant (DA2) discussed the involvement of autistic students in developing or delivering university disability awareness training sessions. When discussing what they felt professional university staff required to support autistic students in their first year, DA2 described one autistic student at her university who delivered a presentation to the university's library staff *"about what it was like to be a person on the spectrum, and the things that would be helpful to her"* (DA2, 528-529). For DA2, having the student present this information appeared to be important and a significant contributing factor to its success in improving awareness of autism with library staff.

Overall, participants highlighted the importance of an inclusive campus environment, where all staff have knowledge and understanding of autism. However, they also noted challenges to reaching this goal, including existing assumptions and beliefs staff may hold about autism, as well as the challenge of developing and providing autism-specific training to all staff.

9.6.4 Autistic Students Would Benefit from a Safe Space on Campus

Several participants reflected on the need for autistic students to have access to a *"safe space"* on campus to support their university experience. DA2 identified the library as a

common “*safe space*” for autistic students at their university. She also described a sensory room that was being developed through the university’s peer mentoring program which would provide space for autistic students to meet their sensory needs. DA2 felt that the sensory room “*could be a really good safe place also for first years to know that that’s [the sensory room] there*” (DA2, 759-760). SW similarly reflected that it would be useful for university campuses to have a space where autistic students could “*go have a cup of tea and sit down and have a quiet space*” adding “*somewhere there’s a place they can just go and sit and get rid of the noise of university out of their head*” (SW, 514-518). DA3 described a room her university had established as part of the autism-specific mentoring program, where “*mentors and mentees can meet and mentees often study there. It’s kind of a quiet, safe space*” (DA3, 86-87).

In summary, several participants suggested the need for safe, sensory-friendly spaces on campus. Safe spaces were described as places that students could go, to reduce sensory overwhelm and take a break from the campus environment.

9.7 Chapter Summary

This chapter has presented the themes and sub-themes generated from analysis of semi-structured interviews with six members of autistic students’ support networks. Participants described their experiences providing support to autistic students during their transition to, and first year of university. Participants highlighted the importance of first year success for autistic students and the need for early and ongoing support to ensure successful transition. They also discussed the role of peer-to-peer support networks in providing social and academic support to autistic students in their first year. Participants also highlighted the diversity of autistic student characteristics and experiences and the importance of developing a university-wide understanding of autism, and safe, sensory-friendly spaces on campus for autistic students. In addition, external support network participants described their experiences and the challenges associated with providing support. The following chapter presents an analysis of data collected from family members and university staff through online surveys.

10 ANALYSIS: PARTICIPANT THEMES (FAMILY AND UNIVERSITY STAFF SURVEYS)

This chapter presents the findings from thematic analysis of online survey responses from family members and university staff. The findings provide insight into the lived experience of family members and university staff in supporting autistic students during their transition to, and first year of university (research objectives two and three). Analysis was undertaken using RTA as described in detail in Chapter 6.

This chapter is presented in two parts. Part one presents the findings from analysis of survey responses from family members, while part two presents the findings from analysis of the university staff responses. Each part includes an overview of participant characteristics and summary of responses to closed-ended, Likert-style scales, and multiple-choice questions. Analysis of family member responses to open-ended questions resulted in the generation of three themes and six sub-themes. Analysis of university staff responses generated four themes. Themes and sub-themes are described for each participant group, along with quotes from participants which illustrate each theme.

10.1 Family Members

Of the 11 survey responses from family members, two participants did not complete the eligibility questions and therefore did not complete the survey, and one did not respond to any questions beyond indicating their role and highest level of education. The remaining eight participants have been included in the analysis below. Table 10.1 provides an overview of geographic location and highest level of education. All family member participants identified as a parent of an autistic student.

Table 10.1: Overview of parent characteristics

Parent	1	2	3	4	5	6	7	8
Geographic location	QLD	SA	WA	NSW	NSW	QLD	NSW	Vic
Highest Level of Education	Advanced Diploma	High School Certificate	Diploma	Bachelor Degree	Bachelor Degree	Bachelor Degree	Bachelor Degree	Bachelor Degree

10.1.1 Responses to Closed-Ended Questions

Parent's responses to closed-ended survey questions are summarised in Table 10.2. Six of the eight parent participants had been involved in transition planning meetings during their son or daughter's final years of high school. Half of the parent participants identified

their experience of supporting their child during the transition to university as negative or very negative, while the other half identified their experience as being positive, or very positive overall. Five parent participants noted that they had communicated directly with either academic or professional university staff. Of these five participants, three participants described these experiences as positive or very positive. Awareness and familiarity with the DDA and the DSE were mixed.

Table 10.2: Parent responses to closed-ended questions

Parent	1	2	3	4	5	6	7	8
Where you involved in transition planning meetings for your family member during their final years of high school (e.g., year 9 - 12)?	Yes	Yes	Yes	No	Yes	No	Yes	Yes
Overall experience of providing support during transition to university	Very negative	Very positive	Positive	Very negative	Very positive	Very negative	Negative	Positive
Communication with university staff	Yes – acad. & profess.	Yes – acad. & profess.	No	Yes - academic	No response	No	Yes – acad. & profess.	Yes – acad. & profess.
Experience of communication with university staff	Positive	Very positive	No response	Negative	No response	No response	Negative	Positive
Familiarity with Disability Discrimination Act (1992)	I know a little about it	Heard of it, but don't know much about it	Heard of it, but don't know much about it	I know a little about it	No response	Heard of it, but don't know much about it	Very familiar with it	Very familiar with it
Familiarity with Disability Standards for Education (2005)	Very familiar with it	Never heard of it	Never heard of it	Never heard of it	No response	Heard of it, but don't know much about it	Very familiar with it	Very familiar with it

As presented in Table 10.3, parents undertook a range of support roles. All parents reported providing support with enrolment, health and wellbeing, and accessing university

support services. Only four parents reported providing support with independent living skills and academic skills.

Table 10.3: Overview of parent support roles

Parent	1	2	3	4	5	6	7	8
Enrolment	X	X	X	X	X	X	X	X
Independent living skills		X		X	X			X
Financial	X	X		X	X	X		X
Social Skills	X	X	X	X	X		X	X
Executive Functioning	X	X	X	X	X		X	X
Health and Wellbeing	X	X	X	X	X	X	X	X
Accessing university support services	X	X	X	X	X	X	X	X
Academic skills	X		X				X	X
other		Getting to and from uni				Unable to get involved		

10.1.2 Summary of Themes

Parent participants' responses to the six open-ended questions (see Appendix E) were analysed using RTA. Three themes were developed: *limited high school transition support and preparation*; *parent support*; and *university supports*. Table 10.4 provides an overview of these themes and their relevant sub-themes. The themes and sub-themes are discussed in more detail in the following sections.

Table 10.4: Themes and sub-themes developed from family member survey responses

Theme	Sub-theme
Limited high school transition support and preparation	No sub-theme
Parent support	Parents played a functional and practical support role Parents as advocates: “Fighting” for support Benefits of parent support The challenges of balancing autonomy and support need
University supports	Delays and difficulties engaging with university support Recommendations for university transition support

10.1.2.1 Limited High School Transition Support and Preparation.

Parents indicated that support from high schools in preparation for the transition to university was lacking, with some indicating that their child’s school had not seen university as a suitable or potential post school option. For example, Parent 2 explained:

The school did not believe in my son. They were very unhelpful. They did not provide any options or suggestions on transitioning. They even tried to stop him from studying the subjects he needed to get into uni [sic]. I had to set up Open Access subjects and even then the school were not supportive with limited involvement (Parent 2)

A similar experience was described by Parent 5:

Teachers not believing our son should do atar [sic] [Australian Tertiary Admission Rank] subjects as they would be too difficult to provide him with support at school. He was strongly discouraged from doing hsc [sic] [Higher School Certificate] physics so didnt [sic] but at Uni [sic] completed a physics course achieving a distinction (Parent 5)

The same parent also noted: “One staff member told me ‘Us parents need to stop thinking our kids would get to uni [sic]’” (Parent 5).

Where transition support was provided it was commonly reported as being minimal or unhelpful:

“We were only provided with one meeting, we were encouraged to sign our son up for a generalised program. I indicated we would like a more individual approach (...) we received no further support for transition”
(Parent 1)

“staff had a lack of knowledge navigating special provisions- left very much to me his mum to research” (Parent 5)

“we had a few meetings with the careers guidance counsellor to discuss university applications (...) She wasn’t particularly helpful as I recall”
(Parent 8)

Another parent (Parent 7) noted that their son’s high school had provided transition support which primarily focused on supporting students to transition into a work program. In relation to university transition support, they explained:

The school did not provide any extra support for transition to adult learning environments. The school did however offer transport to and from an open day at a university campus - but nil preparation or support was offered as to how to complete a University application, nor support on what to expect or how to best negotiate the complex world of university
(Parent 7)

In contrast, one parent described a positive experience with high school transition support:

[I] Attended sessions in [sic] school counsellor in selecting subjects that would suit her [participant’s daughter] interest in university course. It was important to select the courses of interest as she then was much more likely to do well (Parent 3)

Overall, high school transition support appeared to be lacking. Transition support that encouraged the transition to university appeared to be particularly limited, which resulted in parents having to undertake the majority of transition support tasks themselves.

10.1.2.2 Parent Support.

Parents described the variety of support roles they undertook, the advocacy required to engage with services, the benefits of the support they provided, and the challenges of balancing the student’s need for autonomy with their need for support. Four sub-themes were developed within the theme of *Parent Support*:

1. *Parents played a functional and practical support role*
2. *Parents as advocates: “Fighting” for support*
3. *Benefits of parent support*
4. *The challenges of balancing autonomy and support need*

10.1.2.2.1 Parents Played a Functional and Practical Support Role.

Parents reported providing support across a range of areas, which were predominantly functional and practical in nature. Specific support areas included activities of daily living such as transportation/driving or travel training (Parents 1, 2 & 5) and grooming/personal hygiene (Parent 6), as well as social skills support (Parent 5). Only one parent (Parent 5) reported that they provided financial support for their son.

Support was also focused on preparation and planning for university. For example, one parent described how they and their son *“tried every café (...) explored the library together (...) and went repeatedly to the book shop to check for 2nd handbooks (...) worked out where the lecture theatres, classrooms and bathrooms (...) were”* (Parent 8). The same parent also helped prepare their son for his transition to university by: *“driving to campus every week over summer and before O-Week [orientation]”* (Parent 8).

Parents also assisted their son or daughter to access support services at university. For example, Parent 3 contacted the Disability Services to request information about the supports available prior to their daughter commencing university. They were provided with *“information on the support they would offer if she chose to approach them with her report of diagnosis”*. However, they noted that after commencing university their daughter chose not seek support from Disability Services. Parent 2 also assisted with access to university services by providing communication support for their son to request assistance when seeking to change degrees.

Four parents described providing academic support, including support with organisation and time management skills (Parents 1, 3, 7 & 8). For example, one parent assisted *“with making sure assignments were completed on time”* (Parent 1), while two parents (Parents 3 & 7) reported providing support with tasks such as assignment planning, and time management. Another parent described how they provided academic support in the early stages of transition: *“For his early assignments, I sat with him to help him understand the requirements and I offered to proofread his drafts. After the first couple of assignments, he was fine and didn’t need my help any more”* (Parent 8).

In summary, parents appeared to undertake a range of support roles for their child during the transition to and first year of university. Support commonly centred around functional and practical support needs such as support with daily living tasks, as well as support to manage university expectations.

10.1.2.2.2 Parents as Advocates: “Fighting” for Support.

Several parents described their role “advocating” or “fighting” for their son or daughter during both high school and the transition to, and first year at university. For example, Parent 5 stated: *“I had to strongly advocate for my son to be allowed to do atar [sic] [Australian Tertiary Admission Rank] eligible subjects [in high school]”*. In addition, Parent 5 noted:

He needed an advocate to fight for him (...) to be given extra provisions- hours and hours of work went into doctors visits, meetings and paper work (...) if a student didnt [sic] have an advocate to do all the paper work no way would they get the provisions (Parent 5)

One participant (Parent 2) described their experience of advocating for support at the university, describing this experience as *“mentally exhausting”*. She explained:

A support worker was allocated temporarily [funded by the university] (...) This unfortunately was only able to be temporary but luckily the NDIS funding commenced (which I had to take to the AATribunal [NDIS Administrative Appeals Tribunal] as they could not comprehend a non verbal kid with autism needed support if they didn't have an intellectual disability!). every year I have to fight for funding for my son to remain at uni [sic] (Parent 2)

Similarly, Parent 7 described *“fighting to ensure that he [their son] not only better communicates his needs, but that they are addressed in a timely and professional manner”*, during their son's second attempt at university.

Overall, it was evident that parents undertook a role as advocate for their child during the transition to university, across both high school and university settings.

10.1.2.2.3 Benefits of Parent Support.

Parents described benefits they observed resulting from the transition support they provided. Reported benefits included student participation and engagement in the university experience, increased independence, increased confidence, and decreased anxiety. One parent described providing transition support *“to make sure my son could take part in the*

learning experience” (Parent 1). Similarly, Parent 4 stated that because of the support provided *“He [their son] at least gave uni [sic] a go for a while”*.

The support provided by Parent 5 to assist their son to access special provisions in high school enabled him to progress to university:

I clearly remember him doing hsc work and me doing massive amounts of leg work and paper work. So many forms needed to be signed off by different professionals. Without the provisions I suspect he wouldn't [sic] have got into uni-[sic] (Parent 5)

Parent 2 had organised and engaged an NDIS funded support person to provide support for their son during the first year of his university degree and beyond. This support had been necessary as the university were unable to fund a support person in an ongoing capacity. As a result of engaging the NDIS funded support person, Parent 2 observed an increase in their son's confidence and self-esteem:

My son has developed the confidence to join workshops and work/ participate in a team (...) he is gaining a sense of self worth and now sees a future and this us [sic] perpling [sic] his ability to step up and be more and more independent in his communicating, his organisational skills, desire to continue to study and belief in himself to make new friends (Parent 2)

Another participant described providing support in the early stages of their son's degree, by helping him to understand university requirements and offering to *“proofread his drafts”* (Parent 8), explaining that her son was then able to manage this independently:

after the first couple of assignments, he was fine and didn't need my help any more [sic]. He's since taken great pride in managing his studies on his own, and earned many high distinctions. He's gained his double degree with distinction and is now doing honours (Parent 8)

Two participants (Parents 3 & 8) suggested that their support provided mental health benefits for their son/daughter. For example, Parent 3 suggested that helping their daughter to stay organised with university work, also assisted *“with her anxiety and mental health”*. Similarly, Parent 8 noted: *“By helping him become familiar with the campus environment and uni [sic] processes, we lowered his anxiety”*. Parent 8 provided support to their son prior to his commencement at university, which they reported had consequently enabled him to support other students during the university's orientation week: *“he [son] loved being able to*

help other first-year students, as he and I had already worked out where to queue for things, where the bookshop etc were located". Parent 8 added: *"In 2nd year he was invited to work as a (paid) peer advisor, which he really enjoyed. I think the good start he had in the first year made many things possible for him".*

The two parents (Parents 6 & 7) who did not report benefits to the student resulting from their support both described challenging experiences of attempting to provide transition support, such as difficulties communicating with university staff. However, Parent 7 noted: *"The benefits of my supporting him, was that I learnt more in the process of supporting him in an adult educational setting".*

Overall, parents noted a range of benefits for their autistic child which had resulted from parental support including their child having the opportunity to attempt university, assisting students to familiarise themselves with the university campus. and providing the opportunity for students to develop new skills.

10.1.2.2.4 The Challenges of Balancing Autonomy and Support Need.

The complexity of balancing the student's support needs with their right to autonomy and independence was noted by parents. Additionally, they reflected on university expectations of the student as an adult within an adult learning environment, and the challenges of recognising this while also trying to provide necessary support for their son or daughter. Parents observed that universities, as adult learning environments, were at times not responsive to parental support provision. For example, Parent 7 described their experience trying to provide support as: *"disempowering as the parent when trying to deal with the University when your child is deemed an adult"*, while Parent 6 described feeling like they were *"an interfering parent"* when attempting to provide support for their child. Similarly, Parent 6 reported: *"I was treated like a pariah by the disability [staff]"*. Another parent explained: *It's hard to navigate the University as a parent, with your child now an 'adult' and treated as independent... but in reality 2-4 years behind socially and emotionally* (Parent 4).

Connecting and communicating with university staff on behalf of their child was also noted as challenging. Parent 4 noted: *"We never managed to connect with any professional staff, as parents"*, while Parent 2 felt that university staff expected the student to engage with support services independently without support from a parent or family member, explaining: *"Communication between the disability coordinator, me and my son does lapse as she seems to think it's his responsibility to contact her when there is a problem...however this is his disability"*. Challenges trying to communicate with university staff which resulted from expectations of independence within an adult learning environment were described by Parent 8: *"When I tried to participate in a call with the admin staff over some unit enrolment confusion, they asked him to take the call off speaker and move away from me, which*

seemed a bit unnecessary". To overcome this challenge and provide support for her son, Parent 8 assisted him by *"reviewing emails"* before he sent them, or *"sitting with him while he worked out enrolment processes"*.

Parents also reflected on the student's own resistance to receiving parental support, and the need to balance this with potential support needs. For example, Parent 4 described their son's tendency to *"resist help"* from his parents: *"He is not very open with us and does not trust our advice because we are not 'experts' so it is very hard to guide him"*. Similarly, Parent 3 stated: *"The main challenge was her wanting to do it herself but if left to manage herself she would end up with anxiety and melt downs so she would realise that she still needed my guidance"*. Parent 7 felt their son's resistance was due to his desire to *"[have a] new start and to 'blend in' with the other students and not be singled out as being different"*.

While parents were willing to provide support to their son/daughter during the transition to, and first year of university, it was evident that they also recognised the need to support their autonomy and independence. Parent 8 summarised this experience, stating: *"Balancing respect for autonomy while helping him [son] to understand how the uni [sic] system works (...) It is a balancing act to ensure he knows what he doesn't yet know, while not overstepping the mark"*.

Overall, parents described varied experiences of providing support while also attempting to encourage their child's independence and autonomy. This was often made more difficult by university expectations of student responses to support provided. However, it appeared parents were conscious of the importance of balancing support need and independence.

10.1.2.3 University Supports.

Parents described the challenges they and their children experienced when attempting to access university support services, often resulting in delayed support provision. Parents also outlined transition support recommendations, along with their desires for how transition support should look in the future. Two sub-themes were developed within the theme of *University Supports*:

1. *Delays and difficulties engaging with university support*
2. *Recommendations for university transition support*

10.1.2.3.1 Delays and Difficulties Engaging with University Supports.

Most parents described negative experiences of university support for transition. Access to university-based supports was reported as being provided too late, difficult to find or access, or being provided in response to challenges rather than proactively upon

enrolment. Two parents discussed their experiences supporting their sons to access support from the university, noting that support had been provided *“too late”* (Parent 4) or only after contact from the parent to enquire about support options (Parent 2). Parent 4 also explained that her son had only been able to access support after he had withdrawn from his studies during his first semester, despite the fact he had specified his diagnosis of Asperger’s on his enrolment form.

Participants also found the experience of locating and interacting with university support services challenging. Parent 7 described the experience of supporting their son to access support at university as *“overwhelming and very disempowering for both my son and myself”* (Parent 7). They also described feeling like *“we were totally on our own”*, noting that their son *“was able to located [sic] student wellbeing with my assistance after about 4 weeks but it was a disaster”*. Similarly, Parent 6 described their interactions with the university as *“a confusing mess”*, which reportedly created stress between them and their child.

Only one parent described a positive experience engaging with university support services during their son’s transition to university: *“The uni [sic] disability coordinator took us on a tour of the uni [sic] grounds and showed my son each room he was going to need to attend during the semester. She does this every semester”* (Parent 2).

In summary, several parents described accessing university support services as challenging or delayed. Locating support appeared to be difficult, and support was often only provided in response to difficulties the student was already experiencing with their studies.

10.1.2.3.2 Recommendations for University Transition Support.

Parents described their hopes and recommendations for future improvements to transition support. Suggestions centred around earlier access to transition support, with better links between high school and university, as well as the need for consistent transition support programs and opportunities. Parents highlighted the need for transition support to start during high school and the importance of effective connection between high school and university. For example, Parent 4 noted: *“I needed pathways to be more involved SOONER [sic]”*, while Parent 7 explained:

There needs to be far more assistance and support right from high school on. I believe conversations need to start in early year 10 (...) Year 11 should be looking at the options and visiting Universities. Year 12 should be again planning, support by school to assist with the admissions and enrolment into Uni [sic] - that way it is not the parents doing it - but the student being empowered to complete the applications with support
(Parent 7)

They also suggested:

Once a Uni [sic] is aware of a student with disability – there should be added transition and planning completed once the application for Uni [sic] has been accepted – planning with adjustments and other items required should all be considered and completed before the Uni [sic] semester begins (Parent 7)

Two parents (Parents 4 & 8) identified the need for transition support programs within universities, including those providing foundational skills and familiarisation with the university in preparation for student transition. For example, Parent 4 explained: *“I wish there was some ‘foundation’ or familiarisation program in the months before [university]”*. However, another parent also commented on the reluctance of some autistic students to engage in such programs, stating: *“I look forward to the day when autistic transition programs are widespread, and perhaps most importantly, widely accepted by the people they are designed to help!”* (Parent 8). In addition, the need for staff education and training was noted by Parent 4, who suggested the need for *“Counsellors, lecturers and other students (...) to be educated to be more understanding of people with (not immediately visible) differences”*.

Overall, parents identified the need for improvements to university support for autistic students which included earlier access to transition planning and support, along with staff education and training. Parents also suggested the implementation of transition programs to enable students to develop practical and academic skills to support their learning.

10.2 University Staff

Thirty university staff members responded to the online survey. Three participants were identified as ineligible via the eligibility questions, and an additional three responses were also excluded as the respondent had not provided responses to any questions beyond the eligibility questions. A summary table of staff participants' role and years employed in higher education is available in Appendix AB. Sixteen participants were employed in academic staff roles (e.g., Topic/Unit Coordinator, Lecturer, Tutor). Four participants indicated they were employed in a professional role (Disability Services), three across both professional and academic staff roles, and one participant in a professional role (library). Years worked in higher education varied across all participant groups, ranging from 1 year to 15+ years.

10.2.1 Responses to Closed-Ended Questions

Twenty-four participants responded to the questions regarding awareness of the DDA and confidence working with autistic students (see Appendix AC and Appendix AD).

Most staff members (n=20) indicated they were familiar with the DDA and the impact it had on their role. Confidence working with autistic students varied. Nine participants were somewhat confident; six were very confident; one was not very confident; one was not at all confident; and seven participants did not provide a response.

Seventeen participants responded to the questions regarding experiences of training in autism and interactions with family members (see Appendix AE). Most staff members (n=12) indicated they had not received training specific to autism. Those who had received autism-specific training indicated that this was primarily through their degree qualification, previous employment (outside of university), or learning from autistic students themselves. Eleven staff indicated they had not had any interaction with family members; while six members indicated they had interacted with family members. Seven participants did not respond to the question about training in autism or interactions with family members.

10.2.2 Summary of Themes

Of the 24 eligible responses outlined above, seven were unable to be analysed using RTA as they had not responded to any of the open-ended questions regarding their experiences of providing support to autistic students during their transition to university. A total of 17 responses were therefore included in the thematic analysis. University staff responses to the four open-ended questions (see Appendix E) were analysed using RTA.

Staff described their experiences providing support to autistic students, including the benefits and challenges. Staff members also described their experiences supporting autistic students who may or may not disclose and provided suggestions for improving transition support in the future. Four themes were developed, with no associated sub-themes. An overview of the themes is provided in Table 10.5.

Table 10.5: Themes developed from staff survey responses

Theme
University staff support: Emotional, practical and academic
The benefits and challenges of providing support to autistic students during transition
Improving support for autistic students' transition in the future
Interacting with family members: Advocacy and developing independence

10.2.3 University Staff support: Emotional, Practical and Academic

Support provided by staff members commonly centred around emotional, academic, and practical support needs. Academic staff described providing emotional and moral support to autistic students in the form of “*encouragement and nurturing*” (Staff Member 8) or

supporting students when they became distressed or overwhelmed (Staff Member 17). They also provided practical support such as helping students with *“breaking down tasks”* (Staff Member 8).

Staff also described various types of academic support provided to students. These included providing time to go through course requirements, explaining course concepts and assessment requirements (Staff Member 16); providing opportunities for students to visit science labs during quiet times to familiarise with the space (Staff Member 14); and assessment extensions, alternative exam arrangements, and writing supports (Staff Member 10). Staff indicated that academic support was often facilitated by meeting with students individually and discussing their support needs directly.

Disability Services staff reported one of their roles as liaising with academic staff, noting that this communication could be potentially challenging for autistic students to manage without their support. For example, one disability advisor explained: *“[I] have worked with some students to access 1:1 support from academic staff too - supporting disclosure (...) building relationships, and providing instruction and guidance to staff about how to support student”* (Staff Member 7). Another disability advisor suggested that without their support autistic students may find it difficult to communicate with academic staff members, explaining: *“Another way that I support these students is by assisting in the communication with academics as some students of [sic] the spectrum find this particularly challenging”* (Staff Member 2).

Referral to internal (e.g., Disability Services, mentoring programs) and external (e.g., NDIS) supports was mentioned by both academic and professional staff. Two Disability Services staff members (Staff Members 2 & 3) reported arranging mentoring support for an autistic student to help with study planning and establishing social connections on campus, while one academic staff member (Staff Member 5) reported engaging a mentor to provide academic support.

Overall, staff roles varied but were primarily focused on emotional, practical, and academic needs. Staff were also involved in supporting the interaction of autistic students with other staff members and relevant services.

10.2.4 The Benefits and Challenges of Providing Support to Autistic Students During Transition

Staff described both positive and negative aspects of providing support to autistic students during their transition to university. Positive experiences were associated with the ways in which students engaged with their studies. For example, Staff Member 13 described their experiences of autistic students as being *“very engaged”*, while Staff Member 16

described experiences with autistic students who were *“self aware enough to initiate and seek help”*. Staff Member 13 added: *“[autistic] students openly share their experiences of autism within the classes and they are valued members of the class both to me as their tutors [sic] and their peers”*. One staff member who had experience working both as a professional and academic staff member also reported positive experiences supporting autistic students during their transition: *“It has been a delight to see students thrive and achieve their potential, when provided with the appropriate academic and social support”* (Staff Member 9).

Difficulties supporting autistic students during their first year at university were associated with not having enough time to get to know students (Staff Member 12), limited resources for staff (Staff Member 1), and the physical challenges posed when working in large lab settings (Staff Member 14). Peer interactions were also noted as presenting challenges for some students, with Staff Member 16 noting difficulties they observed *“with other students who have found group work difficult with students living with autism”*. They described their role in this situation as *“facilitat[ing] conversation with these group members in demonstrating understanding and empathy”*. Two staff also reflected on the university as a whole in providing support to autistic students, with both describing universities as *“failing”* autistic students (Staff Members 1 & 12). Staff Member 12 described the lack of specific support provided by universities to cater for autistic students’ needs, adding *“Given that many Autistic students thrive in the HE [higher education] context when adequately supported, I feel that we are failing as a university in not providing such supports”*.

Challenges experienced by academic staff supporting autistic students during transition were commonly associated with students choosing not to disclose their autism diagnosis. Staff noted that they were aware of students who *“self identified”* to them as being autistic, but also noted that some autistic students did not disclose their diagnosis or support needs to academic staff. For example, one participant stated: *“I think there are probably more students in my class who prefer not to discuss their experience with me (& that’s fine!)”* (Staff Member 6). Similarly, another participant noted: *“I have a large number of students on the spectrum, some of which I know about and some that I don’t know about”* (Staff Member 16). One staff member (Staff Member 1) noted that some students may not disclose until they had reached a crisis or *“point of distress”*, which made it challenging to provide appropriate support. Due to the need for students to self-disclose and ask for assistance, they also felt that the support they could provide was often *“limited”*.

Academic staff suggested they were aware that not all autistic students would choose to disclose their diagnosis, resulting in some staff making assumptions about whether or not students may be autistic. For example, one staff member stated: *“I have*

taught some students who I suspect may be on the autism spectrum but clearly I have no qualifications to make such judgements” (Staff Member 11); while another noted: “I have had a few students in my topics whom I have suspected to be Autistic” (Staff Member 12).

Staff acknowledged that some students may choose to disclose their support needs through the provision of an access plan or similar supporting document. However, they noted that access plans were often “*vague*” and generally did not specify the student’s autism diagnosis. Two academic staff members suggested that knowing a student’s diagnosis, rather than the more general information provided in students’ access plans would be helpful. For example, Staff Member 12 stated: “*Knowing a student is Autistic gives me a great deal more information than vague instructions like ‘struggles in group tasks’*”. Similarly, another staff member stated: “*if such a status [autism diagnosis] was identified early in a student’s university study it would make it easier for tutors to help them*” (Staff Member 11).

Some staff suggested they were aware there may be autistic students in their classes who had chosen not to disclose. To address the challenges associated with lack of disclosure, two participants (Staff Members 4 & 6) described using inclusive teaching practices. For example, Staff Member 6 explained:

I try to be aware of this [that there may be students in their class who choose not to disclose], and make my teaching methods accessible by not using overly busy fonts and formats; providing opportunities to refresh key information; not requiring compulsory social engagement to complete student activities (but supporting ways to get to know one another that have a structure); using concrete language ... etc (Staff Member 6)

In summary, staff members suggested the support they provided enabled students to engage and participate successfully at university. However, staff also identified a range of challenges to providing this support, including students not disclosing their diagnosis, and the lack of specific information provided in access plans to support students learning and participation.

10.2.5 Improving Support for Autistic Students’ Transition in the Future

Suggestions and recommendations for improving transition support for autistic university students were described by some staff. Three academic staff (Staff Members 5, 8 & 14) indicated that they would like to see further professional development and training opportunities for themselves and other university staff. For example, Staff Member 14 noted: “*I would be very interested in attending training to help improve the way support is provided*

to students on the autism spectrum. With diversity and inclusion come new challenges that educators need to be better prepared for”, while another staff member suggested: “Universities need to train all staff at all levels and this professional development needs to extend to all students living with a disability” (Staff Member 8).

In addition, Staff Member 8 acknowledged the importance of consistent support and the time and resourcing that this can require, stating:

Success requires a holistic level of support across the Uni [sic] not just with teaching staff... people living with autism can be highly successful but they need consistent, calm support and individual adjustments and teaching staff need time to do this in their workloads (Staff Member 8)

The need for explicit support that addresses the specific support needs of autistic students was also highlighted. For example, Staff Member 5 suggested that they would like to see *“more explicit support for students with ASD and more training on how to adapt for their needs”*. Support mechanisms that could be implemented to improve student experiences were suggested by professional staff, such as *“mentor programs”* and improved transition support from school to post-school options, including *“Longer lead times, intro [sic] visits, taster skills sessions, [and] family events (...) to help young people get used to a new environment, new expectations and be comfortable within themselves to be able to access relevant services as needed” (Staff Member 7)*. Staff Member 2 also suggested the need for a

designed [designated] role for a staff member who has specific skills and training to support students on the autism spectrum that could work more intensely and on a [sic] on-going manner, a type of case management role would be beneficial in supporting students get through their studies (Staff Member 2)

Overall, staff members’ suggestions for future improvements to support autistic students at university focused on staff training, with an emphasis on the need for staff training across the whole university. Staff also suggested the need for autism-specific support strategies, peer mentoring programs, and improved orientation opportunities. The time and resourcing required to implement this support effectively was also noted.

10.2.6 Interacting with Family Members: Advocacy and Developing Independence

Five staff reported their experiences interacting with family members, commonly parents of an autistic student, reflecting on the role parents played in supporting and advocating for students. Staff Member 12 explained: *“In a number of cases I have been involved with, parents/families [sic] have been critical in advocating for support as the student concerned is often struggling to navigate rather unfriendly university systems”*. Interactions with parents were generally described by staff as a positive experience that enabled them to better understand autistic students and their needs. Staff Member 12 explained: *“In my experience, these parents have provided a strong voice for the student and I do wonder what happens to students who might have limited self-advocacy experience or capacity and whether these students fall through the cracks”*. However, staff also reflected that at times, family support may be unwanted by the student, or create additional challenges to providing effective support. For example, Staff Member 7 noted that the perspective of the student and family member may differ, or the student may not wish to have their family member involved. Similarly, another participant suggested that family members may at times feel like they *“need to speak for or on behalf of the student, which isn’t always helpful”* (Staff Member 2). The same staff member explained that they also used strategies to ensure the student was contributing to the discussion, stating: *“the student needs to be able to feel [sic] independent and capable of making decisions. so I [sic] always check in with the student to make sure they are having a say in the discussions”* (Staff Member 2).

While acknowledging the advocacy role played by parents, staff members also highlighted the importance of supporting the student to develop their own independence and self-advocacy skills and decrease the need for family support. For example, one staff member explained: *“there are sometimes steps I take to acknowledge parental wish to be involved, but respectful of individual student to develop their own self advocacy skills”* (Staff Member 7). Similarly, Staff Member 2 stated:

having a family member for the first few meetings can be very helpful as the student can initially be difficult to engage with. but once the rapport has been established, there isn't such [a] need for the family member to be there (Staff Member 2)

In summary, staff described both negative and positive interactions with family members. Positive situations were generally described in terms of enabling access; however, negative interactions were associated with staff concerns about ensuring student independence, autonomy, and self-determination.

10.3 Chapter Summary

This chapter has presented the themes and sub-themes generated from analysis of online survey data collected from eight parents and 24 university staff members. Participants described their experiences providing support to autistic students during their transition to university. Parents described their experiences of providing transition support, highlighting the lack of existing high school transition support as a significant challenge. They also discussed their experiences engaging with university staff and the importance of balancing support need with student autonomy.

University staff described their experiences of supporting autistic students during their transition to university, highlighting the challenges they faced in providing this support, such as the need for time and resources to provide effective support and the challenges faced when students choose not to disclose their autism diagnosis. They also provided recommendations for improvements to future transition support practices, such as staff training, autism-specific support strategies, peer mentoring, and improved orientation programs. University staff also discussed their experiences of engaging and interacting with family members to support autistic students' transition to university, noting that parents often undertook advocacy roles to support their child.

The following chapter presents a discussion of the overall findings of this research, including the identified facilitators and barriers, as they relate to the bioecological theory model framework utilised throughout this research. Findings are discussed as they relate to existing literature and current understanding of the experiences of autistic students in higher education.

11 DISCUSSION

An increasing number of autistic students are enrolling in university, yet their completion rate is still lower than that of their peers with and without disability (Australian Bureau of Statistics, 2019; Newman et al., 2011), as discussed in Chapter 2. The experience of autistic university students is an expanding area of research. However, as highlighted in the systematic literature review presented in Chapter 4, limited research has specifically examined the transition experiences of autistic students, especially within the Australian higher education context. In addition, much of the existing research focuses on strategies and skills that autistic students should develop, rather than examining the broader systemic and cultural issues impacting on their transition. This thesis has therefore addressed this gap, by exploring the facilitators and barriers to transition to university for autistic students in Australia through a bioecological systems lens.

Identifying factors that facilitate the transition to university for autistic students is important, as it can provide a deeper understanding of existing strategies that enable positive transition experiences. Conversely, identifying factors which act as barriers for autistic university students and members of their support networks during the transition period, can highlight areas for future improvement in university transition supports, strategies, and programs.

To identify the factors that facilitated or inhibited transition to university for autistic students, semi-structured interviews were undertaken with autistic students, and members of their support networks. Data were also gathered via an online survey for autistic students, family members and university staff. Previous chapters have presented the findings from analyses of the data gathered from these sources. The current chapter discusses the findings as they relate to existing literature and current understanding of the university transition experiences of autistic students, within the framework of the bioecological theory model (Bronfenbrenner, 1979; Bronfenbrenner & Morris, 2006).

Lizzio's Five Senses model (Lizzio, 2006; Lizzio, 2011) provides a framework for describing the needs of students as they relate to their early success and engagement in higher education, which can in turn facilitate the development of strategies to support the transition and participation of university students. Implications for Lizzio's Five Senses model are discussed throughout this chapter, as they relate to relevant elements of the bioecological theory model, with consideration as to how this model specifically applies to the experiences of autistic university students.

11.1 The Bioecological Theory Model and Transition to University for Autistic Students in Australia

The bioecological theory model was the theoretical framework utilised throughout this research project and provides the lens through which the facilitators and barriers to transition for autistic university students were explored. At the individual level, the current research identified individual characteristics such as time of diagnosis, sense of self and identity, help seeking behaviours and disclosure, that contributed as both facilitators and barriers to transition for autistic students. Within the microsystem level, this research identified facilitators and barriers related to interactions with external support network members including high school staff, university staff, family, and friends. Interactions between these microsystem elements were also identified and examined, indicating that barriers exist that limit effective communication and engagement between microsystem elements. At the exosystem level, the research identified systemic elements such as university policies and programs, along with legislation which may impact on the students' transition experience. Finally, at the macrosystem level, broader socio-cultural elements such as community understanding of autism, were highlighted, which set the background for the overall acceptance and inclusion of autistic students at university.

The following sections discuss the factors which acted as facilitators and/or barriers as they relate to each of the systems within the bioecological theory model (see Figure 11.1). Utilising the bioecological theory model as a framework enabled the researcher to explore factors that hinder or enable the transition to university for autistic students, from the individual through to the systemic level. Importantly, using the bioecological theory model also highlighted the complex interrelationships between elements at each of the bioecological system levels.

It is important to note that each participant's experience was unique and influenced by a complex range of individual characteristics and situational factors. Therefore, it was not possible to clearly distinguish between those factors which acted as facilitators and those which acted as barriers. Instead, it was noted that factors could act as either a facilitator or barrier dependent upon the context within which they occurred. For example, interactions with university staff could act as a facilitator or barrier, depending upon the level of knowledge and understanding the staff member had of autism.

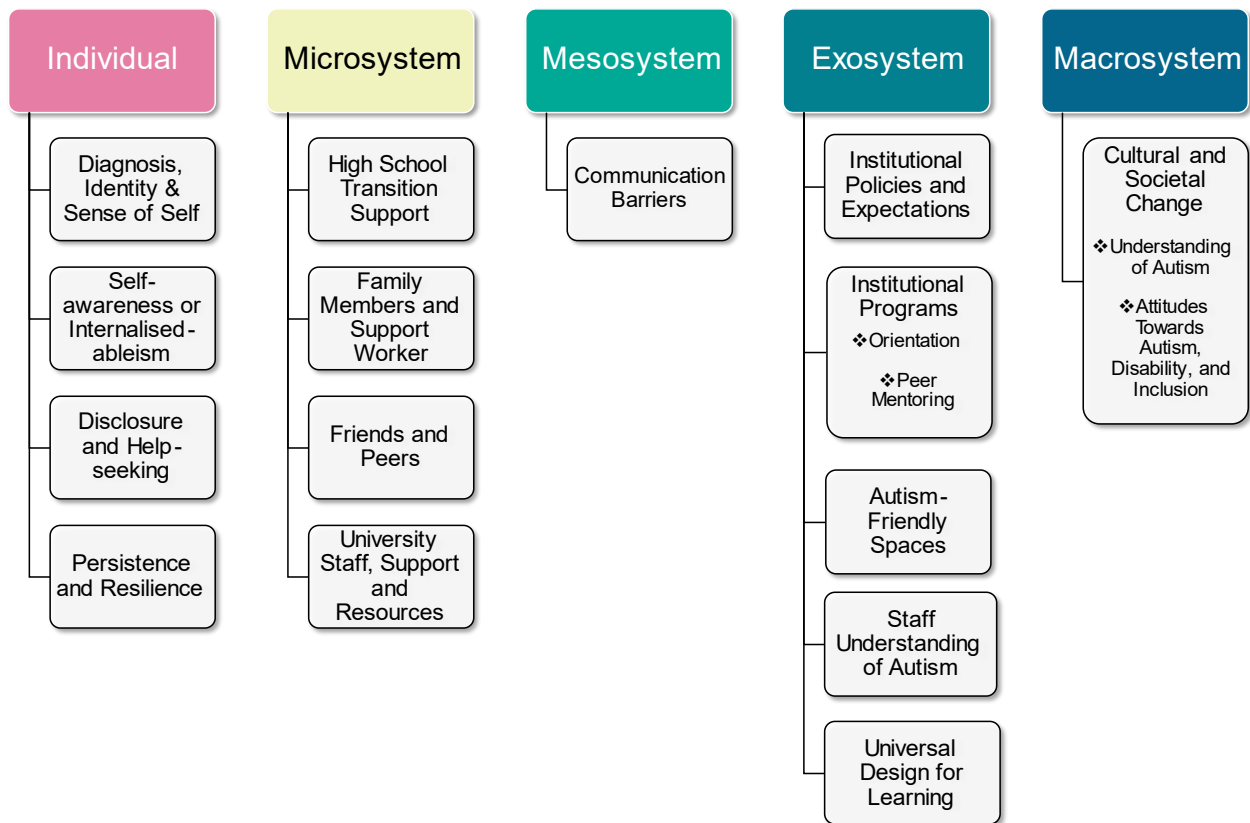


Figure 11.1: Factors which acted as facilitators and/or barriers within each of the bioecological theory model levels

11.2 Individual

In the current research, the autistic student is at the centre of the bioecological theory model and brings with them a range of personal characteristics which can impact upon their experience of transition to university. Individual characteristics included the students' age at diagnosis, their sense of self and identity, their self-awareness, and their ability and willingness to seek out support and disclose their diagnosis. In addition, dispositional characteristics such as persistence and resilience also played a significant role in students' transition experiences. Each of these factors, which are discussed in more detail in the following sections, acted as facilitators and/or barriers to the transition experience, although the ways in which they impacted on transition varied for each student and was often dependent on other contextual factors.

11.2.1 Diagnosis

Access to a formal autism diagnosis and age at diagnosis appeared to be important factors that could act as facilitators and/or barriers during the transition to university. Similar to previous research (Oredipe et al., 2023), age at diagnosis also appeared to be linked to students' sense of self and identity. Oredipe et al. (2023) conducted an online survey with 78 autistic university students from 50 institutions across eight different countries. Content analysis of the open-ended questions indicated that students who received their diagnosis in

early childhood viewed autism as “a natural part of who they were” (p. 208). Similarly, autistic students in the current research who were diagnosed in childhood, described autism as something they found difficult to separate from other personal characteristics or experiences. However, in contrast to findings from Cox et al. (2017), students in the current research who received an autism diagnosis in childhood did not appear to demonstrate greater comfort in their sense of self or a more positive view towards their autistic identity. Instead, they appeared to have neither a positive nor negative attitude towards autism, but a neutral reflection of autism as something that was just a part of who they were. According to Gobbo and Shmulsky (2016) a positive or neutral framing of autism rather than a negative one, can support the development of positive identity. However, for students in the current study who received their autism diagnosis in childhood, the neutral perspective towards autism appeared to make it difficult for them to identify whether the challenges they experienced during their transition were related being autistic, or not. Consequently, it may be more difficult for these students to identify appropriate strategies and supports to address the challenges they experience. Given the small sample of both studies, further research is needed to explore the impact of age at diagnosis on autistic identity and sense of self and how this may relate to the implementation of supports and strategies, particularly during the transition to university.

Receiving a formal autism diagnosis in childhood has also been associated with higher levels of wellbeing and quality of life, than is experienced by those who learn they are autistic later in life (Oredipe et al., 2023). While the current research did not examine quality of life or wellbeing specifically, it is worth noting that barriers to transition experienced and discussed by students diagnosed in early childhood were similar to those described by students who were diagnosed in adulthood. However, the current findings do suggest that a lack of formal autism diagnosis prior to transition to university may present additional barriers for autistic university students. For example, students without a formal diagnosis are likely to face barriers when seeking to access Disability Services, which may prevent them from receiving reasonable and necessary adjustments and accommodations. They may also have difficulties identifying the cause of certain difficulties they are experiencing and therefore be unable to implement relevant strategies. For example, one student who had been undiagnosed during their first attempt at university indicated that they had difficulties making social connections.

Receiving a formal autism diagnosis in adulthood enables a process of meaning making and self-understanding that can empower students and enable them to access support (Oredipe et al., 2023). This appeared to be the case for four students in the current study who received their autism diagnosis in adulthood. Three of the four students diagnosed in adulthood had attempted university at least once prior to the degree they were

enrolled in at the time of their interview. These students had been unable to complete their previous studies, describing a range of challenges, including sensory, social, and executive functioning difficulties, which they now attributed to their autistic characteristics. Reflecting on these challenges, the students acknowledged the impact these difficulties had on their previous and current transition experiences. Cage and Howes (2020) found similar results when they interviewed autistic students who had dropped out of university in the UK. Many of those interviewed in Cage and Howes' (2020) study had received their diagnosis after dropping out of university and reflected that knowing their autism diagnosis earlier may have improved their experiences and potentially enabled them to continue with their studies. While students in the current study did not suggest that having an autism diagnosis earlier would have changed their previous experiences, they did highlight the benefits of having a formal diagnosis, including accessing supports and services, and being able to identify challenges and develop new skills to address them.

Students explained that receiving their formal autism diagnosis enabled them to access support and accommodations that promoted their participation and engagement at university. In Australian universities, students with disabilities are required to provide written evidence of a disability, or ongoing medical or mental health condition in order to access reasonable adjustments and accommodations (Cunninghame et al., 2016; Nuske et al., In press). Therefore, not having a formal diagnosis or access to their diagnostic report prevented some students in the current study from accessing Disability Services when they first attempted university. One participant was an exception; having previously been diagnosed with ADHD, Kimberley had been able to access Disability Services, supports, and strategies relevant to this diagnosis. However, she noted that she continued to experience some difficulties until her autism diagnosis had been received providing her with a new understanding of some of her previous challenges. These findings echo those of Fabri et al. (2022), reinforcing the importance of a formal diagnosis for autistic university students. In addition, they build upon these findings by highlighting the importance of formal diagnosis, not only for students' wellbeing, but also in enabling access to support, as well as providing students with the opportunity to develop a stronger understanding of themselves and their needs.

Gender bias in autism diagnosis is well recognised (Lai & Baron-Cohen, 2015; Zener, 2019). In addition, barriers to diagnosis, such as access, cost, and lengthy wait times, are commonly experienced by autistic females and autistic adults more broadly (Lewis, 2017; Loomes et al., 2017; Zener, 2019). As a result, there may be an increased likelihood that female autistic students commence their studies without a formal diagnosis, as was the case for the two female students in the current research. Both experienced challenges accessing a diagnosis; however, once received, the diagnosis provided them with a new lens through

which they could develop a better understanding of their difficulties and explore potential strategies to address them. It is therefore important for Disability Services staff to be aware of the potential for female autistic students to be undiagnosed. In these instances, Disability Services staff may need to consider ways they can support students while they await a formal diagnostic assessment, by referring them to general student support services and resources. Students in the current study who were awaiting their formal diagnosis had identified challenges they were experiencing, with some having attempted to engage with Disability Services to address these difficulties. Ensuring Disability Services staff have a strong understanding and professional knowledge of autism will enable them to provide strategies and suggestions to students who may contact the Disability Service while awaiting their formal diagnosis.

11.2.2 Identity and Sense of Self

Positive identity is a central feature of wellbeing in adulthood and plays an important role in the development of positive social and professional relationships (Gobbo & Shmulsky, 2016). Identity has been highlighted as a key factor in the successful transition and engagement of commencing students both with and without disability (Kift, 2015, 2021; Lizzio, 2011). While identity development in the context of disability is complex (Anderson-Chavarria, 2022), the emergence of the neurodiversity paradigm and shift away from medical perspectives of autism have the potential to support the development of positive autistic identity and sense of self (Anderson-Chavarria, 2022; Gobbo & Shmulsky, 2016). Autistic identity development is an emerging area of research, with existing literature highlighting the complexity of identity development for autistic students in higher education and the resulting impact this can have on disclosure and access to support (Cox et al., 2017; Oredipe et al., 2023).

It has been suggested that positive autistic identity may be a contributing factor to successful participation in higher education for autistic students (Gobbo & Shmulsky, 2016). Universities can support autistic identity development by creating safe and inclusive campuses and providing opportunities for autistic students to explore their autistic identity (Gobbo & Shmulsky, 2016). The current research findings also support this suggestion and emphasise the importance of universities promoting an inclusive campus culture, and avoiding the reinforcement of negative, deficit-focused and pathologizing views of autism. As such, there is a need to improve understanding of autism for all university staff. Disability Services play an important role in facilitating the development of knowledge and understanding among university staff. Disability Services staff may need to consider how they communicate about autism and the language they use in the development and implementation of access plans, and when discussing autism more broadly with university

staff. It may also be beneficial for staff to familiarise themselves and implement the recommendations from recent research by Bottema-Beutel et al. (2021) and Bury et al. (2023). For example, avoiding the use of deficit-based language and descriptions of autistic students' challenges. Instead, focusing on the strengths, skills, and strategies students can implement to overcome these challenges. Similar recommendations are also outlined in the best practice guidelines produced by the Autism&Uni research initiative (Autism&Uni, 2014; Fabri, 2016). In addition, Disability Services staff may play a significant role in actively dispelling myths and misconceptions associated with autism, and supporting the development of improved knowledge, understanding, and acceptance of autism within the broader university community.

Universities can also play a crucial role in supporting the development of positive autistic identity through enabling social relationships and networks with other autistic and neurodivergent students. Disability Services staff may need to consider how they can facilitate the connection between new and existing autistic university students to enable opportunities for cultural and identity development in safe, autism-friendly spaces. This may be through the implementation of autistic-led peer mentoring programs or more informal social groups and activities. The use of peer mentoring programs and social groups appeared to facilitate social connection and networking for autistic students in the current research, which echoes findings of previous research (e.g., Gobbo & Shmulsky, 2016). These strategies are discussed in more detail in Section 11.5.2 of this chapter.

The current research adds to our understanding of identity development for autistic university students and highlights the ways in which autistic identity development at the individual level may be influenced by factors at the microsystem and exosystem levels, such as campus culture and the presence of peer-mentoring programs and autism-friendly spaces. In addition, there may be a need to revise existing transition frameworks, such as Lizzio's Five Senses model (2006; 2011), when supporting autistic students; by expanding the concept of identity beyond that of "student identity", or "future graduate" and considering how universities can help autistic students to develop their sense of autistic identity.

11.2.3 Self-awareness or Internalised Ableism?

Previous research examined in the systematic literature review undertaken by the researcher (Nuske et al., 2019) suggested that autistic university students demonstrate a lack of self-awareness of their own difficulties and support needs, contributing to the challenges experienced during their transition to university. The current research challenges this notion and suggests that autistic students did in fact demonstrate self-awareness. For example, when reflecting on their previous university attempts, two students described difficulties and challenges they had experienced, as well as strategies which could support

them in the future. Awareness of individual strengths and weaknesses is not in itself a problem. However, the consistent internalisation of difficulties as personal faults for which the student was responsible to resolve, reflected elements of internalised ableism.

Internalised ableism stems from the broader concept of ableism which prioritises and privileges the “able-bodied”, creating cultural and systemic barriers for those with disability (Campbell, 2009; Campbell, 2019). According to Campbell (2019), ableism is pervasive within our culture, and perpetuates the belief that anything outside of the “norm” should be viewed as unwanted or negative. Internalising these views results in the individual seeing their own disability related challenges as wrong or something to be fixed. For two students, these difficulties appeared to be internalised as personal deficits, referring to them as things they were “not good at” or “could not do” (see Section 8.2.3 for further examples). Gobbo and Shmulsky (2016) identified internalised ableism as one challenge facing autistic university students and suggested that universities can play a significant role in overcoming this challenge by promoting a campus culture of autism acceptance and supporting the development of autistic social networks.

Internalisation of difficulties may also be a reflection of the often hidden nature of autism as a disability, which Cage et al. (2020) suggested can result in students feeling as though they “should be” coping because others perceive them as not looking like they require additional support. The internalisation and negative perspective these students held towards their own experiences was unlikely to contribute to the development of a positive identity or sense of self. It was not until after receiving their formal autism diagnosis that both students were able to reframe these experiences in a more positive light.

Internalised ableism was also reflected in students’ attempts to hide or conceal the difficulties they were experiencing. Two students demonstrated behaviours that appeared to reflect efforts to camouflage or “mask” their difficulties, by hiding them from others or “performing” to overcome these challenges. Shpigelman et al. (2022) noted that students with disabilities, especially students with hidden disabilities, were likely to “conceal or minimise their disability in the academic environment” (p. 1786) in the absence of positive perceptions of disability. They also suggested that a negative perception towards disability as an identity is likely to lead to the development of self-stigma (Shpigelman et al., 2022). This therefore reinforces the importance of positive autistic identity and inclusive campus culture.

While it can be useful for all students to develop self-awareness of their difficulties, internalised ableism can have negative impacts on a person’s health and wellbeing (Jóhannsdóttir et al., 2022). Similarly, studies have shown that masking or camouflaging can

also have negative impacts on mental health and wellbeing (Cage & Troxell-Whitman, 2019; Hull et al., 2017; Miller et al., 2021). Therefore, in addition to ensuring a university culture that accepts and supports autistic students, it is important that students are supported to reflect on their challenges as barriers rather than internalising them as faults. Supporting these actions will require universities to make a shift from the traditional deficit discourse about autism to a focus on dismantling systems of oppression that currently operate within the university space.

11.2.4 Disclosure and Help-seeking

Disclosure has been identified as a significant challenge for autistic university students in several previous studies (Anderson et al., 2017; Cai & Richdale, 2016; Davis et al., 2021; Dymond et al., 2017; Huang et al., 2022; Van Hees et al., 2015). Similar to previous studies (Anderson et al., 2017; Evans et al., 2023; Kim & Crowley, 2021), autistic students in the current research sometimes chose to delay help-seeking or disclosure for a range of reasons including: not seeing disclosure as relevant or necessary, not wanting to be labelled, not knowing support was available, and fear of stigma or negative reactions in response to disclosure. Addressing these concerns will require universities to improve knowledge, understanding, and acceptance of autism for all staff, and ensure an institutional culture that recognises, respects, and accepts difference and diversity.

A previous Australian study conducted by Anderson et al. (2018) found that autistic students who delayed disclosure reported receiving less support than those who did not delay. In addition, students who delayed disclosing were more likely to have withdrawn from a unit of study due to a lack of support (Anderson et al., 2018). University staff in the current research noted that delays in help-seeking were a significant factor which limited the support they could provide to autistic students during their transition to university. Similar to findings by Cai and Richdale (2016), university staff in the current research also noted that some autistic students were likely to delay seeking support until after they had experienced a crisis or when they were already seeking to withdraw from their studies. However, some participants noted that after this period of crisis, students had been able to access much needed support upon returning to their studies. Finding ways to engage autistic students prior to the commencement of their studies may therefore be crucial to avoiding these negative experiences. It is also likely that developing early communication and engagement strategies will support the participation of all students with disabilities, not just those who are autistic.

Several staff and family members described the delay in help-seeking in terms of autistic students being overwhelmed or unable to advocate for themselves, with some suggesting that autistic students would be unlikely to independently seek out support

options. However, to suggest that autistic students are unable or unwilling to advocate for themselves or seek support may be oversimplifying a very complex experience. Accessing Disability Services in higher education requires students to first locate the service, schedule an appointment with a staff member, and ensure they can provide the required supporting documentation for eligibility. Similar to the findings of Cage and Howes (2020) each of these factors posed challenges for autistic students in the current research.

Students identified their delays in help-seeking and disclosure as resulting from not knowing the services were available, not being able to locate the service, or feeling that they were ineligible to access the service without a formal diagnosis. These challenges are not unique to autistic students alone. Previous research has shown that difficulties locating and accessing Disability Services are common for students with a variety of disabilities (Fossey et al., 2017). Students in the current study who had been unable to locate the Disability Services or unable to register with them due to a lack of supporting documentation were consequently unable to access the support that they required during their transition to university. In some cases, this resulted in students withdrawing from their studies. It is therefore important for universities to consider how they promote their services and supports and ensure their services are easy to locate and engage with. Simplifying booking procedures, for example by enabling online booking, may assist in achieving this. In addition, Disability Services should consider how they communicate relevant information to students to ensure they are not inadvertently discouraging students from connecting with them. This may require clarification of what constitutes appropriate supporting documentation, and encouraging those without documentation to contact the Disability Service to discuss more generalised support options that may be available outside of disability specific support. In addition, it is important for universities to ensure that general support options, available to all students, are promoted widely, and that staff who facilitate these supports have the knowledge and understanding to support autistic students and students with other disabilities.

Delays in help-seeking may also be the result of autistic students' need to carefully consider whether they wish to disclose their autism diagnosis. Several students explained that while they were not actively trying to hide their diagnosis, they also recognised potential risks associated with disclosing. These included negative responses or reactions from staff, the potential for stigma, discrimination, and being treated differently to other students, and the potential for someone to use the information to take advantage of them in future. As noted in previous research, disclosing a diagnosis of autism is a complex decision (Botha et al., 2022; Evans et al., 2023; Huang et al., 2022).

The findings of the current research contribute additional qualitative evidence which supports and strengthens previous findings by Evans et al. (2023) who conducted a mixed-methods survey of 74 autistic students from one university in the US, exploring the academic, social, institutional, and environmental challenges they experienced at university. Similar to students in Evans et al.'s (2023) study, autistic students in the current research explained that deciding to disclose involved evaluating and assessing the purpose, benefits, risks, and potential outcome of disclosure. Some students reported only disclosing when it was necessary, for example when seeking a reasonable adjustment for an assessment, which, Cox et al. (2017) described as a "pragmatic approach to disclosing" (p. 78).

Some students also noted that finding the right time or opportunity to disclose was sometimes challenging. For example, one student noted that it would be strange to discuss their diagnosis with someone unprompted, while another student suggested that the right time to disclose had never presented itself. This issue has been previously underexplored in the literature. Further research is needed to investigate autistic experiences of disclosure at university in more detail, to better understand the social and pragmatic barriers to disclosure for autistic university students. In the meantime, Disability Services staff should work with autistic students in the early stages of their degree to develop strategies for disclosing to academic staff. For example, Disability Services staff could scaffold formal disclosure strategies such as emailing the academic staff member at the beginning of the teaching period, by providing example templates or suggested wording.

Students' experiences of disclosure in the current research were mixed. Some reported positive experiences and reactions from academic staff, while others experienced negative responses, including questions regarding their right to support. These responses demonstrated the varied levels of awareness and attitudes of university staff. The response that would be received upon disclosing was also difficult to predict. As a result, students faced the challenge of deciding whether or not to risk disclosing in order to request accommodations or adjustments they require to successfully participate at university. Illustrating this dilemma, in the current research, the disclosure of an autism diagnosis, especially to academic university staff, presented as either a facilitator or barrier depending on the response of the person the student disclosed to. This again reiterates the importance of developing a university environment which is respectful and accepting of autistic students, where they feel safe and confident to disclose their diagnosis. Additionally, it emphasises the interrelationship between disclosure at the individual level, and university policies and campus culture at the exosystem level.

Previous Australian (e.g., Ward & Webster, 2018) and US (e.g., Barnhill, 2016; Dymond et al., 2017; Elias & White, 2017) studies have suggested the need for autistic

students to develop skills in self-advocacy and self-determination. Of note, participants in the three US studies did not include autistic students themselves. In addition, disclosure resources, such as those developed by the National Disability Coordination Officer (NDCO) Program and Western Sydney University, which provide guidance and advice on disclosing a disability during study (Western Sydney University, 2023), focus on the development of self-determination and self-advocacy skills. While the development of these skills may be beneficial, the current research suggests this alone will be insufficient to overcome the challenges autistic students face when deciding to disclose. The current research highlights the importance of systemic strategies which support disclosure, and reinforces recommendations made Nuske et al. (2019) and Anderson et al. (2018) to implement proactive strategies to engage autistic students, simplify the disclosure process, and develop an institutional culture which embraces inclusion and reduces stigma. Improving autism and disability awareness and acceptance on campus have been suggested as important steps to reduce stigma, and create an environment where students feel more confident and comfortable to disclose their diagnosis (Cox et al., 2017; Dwyer et al., 2023; Huang et al., 2022; Schembri-Mutch et al., 2023). Further considerations for university-wide approaches to improving autism awareness and understanding are discussed in more detail in Section 11.5.4.

A students' ability to seek help and proactively manage challenges during their studies is an important contributor to their sense of resourcefulness (Lizzio, 2006). This requires students to demonstrate that they know where to seek help, who to seek help from, and have the help-seeking and advocacy skills to do so. Given the challenges described above, it is evident that the development of this sense of resourcefulness may be challenging for autistic university students, particularly during their transition to, and first year of university. Supporting students to achieve a sense of resourcefulness requires universities to remove potential barriers to support access, by ensuring the support services are accessible and easy to locate, and students are encouraged to seek support in a timely manner (Lizzio, 2006). This appears to be especially important for autistic students during their transition to university. Transition programs and strategies need to consider ways in which they can minimise additional barriers experienced by autistic students such as the need for formal confirmation of their diagnosis before engaging with support services, and reducing the barriers associated with parental support for help seeking. While there may be limitations to the support that Disability Services staff can provide without a formal diagnosis, opportunities to connect students with mainstream supports within the university should be prioritised. In addition, decisions regarding support provision should also be based on the functional impact of the disability. Students with imputed disability, that is a disability which is likely to be impacting on the student's learning but is currently undiagnosed, are already

covered by Australian disability legislation (Australian Government, 2018). By assessing support need based on functional impact, Disability Services staff can ensure that autistic students both with and without a diagnosis are able to seek and access the supports and accommodations they require. This should also be promoted to students so that those who suspect they may be autistic or identify as autistic but do not have a formal diagnosis are able to seek and discuss disability-specific and general services and supports that may be available to them.

11.2.5 Persistence and Resilience

Autistic students demonstrated persistence and resilience, particularly in the ways they overcame significant anxiety and navigated their journey to and through university. The process of adjusting to university is not unique to autistic students. However, students in the current research reflected on their experiences of transition to university as an autistic student as being more challenging than that of their non-autistic peers. Students suggested that their increased levels of anxiety contributed to additional challenges they experienced during the transition period. Anxiety is a well-recognised co-occurring condition for autistic students (Anderson et al., 2019; Lei et al., 2020). Of the students who took part in an Australasian study conducted by Anderson et al. (2019), 68% indicated they had a co-occurring diagnosis of anxiety. Similarly, six of the eight students interviewed for the current research also disclosed anxiety. Additionally, students highlighted the contribution that sensory processing issues, a common characteristic associated with autism, made to their increased levels of anxiety. As such, autistic students highlighted the need for them to overcome anxiety related barriers to successfully engage in their university studies. For some students, this was seen as an additional challenge, beyond that which is experienced by non-autistic students during their transition to university.

For some students in the current research, the anxiety associated with transition resulted in the need for them to take leave from their studies, often choosing to resume their studies later with renewed support and additional strategies to facilitate their return. The impact of anxiety on transition, and the resulting potential for withdrawal is consistent with findings from previous Australian research (Cai & Richdale, 2016), and highlights the importance of autism-specific strategies to support positive and effective transition experiences for autistic students. However, what is notable in the current research is student persistence and motivation to return to their studies despite these challenges.

Previous literature has primarily described autistic students' persistence in relation to their ability to complete their studies and obtain their degree (Anderson et al., 2020; Fabri et al., 2022; Ward & Webster, 2018). The current research adds to this understanding, suggesting that persistence and resilience is also demonstrated by autistic university

students who withdraw or take leave from their studies and then return to complete at a later date. Autistic students in the current research who chose to return to their studies after taking time off often did so with additional knowledge of their strengths and challenges, as well as further insight into their previous difficulties. In addition, some students reported returning to their studies with renewed opportunities to access and engage with supports and services that would enable them to participate successfully. Some autistic students utilised the opportunity to take leave from their studies to undertake personal development and learning, to improve their own skill set and knowledge prior to returning to university for another attempt. Overall, it appeared that withdrawing or taking leave from their studies provided students with positive benefits upon their return, which contrasts with previous research noting that taking time away from their studies may negatively impact on students' self-esteem and opportunities for success (Fabri et al., 2022).

It is important to acknowledge that autistic students who withdraw from their studies may choose to return to university in the future with positive outcomes. As such, university services who are aware of autistic students seeking to withdraw should implement strategies to support or enable autistic students to return to their studies in future, should they wish to do so. For example, ensuring students who withdraw or take leave have a direct point of contact for establishing access to supports should they choose to return.

Persistence and resilience demonstrated by autistic students who withdraw or take leave from their studies and return to study later is a phenomenon that is currently missing from existing literature and warrants further research. Statistics commonly cited in academic literature in reference to the non-completion rates of autistic university students, such as Newman et al. (2011), may not accurately reflect the experiences of these students. According to Newman et al. (2011) only 38% of autistic students in higher education will graduate, but this statistic is based on data collected in the US over 10 years ago between 2001 and 2009, and prior to the revised diagnostic criteria for Autism Spectrum Disorder (DSM-5, 2013). Therefore, this may not reflect the diversity of autistic experiences that exist across universities in the US or internationally today. Additionally, it may not be an accurate reflection of students who leave and return later to complete their studies, or those who withdraw from one degree and transfer to a different degree. Updated data on completion rates, which reflects the variety of completion pathways are needed, to provide a revised picture of current enrolment and completion rates for autistic students in higher education. This would enable universities to make more informed decisions about support practices and strategies to enable the engagement and completion of autistic students.

11.3 Microsystem

The microsystem level of the bioecological theory model consists of elements that directly influence the students' experience of transition to university. Four factors were identified at the microsystem level which could act as facilitators or barriers to transition to university for autistic students. These included: high school transition support; support from family members and support workers; peers and social connections; and university staff. Each of these areas are discussed in more detail in the following sections.

11.3.1 High School Transition Support

While not the primary focus of the current project, a lack of high school transition support created barriers to transition for some autistic students, according to parents who participated in the current research. Similar to the findings of a previous Australian study (Cai & Richdale, 2016), parent participants reported limited or no support from high school staff to prepare or plan for university transition. Parent participants in the current research indicated specific areas that were lacking in the provision of high school transition support. School staff were described as not providing support or guidance regarding university applications, not having the knowledge or expertise to assist with the process of seeking special provisions for university entry, and/or not providing guidance regarding university expectations. Furthermore, some parents reported that high school staff did not see university as an option for their child, and actively advised against it. When support was provided it was described as minimal or unhelpful. The impact of this lack of transition support on the autistic student is unclear; however, family members reported having to undertake much of the transition support planning themselves.

Previous research suggests that a lack of preparation and planning may increase student experiences of anxiety during the transition to university (Nuske et al., 2019). Given the high levels of anxiety already described by autistic students in the current and previous studies, this is likely to create additional barriers for autistic students during their transition to university. As Anderson et al. (2018) highlighted, there are no legal mandates in Australia for high schools to provide transition planning. This contrasts with legislative requirements in other countries such as the US and the UK, where transition planning is mandated by the Individuals with Disabilities Education Act (US) and the Education Act of 1996 (UK). The current research findings provide additional qualitative evidence that reinforces previous findings (Anderson et al., 2018; Cai & Richdale, 2016) regarding the lack of post-secondary transition planning and support in Australian high schools. Consequently, the current research echoes the sentiments of Anderson et al (2018), that legal mandates for transition support in Australian high schools should be considered. Without legal mandates, high

school transition support strategies and programs continue to be optional and are likely to remain inconsistent, and ineffective.

11.3.2 Family Members and Support Workers

Family members play an important role in advocating for and supporting their autistic child during their primary and secondary school years (Boshoff et al., 2016; Widman & Lopez-Reyna, 2020). Consistent with previous findings (Anderson et al., 2020; Mitchell & Beresford, 2014; Peña & Kocur, 2013), the current research suggests family members also play an important role supporting the transition to university for autistic students. However, research exploring the role of parental support for autistic university students remains limited (Widman & Lopez-Reyna, 2020). This is despite extensive research recognising the crucial role of parental support from pre-school to high school (Widman & Lopez-Reyna, 2020). In the current research, support received from family members was described by most students as helpful and appeared to act as a facilitator to positive transition and first year experiences. Support provided by family members (parents) included financial support, practical support, and emotional support, as well as advocacy and support to navigate university services. This is consistent with previous Australasian findings (Anderson et al., 2020; Cai & Richdale, 2016) as well as international studies (Baric et al., 2017; Bell et al., 2017; Dymond et al., 2017; Mitchell & Beresford, 2014; Peña & Kocur, 2013; Van Hees et al., 2015), and highlights the range of roles undertaken by family members when supporting an autistic students' transition to university.

As has been reported previously (Cai & Richdale, 2016), student participants described benefits of family support including feeling emotionally supported, being able to live independently, or having a quiet environment to study in. Similarly, parent participants suggested that their support provided autistic students with the opportunity to participate in university, as well as mental health benefits. While these findings demonstrate potential benefits of family support, there remains a need for further research which explores the perspectives of autistic students in relation to the support provided by family members during the transition to university.

Parents reported challenges providing support due to barriers associated with university expectations of independence and autonomy, and policies and legislation regarding privacy. Barriers associated with balancing autonomy and support needs are discussed further in Section 11.3.2.1 and echo the findings of Cai and Richdale (2016). These challenges highlight the complex interrelationship between elements at the exosystem and microsystem level when supporting transition to university for autistic students.

Only one NDIS funded support worker took part in the current research. Their role appeared to function in a similar way to that of family members. The support worker described providing emotional and practical support for the student they worked with. NDIS funded support workers assisting autistic students during their university studies is a relatively new phenomenon in Australia, with the full implementation of the NDIS across all Australian states and territories only completed in 2020. Guidelines have been developed to support the role of external support workers in Australian higher education settings (Disability Awareness, 2023). These guidelines are a free online resource which informs support workers of their roles and responsibilities and guides them on how best to provide support to students on campus. However, there is a lack of research specifically examining the role that NDIS funded support workers play in supporting autistic students at university. Further research should explore the role, responsibilities, experiences, and challenges of NDIS funded support workers, to enable a better understanding of how they may contribute to the transition to, and first year of university for autistic students. However, it is crucial that universities also recognise that not all autistic students will have access to family or NDIS funded support. As such, while understanding the role of external support members is important, universities must continue to examine ways in which they connect with and support autistic students to develop their independence and autonomy, regardless of the presence of external support.

Overall, family support appeared to facilitate positive transition experiences. However, most support network participants reported challenges providing support for autistic students during their transition to university. For some this was the result of resistance from the student themselves; however, for most, these challenges arose from communication difficulties and barriers which prevented them from engaging with university staff. These challenges are discussed in more detail in Section 11.4.

11.3.2.1 *Balancing Autonomy and Support Need.*

For many autistic students the transition from high school to post-secondary education brings with it an opportunity to develop their independence and work towards future career aspirations (Lambe et al., 2018). However, as support received from family members in post-secondary education settings generally does not align with institutional expectations of student independence (Kim et al., 2021), this may be the first time that autistic students are required to advocate for themselves to access reasonable and necessary adjustments and supports. In addition, university staff appear to expect autistic students to engage autonomously and independently in the same way as their non-autistic peers (Widman & Lopez-Reyna, 2020). However, parents in the current research suggested that this may be an unrealistic expectation for some students during the early stages of their

degree. Therefore, parents found themselves needing to carefully balance the student's need for support with their right to autonomy and independence and university staff expectations that students would engage with them independently.

While some university staff recognised the benefits of family support, others viewed it as a “problem”, suggesting that at times it may be “unwanted” or “unhelpful”. Staff participants who reflected negatively on family support often related this to the need for students to demonstrate independence in an adult learning environment. One participant suggested that the implementation of the NDIS may increase the likelihood of autistic university students accessing external support workers. It was suggested that this support worker role may help to bridge the gap between reliance on family support and development of independence and autonomy. However, the current findings suggest that university staff responses to the external support worker were similar to their responses to family members, with the support worker experiencing many of the same challenges and barriers as family member participants. As such, further research is needed to explore how the role of external NDIS funded support workers may enable the development of independence and autonomy for autistic university students during their transition to, and first year of university. This reiterates the need for research which examines how NDIS funded support workers are currently being engaged to support autistic university students, to determine any existing barriers and potential benefits of this support.

As previously discussed, family members appear to play a significant role in supporting the transition to university for autistic students. However, barriers exist which limit their ability to interact with university staff. The current research reinforces the need for universities to develop new approaches that enable family support while also respecting student autonomy, as previously highlighted in the researcher's systematic literature review (Nuske et al., 2019). The current research suggests that at present this remains to be addressed across Australian universities. In addition to developing strategies for enabling family support, recommendations developed by Dwyer et al. (2023), from the US and Canada, suggested universities should also work towards decreasing the stigma associated with utilising support from family or support workers. However, universities must respect autistic students' preferences regarding family support, including whether or not they wish family members to be involved in supporting them while at university (Dwyer et al., 2023).

11.3.3 Peers and Friends

Students in the current research reported mixed experiences of social connection. Some students found social connection beneficial in supporting them during their transition to university. However, several students reported difficulties making and maintaining connections with their university peers. A study conducted by Lambe et al. (2018) explored

the preparation and hopes of 25 autistic students attending a transition program in the UK. Similar to their findings, several students in the current research discussed their hopes that university would provide them with opportunities to develop social connections. However, students also explained that they had difficulty making and maintaining social connections, leaving them feeling disappointed and isolated. Where students were able to develop peer relationships early in their degree, this acted as an important facilitator for transition. Peers provided autistic students with support to navigate university life, as well as emotional and practical support.

Social connection and belonging have been identified as key factors supporting the retention and success of university students both with and without disabilities (Baczewski et al., 2022; Flegenheimer & Scherf, 2022; Kift, 2009, 2015, 2021; Lizzio, 2006; Pedler et al., 2022). For autistic students, social connection has been found to increase their sense of belonging, decrease anxiety, and contribute to their feeling of adjustment to university (Kim & Crowley, 2021; Kim et al., 2021). Social connection and belonging have also been found to have positive impacts on success and wellbeing for autistic students (Bailey et al., 2020; Fabri et al., 2022). In contrast, limited or superficial social connections are often reported by autistic students who did not complete their degree (Cage et al., 2020), and are related to feelings of loneliness, isolation, worry and distress (Flegenheimer & Scherf, 2022). Yet, both nationally and internationally, social support is generally not considered a reasonable adjustment that universities are required to provide, as it would be considered a personal support need rather than an educational one. In Australia, personal support needs of a more general nature, such as support with the development of social skills, would be funded under the NDIS (Nuske et al., In press). Given the challenges experienced by students in the current research there is a need for universities to consider implementing further strategies to support social inclusion.

Difficulties with social adjustment at university are not unique to autistic students; however, they may experience additional social-communication difficulties compared to their non-autistic peers, which make their experiences more challenging (Flegenheimer & Scherf, 2022). Social-communication difficulties are a core characteristic of an autism diagnosis (American Psychiatric Association, 2013) and have been identified by autistic students as potential barriers to social connection at university (Goddard & Cook, 2022). However, as Cage and Howes (2020) highlighted, establishing social connections should not be solely the responsibility of autistic students. While providing opportunities for social connection is important, universities should also consider how they can improve autistic students' sense of social connection and belonging by creating campus environments where autistic students feel safe and included.

Previous research has identified a range of strategies to support social inclusion and participation for autistic students, which are particularly relevant during the transition to university. These strategies include peer mentoring (Duerksen et al., 2021), structured social activities (Flegenheimer & Scherf, 2022; Kim & Crowley, 2021; Lambe et al., 2018), support groups (Evans et al., 2023; Widman & Lopez-Reyna, 2020) and autism/sensory-friendly spaces on campus (Sarrett, 2018). Participants in the current research suggested additional strategies such as autism-specific social groups, structured orientation programs and activities, and disability-friendly study spaces on campus. These strategies may provide opportunities for autistic students to develop social connections in a safe and autism-friendly environment, with the potential to improve their social and academic experiences. These findings again highlight the importance of understanding the interrelationships between various elements at each of the bioecological theory model levels. While social skill development may assist students to develop connections with peers and friends, it is likely to be more successful in a campus environment that promotes inclusion and facilitates opportunities for connection with other neurodivergent students.

11.3.4 University Staff, Support and Resources

Access to university staff and support had the potential to act as either a facilitator or barrier to university transition depending on the experience of the student. This supports findings of previous studies conducted in the US (Evans et al., 2023; Kim & Crowley, 2021), in that students in the current research reported varied experiences engaging and interacting with university staff or accessing university support services. Negative experiences with university staff, and delays in accessing university support were also reported and created barriers to transition. However, positive experiences with university staff members acted as facilitators for some students, by motivating them to engage and providing a safe space for them to participate. Positive experiences with university staff, were generally associated with the provision of emotional, practical, and academic support.

Parents and university staff emphasised the importance of early access to university supports, such as those provided by Disability Services. Where autistic students had difficulties accessing university supports and services within the early stages of their transition, this was noted by staff participants as a potential barrier to successful transition. When students were able to connect with supports in the early stages of or prior to commencing their studies, staff felt this acted as a facilitator to successful transition. It may be beneficial for autistic students to connect with Disability Services staff prior to commencing their undergraduate studies. However, given the lack of transition planning and preparation provided by high schools, as reported in this and previous studies (Anderson et al., 2018; Cai & Richdale, 2016), this may be difficult to implement. These findings reiterate

the importance of effective transition planning processes or programs from high school to university. However, the current research also reinforces that not all autistic students will transition to university directly from high school. Therefore, universities must also consider mechanisms and processes which will enable early contact and engagement with mature-age autistic students to support their transition to university.

The current research reinforces findings from previous studies, both nationally (Cai & Richdale, 2016; Fossey et al., 2017) and internationally (e.g., Cage et al., 2020; Sarrett, 2018; Thomas, 2020), that highlight the challenges autistic students, and students with other disabilities, can experience when interacting with university staff. Student participants highlighted the difficulties they had accessing Disability Services support, with some indicating that they were unaware of the support available, unable to access support without a diagnosis, or experienced delays in being able to meet with staff. This echoes findings from previous research in which students with disabilities were reported to have been unaware of the disability support available (Fossey et al., 2017) or found the process of accessing support challenging (Fossey et al., 2017; Thomas, 2020). Similarly, students reported difficulties engaging with academic staff, particularly if they were slow to respond to emails, or reacted negatively to the student's request for accommodations or support. This suggests that little may have changed in nearly 10 years, with similar issues reported previously by higher education students in Victoria, Australia (Cai & Richdale, 2016; Richdale et al., 2012). Students also described challenges engaging with casual academic staff (e.g., tutors), and indicated that they felt casual staff had a lack of understanding of autism, or disability in general. However, they also recognised the challenges for casual staff regarding workload expectations and availability.

Given the challenges autistic students experience with the adjustment to university and the development of new relationships, it is possible that autistic students may initially require additional time and resources from Disability Services, beyond that provided to students with other disabilities. In addition, University staff noted challenges in providing support during the transition to university for autistic students, including difficulty finding adequate time to build rapport with students, and challenges resulting from limited staffing and resources. This may suggest a need to review current funding levels for university Disability Services to ensure staff are able to provide appropriate and effective support not only for autistic students, but for all students with disability. Concerns regarding staffing and funding of Disability Services in Australian universities have been highlighted previously (Cai & Richdale, 2016). In addition, previous research has identified variability in funding allocation across universities, and noted that insufficient resourcing has the potential to impact on the study experiences of all students with disability, not just those who are autistic (Kilpatrick et al., 2017). Further research is needed to explore this more closely, to ensure

that support requirements are adequately reflected in funding allocations. In addition, the development of best practice guidelines for supporting autistic students during the transition to and first year of university, similar to those developed by the Autism&Uni research initiative (Autism&Uni, 2014; Fabri, 2016) may assist in providing consistency across Australian Disability Services. The best practice guides available through the Autism&Uni website highlight and promote best practice strategies to support autistic students in higher education and could be adapted to the Australian university context. However, despite the fact these resources were published in 2016, research exploring the efficacy of these best practice guides is currently unavailable, and further research which evaluates the benefits and outcomes of using such resources is needed.

Staff participants also highlighted the importance of university-based support continuing beyond the first year of university, reflecting autistic students' often varied pathways through their first year of university and beyond. The need for support beyond the first year of university is not unique to autistic students, in fact several Australian university institutions who took part in a study conducted by Kilpatrick et al. (2017) discussed the importance of providing support to students with disabilities "at all stages of their student journey" (p.755). However, one staff participant in the current study noted having to fight against the university expectations that autistic students would not require peer-mentoring or other relevant supports beyond their first year of studies.

Building on previous Australasian (Anderson et al., 2020), US (Accardo et al., 2019; Thomas, 2020) and UK (Fabri et al., 2022; Gurbuz et al., 2019) studies, the current research highlights the importance of university staff knowledge and understanding of autism at all levels, and the impact a lack of understanding has on autistic students during their transition to, and first year of university. By exploring transition experiences using the bioecological theory model framework this research demonstrates the relationship between student experiences of support from staff, and the need for systemic and cultural changes to improve knowledge and understanding of autism for all university staff. Systemic and cultural factors which impact on transition to university for autistic students are discussed in more detail in Section 11.5 and 11.6.

Lizzio (2006) suggested that a strong sense of purpose is an important contributor to student success as it enables students to see the relevance behind the content being taught and develop a sense of engagement and connection with their chosen discipline. According to Larsen et al. (2020) students who can identify role models they relate to in university are more likely to develop a stronger sense of purpose as described by Lizzio in the Five Senses model (Lizzio, 2006). However, openly autistic academic role models may not be easy for students to find. Research suggests that while autistic academics exist within a wide range

of disciplines, many are hesitant to disclose for fear of experiencing stigma and prejudice (Farahar & Foster, 2021). Therefore, to support autistic students' sense of purpose it is also important that universities implement strategies to improve campus culture and autism acceptance which will not only support students but may also increase the likelihood of autistic academics disclosing. Universities may also need to consider how they can support autistic students to establish connections with other autistic role models through autism-specific peer mentoring programs and other peer-to-peer social groups and opportunities. These are discussed in more detail in Section 11.5.2.2.

11.4 Mesosystem

The mesosystem component within the bioecological theory model encompasses interactions between microsystem elements, such as professional and academic university staff, family members, or Disability Services staff members. At the mesosystem level, students reported limited interactions between members of their support network. However, support network participants suggested that effective interactions between themselves and university staff may have facilitated more successful transition experiences for the students they supported. As introduced in Section 11.3.2, family members reported barriers which limited or inhibited communication and interaction with university staff. Parents reported that these barriers limited the support they could provide to their child. In addition, some Disability Services staff also noted challenges communicating and engaging with academic staff which resulted in additional barriers for autistic students during their transition.

Support network participants indicated that they were prevented or actively discouraged from communicating with university staff. Some parent participants described their attempts to interact with university staff as disempowering, confusing and overwhelming. Similar to previous Australian and US research (Anderson et al., 2018; Cai & Richdale, 2016; Dymond et al., 2017; Peña & Kocur, 2013), barriers experienced were commonly associated with privacy legislation, along with university expectations of students as independent adult learners. These institutional and legal barriers are discussed in more detail in Section 11.5. While most parents reported challenges interacting with university staff, there were some examples of positive interactions between family members and university staff. For example, where interactions between family and staff were expected and, in some situations, encouraged. This suggests that there may be increasing awareness of the need for mechanisms which support family involvement, since the publication of the researcher's systematic literature review (Nuske et al., 2019). Further work still needs to be done to enable the interactions between family members of autistic students and university staff, during the transition period. There is a continued need for universities to explore ways in which they can improve collaboration between support network members and university

staff to support autistic students, particularly during the already challenging and complex experience of transition to university.

Strategies implemented to support interactions between support network members and university staff must uphold the legal requirements for privacy and confidentiality, and the student's right to autonomy and self-determination. Privacy concerns can be addressed by seeking student permission for this communication to occur. It was unclear in the current research whether students had provided permission for direct contact between support network members and university staff. The opportunity for students to provide this permission should be implicitly discussed with all autistic students, and students with other disabilities, during their initial interactions with Disability Services staff, with associated benefits and challenges clearly outlined. Students should also be provided with the option and mechanisms to withdraw this permission at any stage during their studies should they wish to do so.

While previous research has identified challenges for family members attempting to interact with university staff (Nuske et al., 2019), limited research has examined the communication barriers that exist between Disability Services staff and academic staff when supporting autistic university students. Disability Services staff in the current research described challenges they experienced communicating with other university staff, particularly academic staff; suggesting that academic staff were often too busy or were unavailable for direct communication. This resulted in students having to rely on the information outlined in their access plan to articulate their needs. Access plans are the primary method of communicating the support needs of students with disabilities, including autistic students, to academic staff within Australian universities (Kilpatrick et al., 2017). However, research exploring the effectiveness of these documents and the need for additional communication strategies between professional and academic staff is lacking. This is particularly concerning given descriptions from academic staff and students in the current research that access plans often do not include an indication of diagnosis and are often described as general or "vague" in nature. However, Disability Services staff should carefully consider the benefits and risks of including a diagnostic label such as autism on a student's access plan. For example, disclosing an autism diagnosis may not be advisable on a campus where staff knowledge, understanding and acceptance of autism is low. Research both nationally and internationally suggests that students are likely to avoid disclosing their diagnosis if they fear experiencing stigma or discrimination (Anderson et al., 2017; Evans et al., 2023; Huang et al., 2022; Schembri-Mutch et al., 2023). This therefore highlights the importance of developing an inclusive university campus, where all staff demonstrate knowledge, understanding and acceptance of autism.

Reasons for the lack of communication between academic and Disability Services staff in the current research were not provided; however, previous research, both nationally and internationally, has suggested that inadequate staffing of Disability Services may contribute to these challenges (Cai & Richdale, 2016; Kim & Crowley, 2021). Previous research has also suggested that communication difficulties between Disability Services staff and academic staff results in negative experiences for autistic students, who feel unsupported with their studies (Kim & Crowley, 2021). Further research is needed to identify strategies that can support effective communication between Disability Services staff and academic staff. This is particularly important given reports in the current research and previous studies (Clouder et al., 2020; Sarrett, 2018) of inconsistencies in implementation of academic accommodations and supports for autistic university students.

Consistent with findings from one UK study (Knott & Taylor, 2014) two academic staff participants in the current study suggested that including the student's autism diagnosis on their access plan would assist staff to provide autistic students with better support. With student permission, access plans could provide more specific information. It may be beneficial for Disability Services staff to discuss with autistic students the benefits of providing more specific and detailed information or including disclosure of their diagnosis on their access plan, to provide context to information that has been described as otherwise "vague". Students should be provided with clear information as to the pros and cons of disclosure to ensure they are able to make an informed decision about this option. Research to investigate the experiences of students who do choose to include their autism diagnosis on their access plans may also be beneficial. In addition, further research is needed which examines the purpose, use, and effectiveness of access plans and similar documentation, not only for autistic university students, but for university students with disability more broadly, to ensure these documents are supporting their transition and participation.

University staff participants in the current research also recognised the need for whole-of-university strategies to support communication and improve support for autistic students during their transition. Suggestions highlighted the need for autism-specific training, and broader disability awareness training to improve staff understanding and knowledge of autism. Addressing these issues requires a systemic approach to cultural change which is discussed in more detail in Section 11.5.

11.5 Exosystem

The exosystem level of the bioecological theory model encompasses systemic factors, such as state and national legislation and institutional policies and practices, that may influence the students' experience. At this level, the current research identified

institutional policies, expectations, programs, and practices as potential facilitators and/or barriers to transition. Institutional policies that prevented communication and interaction of family members with university staff acted as barriers to transition. Institutional programs had the potential to facilitate the transition to university for some autistic students. Staff understanding of autism was also an important factor which could support or hinder the transition to university for autistic students. Finally, the implementation of UDL principles across all university courses may address help-seeking and disclosure challenges faced by autistic students.

11.5.1 Institutional Policies and Expectations

As highlighted in Section 11.4, family members experienced challenges engaging with university staff which were the result of institutional expectations of independence and autonomy of university students. Requirements for students to independently seek and engage with support are underpinned by university policies and government privacy legislation, which are often referenced as the rationale for these expectations. Previous research has highlighted the importance of developing and implementing policies and procedures which enable collaboration between all members of the students' support network, including family members and university staff (Nuske et al., 2019). In the current research, most family members reported difficulties communicating with university staff, although it was unclear whether their child had provided permission for this to occur. One parent reported that they were able to engage directly with the coordinator of the university's peer mentoring program to support their autistic child, due to their son having provided permission for them to do so. However, it should be noted that permission for the family member and mentoring coordinator to have direct contact was a condition of the student's participation in the program.

Further research is needed to explore existing policies and practices which facilitate family support for autistic students during their transition to university. This research may provide a much-needed evidence base for the development of policies and practices which can support family involvement while also recognising and respecting students' rights to autonomy and independence.

11.5.2 University Programs

Several university programs, such as orientation and peer mentoring programs, as well as the implementation of autism-friendly spaces on campus, were highlighted as potential factors which may facilitate the transition to university for autistic students. However, at present it appears these programs are inconsistently implemented across universities, and students report mixed experiences of engaging with them.

11.5.2.1 *Orientation Programs.*

Orientation programs in Australian universities are typically held the week before classes formally commence. Program activities range from academic skill development workshops to social events and aim to support students' development of social connections and a sense of belonging; both of which play an important role in the engagement and retention of university students (Kift, 2009). Research exploring the experiences of autistic students during these programs is limited, and students in the current research described mixed experiences of their university's orientation program. Similar to findings from Lambe et al. (2018), some students found their university's orientation program challenging to attend and were unable to participate in the orientation activities offered. Barriers to participation and inclusion of autistic students at orientation events included: unclear expectations, lack of structure, and sensory overwhelm due to noise and crowds. Similarly, previous Australian (Anderson et al., 2020) and UK (Goddard & Cook, 2022) research into autistic students' experiences in higher education has identified orientation-style programs as being unhelpful, overwhelming and noisy. If orientation programs are inaccessible for autistic students this may present a barrier not only to participation in the orientation program itself, but potentially to a students' feeling of connection, inclusion, and belonging within the university.

Facilitating social connection has been found to improve students' transition and adjustment to university (Flegenheimer & Scherf, 2022; Kift, 2009). One factor which appeared to facilitate the development of peer connections during orientation programs was the inclusion of structured and organised activities, supporting the development of peer connections with other students from the same degree. This is consistent with previous research (Davis et al., 2021; Lambe et al., 2018) suggesting that, to support the development of peer connections early in their degree, autistic students prefer structured social opportunities which are directly facilitated by staff. Structured orientation activities, which take place away from the central, busy, campus orientation programs, may provide an effective opportunity for autistic students to develop peer relationships. Given the difficulties accessing and engaging with orientation programs described by students in the current research and previous studies (Goddard & Cook, 2022; Lambe et al., 2018), holding these activities in quieter, autism-friendly locations, on or off campus, may also ensure they are inclusive and accessible for autistic students. However, it is important to recognise that not all autistic students are seeking social connections when they transition to university (Anderson et al., 2020; Flegenheimer & Scherf, 2022). Therefore, universities should provide the opportunity for social connection for those who wish to meet other students, while recognising that this opportunity may not be taken up by all autistic students.

Participation in formal orientation programs and activities also provides important opportunities for autistic and non-autistic students to interact and get to know one another. Opportunities such as this have the added benefit of potentially increasing awareness, acceptance and positive perceptions of autistic university students by non-autistic peers and university staff and may help to reduce prejudice and stereotyped perspectives of autistic university students (White et al., 2019). For this to occur, universities would need to develop inclusive and welcoming spaces where autistic students feel comfortable and safe to disclose their diagnosis. In addition, it would require the implementation of strategies and practices which enable access to orientation activities for autistic students. For example, by providing safe, autism-friendly spaces (discussed further in Section 11.5.3) for students to utilise if overwhelmed; communicating clear instructions and providing accurate details regarding time, location and expectations for each activity or event; and/or providing a peer mentor to support the student during orientation program activities.

Challenges associated with participation in orientation programs are likely to negatively impact on autistic students' sense of connectedness. According to Lizzio (2006), students with a strong sense of connectedness are more likely to be successful as learners. Current participants described challenges of autistic students in accessing and participating in transition-based activities such as orientation programs, due to sensory overwhelm, anxiety, and a lack of clarity around expectations and activities. Only one autistic student described a positive orientation program experience, and this played a significant role in future engagement through the establishment of social connections with peers. Highlighting the potential for orientation programs to play a significant role in the development of social connection and sense of connectedness. However, for orientation programs to function as a facilitator to successful transition to university for autistic students they must be accessible for autistic students to attend. This will require universities to consider mechanisms to support the inclusion of autistic students, such as the implementation of autism-friendly spaces (discussed further in Section 11.5.3) and peer or buddy support, as well as ensuring activities are structured and relevant information is clearly communicated to all students.

11.5.2.2 *Peer Mentoring Programs.*

Autism-specific peer mentoring programs currently exist within a number of Australian universities seeking to support the transition to university for autistic students. However, research supporting the efficacy of peer-mentoring programs to support autistic university students is still limited (Duerksen et al., 2021; Morris et al., 2022). Students in the current research described mixed experiences of peer mentoring programs. Some students found participation in such programs helpful, while others noted limitations to the types of support available or chose not to take part as they did not feel it would be appropriate for

them. In contrast to students' descriptions, staff accounts of peer mentoring programs were mostly positive, citing the benefits they saw such as students' development of confidence and independence. The current findings highlight the importance of individualised and person-centred support, as autism-specific peer mentoring programs may not be appropriate or welcomed by all autistic students. It also highlights the need for further research to examine the benefits of autism-specific peer mentoring programs, particularly from the perspectives of autistic students themselves.

For some students, their experience of peer mentoring programs appeared to be directly linked to the mentors engaged to provide the support. One student noted that their experience of peer mentoring was dependent on the mentor they were paired with, while another student raised concerns that the mentors may not be adequately trained or informed to support autistic students. In addition, participants reported that peer mentors were usually non-autistic, final-year, or graduate students, often from discipline areas such as psychology or allied health. Only one university appeared to be facilitating autistic mentees to develop their skills to take on mentor roles for commencing students. University staff who described autism-specific peer mentoring programs implemented within their university indicated that mentors were provided with specific training regarding autism; however, details were not provided about the type, length, or content of the training. Other than providing initial training and support for mentors, it was also unclear how autism-specific mentoring programs differed from general university-wide mentoring programs. Further research comparing autism-specific peer mentoring programs with general university-wide peer mentoring programs is warranted, to better understand what differentiates autism-specific mentoring programs from more general programs. Additionally, the findings from the current research have highlighted the importance of inclusive practices and the development of a university-wide understanding and acceptance of autism. The implementation of autism-specific peer mentoring programs may be seen as working in opposition to this goal, again reinforcing the importance of research which compares autism-specific peer mentoring programs with general university-wide mentoring programs available to all students, to determine whether there are particular benefits of autism-specific programs. Alternatively, universities may need to consider how they could adapt existing peer mentoring programs to be more inclusive for autistic students.

Autism-specific peer mentoring programs primarily focus on academic and social skill development (Duerksen et al., 2021; Morris et al., 2022). A novel finding of the current research, that requires further exploration is the potential for autism-specific peer mentoring programs to provide opportunities for autistic students to establish and develop their autistic identity as a university student. Findings from the current research have highlighted the importance of identity and sense of self for autistic students during their transition to, and

first year of university (see Section 11.2.2). As noted previously, the development of a positive sense of identity and self may contribute to positive transition experiences and success at university (Kift, 2015, 2021; Lizzio, 2011). As such, strategies which support the development of autistic identity may be beneficial in supporting the transition to, and first year of university for autistic students. Autism-specific peer mentoring programs which encourage and support autistic students to act as mentors for autistic mentees have the potential to provide an opportunity for autistic identity development through social connection and interaction with other autistic university students (Gobbo & Shmulsky, 2016). The current findings build upon the research of Gobbo and Shmulsky (2016), by providing qualitative research evidence to support their recommendations. Future research exploring opportunities for development of autistic sense of self and identity through the implementation autism-specific peer mentoring programs is needed to determine potential benefits for transition to, and participation in university.

The current research also adds to the existing literature by highlighting the resourcing and funding challenges that autism-specific peer mentoring programs are currently facing. The challenges of resourcing these types of programs have been previously highlighted by Kilpatrick et al. (2017) in their study examining the retention and success of students with disabilities in Australian higher education. University staff participants in the current research discussed the funding and resources required to develop, implement, and maintain these programs, including the resources required to adequately train and support specialist mentors. Some of the programs discussed by participants in the current research had also reached their intake capacity, with students being allocated to waitlists until support becomes available. Given the identified purpose of these programs is to support effective transition to university, delays accessing support are not ideal. Where autism-specific peer mentoring programs had reached capacity, alternative peer-to-peer support opportunities, such as social groups, were identified as providing similar benefits to peer mentoring programs; however, there is a lack of research evidence to support this. Future research is needed to explore the efficacy, as well as the sustainability of autism-specific peer mentoring programs, to determine whether and how funding should be made available to support the implementation of these programs. In addition, further research should explore autistic-led social groups to determine if these may be an effective and beneficial alternative or addition to autism-specific peer mentoring programs.

11.5.3 Autism-Friendly Spaces

Autism-friendly spaces on campus, such as quiet rooms or spaces designed to meet the sensory needs of autistic students, not only provide an opportunity for autistic students to escape the sensory demands of the university campus (Anderson et al., 2019; Anderson et

al., 2020), but they can also provide spaces for autistic students to meet and connect socially (Farahar, 2022; Sarrett, 2018). Social connection within autism-friendly spaces can enable students to discuss their challenges and concerns with students who have had similar experiences (Sarrett, 2018). In addition, these spaces have the potential to provide opportunities for autistic students to explore and develop their own autistic identity (Farahar, 2022). Staff participants in the current research highlighted the importance of autism-friendly spaces on campus to support the needs of autistic students. Student participants did not discuss autism-friendly spaces on campus specifically; however, one student did describe their experience of having access to a disability-specific room on campus. For this student, the space provided not only a safe study area but also an environment where she was able to develop peer relationships.

Sensory processing difficulties were identified by several students and often linked to feelings of anxiety, which impacted on students' experiences of transition to university. Student participants described a range of sensory processing challenges they faced when attending their university campus, similar to those identified in a previous Australian study by Cai and Richdale (2016), including: the busyness and noise of their university campus; the sensory overwhelm experienced in crowded classrooms; and the busyness and noise of the surrounding environment (e.g., central business district) within which their university campus was located. For some students, sensory challenges were compounded by the need to travel to campus using public transport, which can also be noisy and crowded. Having an autism-friendly space on campus, which has been designed with the sensory needs of autistic students in mind, can provide somewhere for students to retreat to, to manage this sensory overwhelm (Dwyer et al., 2023; Sarrett, 2018; Shea & Derry, 2019).

Further research is needed to explore the benefits of autism-friendly spaces on campus, and the potential cost and resourcing involved to implement these spaces. Research exploring the implementation of autism-friendly spaces on campus is emerging, and exploration of the design and implementation of such spaces was beyond the scope of the current research. However, it may be beneficial for universities to consider implementation of autism-friendly spaces on campus, to create more inclusive campuses for autistic students. Universities should also ensure that commencing autistic students are made aware of any autistic or disability spaces on campus which can provide them with a safe environment to manage their sensory and social needs.

11.5.4 Understanding of Autism

Previous research has highlighted the need for improved awareness, acceptance and understanding of autism in the university setting both in Australia and internationally (Anderson et al., 2020; Davis et al., 2021; Kim & Crowley, 2021; MacLennan et al., 2022;

Sarrett, 2018; Thomas, 2020). To achieve this, researchers have suggested the implementation of training and workshops for staff across all university roles, both academic and professional (Anderson et al., 2020; Gillespie-Lynch et al., 2021; Sarrett, 2018).

The current research demonstrates there is still a need to improve university staff understanding of autism. Disability Services staff in the current study described experiences where academic staff members had questioned an autistic student's need or eligibility for support. Similarly, students noted that some staff members did not appear to recognise their entitlement to reasonable adjustments or support, with some students opting not to disclose for fear of experiencing stigma or other negative responses. This may not be specific to autistic students (Osborne, 2019). However, previous research suggests these challenges are particularly evident for students with "invisible" or "hidden" disabilities such as autism (Moriña, 2015; Moriña, 2017).

Without an appropriate knowledge and understanding of autism, research suggests university staff rely on inaccurate assumptions, and stereotypes when engaging with autistic students (Kim & Crowley, 2021). However, simply providing generic training on autism, which focuses on the causes, characteristics and behaviours of autistic people rather than the experiences and needs of the students themselves, is not enough to challenge existing stereotypes, myths and misconceptions of autism (Fabri et al., 2022). Training is needed which expands on, and potentially challenges, the traditional understanding of autism as a behavioural condition, based on medicalised and pathologizing views of autistic characteristics. Doing so will assist in developing an acceptance and understanding of autism, which acknowledges the diversity of autistic experiences. Autism training and additional resources supporting staff understanding of autism should be created and delivered in consultation and collaboration with autistic people (Dwyer et al., 2023; Farahar & Foster, 2021; Gillespie-Lynch et al., 2022), and address not only functional difficulties experienced by autistic students, but also factors such as stigma, identity, and culture (Dwyer et al., 2023). In addition, there is a need for resources and training which support a strengths-based approach to autism. For example, La Trobe university in Australia have developed a neurodiversity toolkit which supports higher education staff to understand the needs of neurodivergent students and ways to develop inclusive spaces and events which support the participation of autistic and other neurodivergent students (Redulski, 2020). The resources promote an understanding of neurodiversity from a culturally sensitive, strengths-based perspective, which supports inclusion and acceptance of neurodivergent students across the university.

11.5.5 Universal Design for Learning

Universal Design for Learning (UDL; CAST, 2015) is a framework that supports the learning of all students, not just those with disabilities, by ensuring that teaching and learning resources are designed with a range of diverse learning needs in mind (Cumming & Rose, 2022). The principles of UDL promote the use of teaching and learning resources which enable multiple means of engagement, representation and action and expression (CAST, 2015). Implementing these principles provides students with multiple ways to engage and participate in their learning and to demonstrate their knowledge and understanding of the concepts learnt (CAST, 2015). As such, this enables all students to participate in ways that best suit their learning needs, without requiring individualised adjustments or accommodations (Cumming & Rose, 2022).

Current systemic mechanisms for accessing support, both in Australia and internationally, put the onus on autistic students to request support on an individual basis and situate the student as a problem which requires fixing (Fabri et al., 2022). Autistic students may require individual adjustments and accommodations to enable them to participate on the same basis as their peers. However, given the challenges identified by participants in the current study when seeking, accessing, and negotiating adjustments, there is a need for universities to explore strategies to improve inclusion and participation for autistic students, and students with disabilities in general, without the need for repeated disclosure to request individual adjustments. Research suggests that the use of UDL principles may be one strategy that will address this need (Cumming & Rose, 2022). For example, Clouder et al. (2020) suggested strategies consistent with UDL principles such as lecture recording, providing materials in alternative formats, access to materials prior to class, and the use of technology in classrooms may be beneficial for neurodivergent students, while also highlighting the benefits of these strategies for all students. Implementing these strategies for all students will reduce the need for autistic students to request these types of adjustments as individual arrangements. Implementing UDL principles in teaching and learning will also ensure that students who are undiagnosed or awaiting a diagnosis are not unnecessarily disadvantaged (Anderson et al., 2018), while also enabling the learning of students with other disabilities or neurodivergence. Thus, implementing UDL principles not only meets the needs of autistic students, but all students (Cage & Howes, 2020).

UDL has also been found to improve students' engagement and capacity to participate in their learning (Cumming & Rose, 2022). However, Cumming and Rose (2022) found that some staff have concerns over the time taken to implement UDL and the impact on student attendance, which created a barrier to effective UDL implementation. There is

therefore a need for further staff training and development to address these concerns (Cumming & Rose, 2022). Therefore, alongside training and development to improve university staff understanding of autism, universities should provide training and resources to support staff to develop and implement teaching and learning tools informed by UDL principles to support not only autistic students, but all students.

11.6 Macrosystem

The macrosystem level of the bioecological theory model consists of social and cultural elements that may influence the students' experience of transition to university. At this level, the current research identified societal understanding, myths, and misconceptions of autism, along with knowledge and awareness of disability legislation as factors which may impact on students' experiences of transition. Research suggests that while most people have heard of autism, understanding and knowledge about autism varies (Jones et al., 2021). This appeared to be the case in the current research, as students described mixed understanding of autism demonstrated by university staff. Students suggested that some staff demonstrated negative attitudes towards autism, which they felt was based on existing societal stereotypes and negative perceptions and assumptions associated with autism. This echoes previous findings which suggest that societal views about autism impact on people's attitudes towards autism (Kuzminski et al., 2019). Therefore, alongside strategies to improve knowledge and understanding of autism at the university level, there is a need for broader systemic reform that address existing stigma and misconceptions about autism. The findings of the current research build upon existing research by Turnock et al. (2022) into autistic people's experiences of stigma, which highlighted the need for cultural and systemic shifts towards inclusivity to reduce stigma towards autistic people and their families. Research also suggests that stigma and negative attitudes towards autism can be improved through the adoption and implementation of identity-first language, and adoption of neurodiversity model approaches to autism, which recognise autism as a variation in human diversity rather than a deficit or condition to be fixed (Walker, 2021).

At the time of completion of this thesis the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (October, 2023) handed down its final report. The Royal Commission was established in April 2019, and collected evidence and testimonies from almost 10,000 Australians, who shared their experience of violence, abuse, neglect, and exploitation. The final report outlined 222 recommendations to ensure a more inclusive Australia, through changes to laws, policies, systemic structures, and practices. The recommendations outlined in the report have the potential to impact macrosystem level elements which can influence not only the experiences of autistic students in higher education, but students with other disabilities as well. The final report highlights the

importance of improving inclusivity, and promoting a human rights approach, which recognises the rights of people with disability as articulated in the UNCRPD. Implementation of the recommendations outlined in the final report will hopefully contribute to wider understanding, knowledge, and acceptance of people with disability, including autistic people, across Australia.

In Australia, people with disability are protected from discrimination or harassment under the DDA (Australian Government, 2018). This legislation applies to people with disability of all ages, and within the educational context, protects students from discrimination or harassment on the basis of their disability. Clarification of the requirements within the DDA as they apply to educational settings is set out in the DSE (Australian Government, 2005). Several students in the current research had heard of the DDA or DSE. Students who were aware of the legislation or standards generally indicated that they knew such legislation existed but were not familiar with the details or how it applied to their experiences at university. Family members reported similar levels of familiarity and awareness of the DDA and DSE. As a result, students and family members who are unfamiliar with the legislation and standards may not be aware of their rights and responsibilities under them. The DDA and DSE work together to address social barriers to participation; however, they do not mandate disability rights or ensure access to support (Nuske et al., In press). Instead, the current legislation places the onus on the student to provide evidence that their support needs are both reasonable and necessary (Nuske et al., In press). Existing legislation also requires any person with disability seeking to pursue a complaint of discrimination to possess the knowledge, capability, and personal resources to do so (Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability, 2023). While it was beyond the scope of this research project, there may be a need for students and family members to be supported to better understand the rights and responsibilities of students under the DDA and DSE in preparation for their transition to university. Strategies for addressing this are discussed further in Section 12.5.2.

Issues relating to the effectiveness and coverage of the current DDA have been highlighted in the final report by the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability (2023). The recommendations set out in the report include the development and implementation of a Disability Rights Act which would translate the rights human rights of people with disabilities into Australian law. It is recommended that the Disability Rights Act provides clear, proactive guidelines and legislative protections for people with disability. The introduction of a Disability Rights Act, alongside existing disability discrimination legislation in Australia, can be seen as promoting a significant shift in cultural and societal attitudes towards people with disability. A proactive approach to disability rights may also work to reduce the burden on people with disabilities and their families to

familiarise themselves with numerous legislative frameworks. It will instead shift the responsibility to organisations, including universities, to make proactive efforts to protect the rights and improve the inclusion of people with disability.

The recommendations outlined in the Royal Commission's final report, if implemented, have the potential to significantly influence cultural views of disability and inclusion in Australia. While these recommendations and associated strategies may improve the awareness and understanding of disability more broadly, there remains a need to improve broader societal understanding of the specific issues and needs of autistic people and their families. In recent years, the Australian government has recognised the need for strategies which address the needs of autistic people and their families specifically. The Australian Government and South Australian Government have committed to the development and implementation of National and State autism strategies, which aim to improve the lives of autistic people of all ages. Autism-specific strategies and legislation have also been implemented in the UK (UK Government, 2009, 2021) and US (Interagency Autism Coordinating Committee [IACC], 2023; US Government, 2019), with development of similar policy drivers also underway in Canada (Government of Canada, 2023; Parliament of Canada, 2023) and Ireland (Department of Children, Equality, Disability, Integration and Youth, 2023). These national level strategies have the potential to contribute to increased understanding and acceptance of autism at the broader societal level, whilst also highlighting the individual and unique needs and issues experienced by autistic people and their families.

Although not specifically discussed by all participants, there was evidence that societal and cultural attitudes towards autism may influence the ways in which staff interact with and support autistic students during their transition to university. The implementation of strategies which promote the human rights of people with disabilities and address the needs of autistic people and their families may contribute to improvements in societal and cultural understanding and acceptance.

11.7 Chapter Summary

This chapter has presented a discussion of the findings of the research in the context of existing literature. The current research highlights a range of individual, systemic, and cultural factors which can act as facilitators and/or barriers to transition to university for autistic students. Positioned within the context of the broader widening participation agenda, which focuses on increasing the inclusion of students from non-traditional backgrounds within higher education, the current research has demonstrated the need for strategies and supports that recognise and address the interrelated nature of these factors.

Although there may be a need for autistic students to develop specific skills in preparation for and during their transition to university, it will not be sufficient for universities to solely support the development of individual skills without consideration of wider systemic improvements. Improving university-wide knowledge and understanding of autism and developing a campus culture which accepts and embraces inclusion is also needed to ensure autistic students will have the best possible experience of transition to university. These issues are discussed further in the following chapter, which presents the strengths, challenges, and limitations of this research project, followed by an outline of future research recommendations, implications and recommendations for practice, and the conclusion of the thesis.

12 CONCLUSION

The final chapter of this thesis begins with a reflection from the researcher on the experiences of being an autistic autism researcher undertaking this research project. The chapter will also present an overview of the strengths, challenges, and limitations of the project, followed by suggestions for future research. Implications and recommendations for policy and practice are then summarised. The chapter concludes with a final summary of the research findings and the contribution of this project to the broader landscape of empirical research on the lived experience of autistic students in higher education.

12.1 Reflection on Being an Autistic Autism Researcher

The unique position of the researcher as an autistic person is a significant strength of this research which adds value to this project, as it contributes an important perspective when compared with existing research on autistic student university experiences. Being an autistic autism researcher brings with it both strengths and challenges. Grant and Kara (2021) suggested that some of the benefits of autistic researchers include attention to detail, analysing data and identifying patterns, and autistic hyper-focus (or “flow”) which can enable the researcher to work well to tight deadlines. The researcher agrees that each of these strengths contributed to undertaking the current research project.

The researcher also noted challenges associated with being an autistic autism researcher. For example, the researcher experiences auditory processing difficulties, which have the potential to impact on the ability to understand, interpret and respond to participants during interviews efficiently. To address this, the researcher opted to include opportunities for follow up email with participants after the interview. The researcher informed participants at the end of the interview that she would contact them via email with a copy of the transcript and explained that this would not only provide participants with the opportunity to clarify any potential misunderstandings but also enabled the researcher to seek clarification if something had been unclear. This strategy proved beneficial for both the researcher and participants. It alleviated the anxiety of the researcher, but also provided participants with an opportunity to reflect on the information they provided and add further details should they wish to do so. On reflection it is likely that this strategy works well for autistic researchers and participants, as it provides both with the opportunity to process the information provided and clarify any potential misunderstandings or misinterpretations.

Being diagnosed mid-way through the PhD candidature also presented some additional challenges for the researcher. The researcher was diagnosed in adulthood, which provided a new lens through which she could view and understand past and present events.

Like several autistic students in the current study, the researcher went through a process of meaning making, self-understanding, and reflection after receiving her formal diagnosis. At times this made it difficult for the researcher to effectively engage with the research project, as the cognitive processing associated with receiving the diagnosis made it difficult to concentrate. In addition, the researcher found that she needed time to adjust to the new lens (of an autism diagnosis) and her autistic identity, and the way in which she interpreted and understood the literature she was engaging with. Receiving her formal diagnosis also resulted in the researcher critically examining previously held beliefs and ideas about her own experiences as being those of a “non-autistic” person. For example, in one post-interview reflective journal entry, she noted:

[D]uring [the] interview today I found myself thinking about whether the participant's experience[s] do seem different to neurotypical [students] (...) The thought popped into my head when [the participant] said they didn't [sic] make any friends at uni [sic] ==> "well neither did I so that's fairly typical". I realised that prior to my own diagnosis I have at times used my own experience as a neurotypical "yardstick" (...) [I] Need to be conscious of this during analysis.

The implementation of a reflective journal throughout the research project, including during data collection and analysis, enabled the researcher to process and reflect on these experiences as they arose. This therefore enabled her to be conscious of her own preconceptions and perspectives, an important component of reflexivity, which is critical to the qualitative approaches utilised for this research.

Finally, the researcher chose not to openly disclose her own diagnosis to participants. As the researcher had already interviewed two students prior to her formal diagnosis, she was conscious of wanting to ensure the interviews were all conducted under the same conditions. In addition, the researcher did not want her own diagnosis to potentially bias or influence participants' responses. However, as the researcher disclosed to some of the organisations and groups who assisted with case study recruitment, one or more of the student participants may have been aware of the researcher's diagnosis. On reflection the researcher does not recommend avoiding disclosure, as not openly disclosing her diagnosis ultimately felt dishonest. The researcher also reflected on the potential missed opportunity for rapport development with participants and representation that openly disclosing may have contributed. The researcher hopes to share further insights into her experiences as an autistic autism researcher in a future publication.

12.2 Research Strengths

In addition to the strengths described in the previous section, there are further strengths of this research project that position it as novel and innovative within the autism research space. The methodological approaches used within the current research were an important strength of the project, which enabled in-depth exploration of the experiences of autistic students and members of their support network. Additionally, the use of the bioecological theory model as the theoretical framework for the project is a unique strength of this research that ensured exploration of factors at an individual and systemic level.

The use of IPA in the current research project enabled the researcher to undertake a detailed exploration of the experiences of autistic students and is a significant strength of this study. The use of IPA enabled idiographic investigation of student's experiences of transition to university, thus privileging and strengthening the voices of autistic students. In addition, the collection of data from support network members enabled exploration of facilitators and barriers to transition across each level of the bioecological theory model. The use of RTA to analyse the data collected also provided the researcher with the opportunity to reflect on their own experience and knowledge; and incorporate this reflective process into the analysis of participant experiences, to arrive at practical recommendations that can have meaningful impact on the university experiences of autistic students.

The current research project is the first to the researcher's knowledge to utilise the bioecological theory model to examine the experiences of transition to university for autistic students. Using the bioecological theory model provided a theoretical framing for the research, which was critical to enabling exploration of not only individual factors that impact on transition, but also systemic and cultural factors. In addition, the bioecological theory model highlights the importance of the interrelationships between each of these factors. This research project builds on findings and recommendations of Fabri et al. (2022), emphasising the importance of moving beyond strategies which rely on the student adjusting to university expectations. By using the bioecological theory model framework, this project has been able to provide a holistic view of the facilitators and barriers which impact on autistic students' transition to university.

The combination of the theoretical framework and in-depth qualitative analysis provides a strong foundation and evidence base for the recommendations for future research, as well as implications and recommendations for practice. Furthermore, the findings have been discussed in the context of existing transition models and frameworks, such as Lizzio's Five Senses model (2006; 2011), which will enable practical application of the findings in the context of existing transition strategies.

12.3 Research Challenges and Limitations

While the strengths describe above have contributed to the rigour, value, and impact of this research, some limitations and challenges should also be acknowledged when interpreting the findings of this research project. These limitations are discussed in more detail in the following sections.

12.3.1 Recruitment: Reaching Potential Participants

Researchers must consider and address the risk of potential coercion when developing and implementing recruitment strategies, particularly when recruiting people deemed as 'vulnerable', including people with disability (NHMRC, 2007 [updated 2018]). As such, recruitment for the current project was conducted via several intermediary sources, for example university Disability Services. Initial attempts to promote the research project via university Disability Services had limited success, with only three of the 26 universities subscribed to the Aust-Ed mailing list providing permission to receive the research flyers to promote the project within their university. Similarly, when university student unions were contacted, only one of the 28 contacted responded and approved promotion of the research project. Several factors may have contributed to this, including staff workloads and availability to engage with project promotion, individual university ethics requirements, interest in the research area, and/or staff concern about whether it was appropriate or permissible to share a research project being conducted outside of their own university. These challenges were further compounded by the impact of the COVID-19 pandemic restrictions which were in place during the case study recruitment period, which resulted in significant disruption for both universities and disability support organisations alike. To address this, the researcher therefore utilised a range of recruitment methods to reach as many participants as possible (see Chapter 6).

12.3.2 Autistic Identity and Disclosure in Autism Research

During recruitment the researcher experienced barriers in the form of concerns raised about the research being conducted by a non-autistic researcher. Autistic-led organisations and other members of the autistic community responded to recruitment requests and social media posts with comments about the fact that the research project was not autistic-led, and the primary researcher herself was not autistic. These issues also demonstrated the assumptions made by community members about the researcher's diagnosis. Farahar and Foster (2021) have highlighted the challenges faced by autistic academics and researchers in openly disclosing for fear of stigma and prejudice, this was made even more difficult for the current researcher given she was awaiting her own formal diagnostic assessment. It concerns the researcher that there appears to be an implicit expectation that autistic researchers should disclose their diagnosis, which neglects to

consider the possible risks and negative repercussions this may have on their personal situation.

Concerns regarding the researcher's positionality as non-autistic also neglected to recognise the inclusive research practices that were implemented throughout the study including the role of the advisory group and co-analyst (Cooperative Research Centre for Living with Autism, 2016). The researcher recommends that future academics, and PhD students, conducting research in this space not only include but clearly communicate inclusive research practices within their study, such as those outlined in the Autism CRC Guidelines (Cooperative Research Centre for Living with Autism, 2016; den Houting, 2021). For example, including a statement regarding any advisory groups or community consultation in all recruitment flyers and social media posts. Autistic researchers may also wish to disclose their own diagnosis; however, this should only be done where the researcher feels safe to do so.

The current researcher also believes there is an important role to be played by research allies in autism research. If we are truly to make change in the lives of autistic people, it will require the input of both autistic and non-autistic researchers. In her recent article, Thompson-Hodgetts (2023) reflects on her own experience as a non-autistic autism researcher. She recommends non-autistic autism researchers recognise the experience that autistic people bring to the research and encourages them to reflect on their own research practices and positionality. The current researcher supports these suggestions and encourages autistic and non-autistic researchers to work collaboratively towards the common goal of improving the quality of life for autistic people.

12.3.3 Data Collection

Only one interview was conducted with each participant. It is possible that some participants would have been able to provide additional relevant information if subsequent interview opportunities were provided. For example, follow up interviews may have provided the opportunity for participants to elaborate on the information provided in their initial interview or reflect on their experiences further, to provide more detail relevant to these experiences. Follow up interviews may have also enabled the researcher to reflect on the information provided in the initial interview and ask supplementary questions to clarify or confirm the details provided. This may also have enabled the researcher further opportunity to develop rapport and gather relevant information about participant experiences. Although subsequent interviews were not conducted with participants, the researcher provided participants with a copy of their interview transcript to review and approve, to enable them the opportunity to expand upon or clarify the information they provided during their interview.

The benefits of providing this opportunity for both autistic participants and the autistic researcher are discussed in more detail in Section 12.1.

The current research utilised semi-structured interviews to gather data from autistic students about their experiences of transition to, and first year of university. The bioecological theory model provided the theoretical framework and guided the overall interview questions for this research project. However, questions were intentionally left broad so as not to influence or lead participants' responses. As such, specific questions regarding societal or cultural perspectives of autism or inclusion were not included. Instead, participants organically discussed their experiences of societal or cultural factors. It may be beneficial for future research to explore the macrosystem more directly, with a particular focus on elements that relate to societal and cultural awareness, attitudes, and understanding, and how these impact on autistic students' experiences of transition to university, and university participation more broadly.

The data collection methods used for this research were also reliant on retrospective self-report. It is possible that participants may have forgotten specific details of their experiences, or that recollection of specific information may have been challenging. Longitudinal study designs, which interview students before, during, and after the first year of university, may be beneficial to expand upon the findings of the current research.

12.3.4 Generalisability of Results

The use of IPA in this research enabled in-depth analysis of individual student experiences. While in-depth focus on experiences is a significant strength of this research, it also brings with it some limitations. The purpose of IPA research is to closely examine individual experiences of a complex phenomenon, it does not seek to produce generalisable results (Smith et al., 2009, 2022). Nevertheless, the findings of this researcher should be interpreted with this scope in mind, particularly due to the small sample size of the project. In addressing the first research objective, this study serves to identify initial themes. These themes should be explored further in future research, to examine the extent to which they may be generalisable to the broader autistic student experience internationally during the transition to, and first year of university.

A key focus of the current research was on exploring the lived experiences of participants. As such, although the response numbers were low, the open-ended, qualitative responses within the survey were well suited for analysis using RTA. Analysing the responses using RTA provided an important opportunity for exploration and examination of potential facilitators and barriers to transition for autistic university students. However, the small sample size must be acknowledged, as it makes it difficult for findings to be

generalised to the broader population of family members, or university staff who provide support to autistic students during their first year of university. It should be noted however, that generalisability and data saturation are not the goal of qualitative research approaches such as RTA (Braun & Clarke, 2021b).

Additionally, all participants were self-selected volunteers, who were engaged through an opt-in process, promoted through university Disability Services and external autism support organisations. These types of recruitment methods are likely to only reach students who are aware of their autistic identity or diagnosis and are willing to participate in the research project to discuss their challenges. This may lend itself to a bias in responses from people who are more likely to have accessed or received support. Therefore, further research is needed to explore the broader experiences of transition for autistic students, with a direct effort to engage students who are not already connected to supports and services within their university. The current research initially tried to achieve this by asking university Disability Services staff to promote the research project in public campus spaces; however, the limited responses to this request meant this was not achieved.

Finally, the geographic scope of this research, focusing on experiences of autistic students at Australian universities means that the findings may not be generalisable to institutions outside of Australia. As there may be significant differences between the higher education system in Australia and other countries, future research should also explore the autistic experience of transition across various international higher education systems, and within international legislative frameworks. However, it should be noted that similarities between the findings of this research project and previous international studies were found and are discussed earlier in this chapter.

12.3.5 Inclusive Research Practices in Autism Research

There are often challenges implementing inclusive research practices within a PhD thesis project such as this one. While every effort was made to include and reflect inclusive research practices throughout the project, challenges inherent to undertaking a PhD program created some limitations to full participatory research. For example, academic integrity requirements, and the need for a PhD to be primarily the individual student's own, original work for assessment/examination purposes, creates potential barriers to the ability to engage and consult with autistic peers and community members. In addition, funding limitations make it difficult for appropriate remuneration of co-researchers to undertake analysis and other consultative work. Nevertheless, the researcher utilised her available research funding to employ a co-analyst to contribute to the project by analysing a subset of the interview data. This provided valuable insight and opportunities for reflection which contributed to the project overall.

12.4 Future Research

This thesis makes a valuable contribution to our understanding of the experiences of autistic students and their support networks during the transition to, and first year of university. While the current research project is the first to explore in-depth the transition to university for autistic students using the bioecological theory model framework, there are several areas which warrant further research. These have been identified and discussed in the previous chapter and key areas for future research are summarised below.

At the individual level, the current research identified the complex decision-making process that autistic students undertake when considering whether to disclose their diagnosis. Uniquely, the findings highlighted the importance of pragmatic factors such as time, location, and situation, which may impact on their likelihood to disclose. Interviews with autistic students exploring these experiences in more detail may help to illuminate the strategies they have used to overcome these challenges. In addition, interviews with academic staff may help to better understand their perceptions of disclosure, particularly in relation to situational factors that enable or hinder students' disclosure.

At the microsystem and mesosystem levels, participants described the support they received from family members and external support workers. Support network participants in the current research highlighted the potential benefits of family support. Additionally, autistic students in the current research generally described family member support as helpful. However, research exploring the perspectives of autistic students who have received support from their family members during their transition to university is limited. Further qualitative studies are needed to explore these experiences in more detail, from the perspective of autistic students themselves. Seeking the perspectives of autistic students may help to better understand their perceptions of receiving support from family members.

The current research has also highlighted the need for further research which explores the role and experiences of NDIS funded support workers who support autistic students during their transition to, and first year of university. There is currently a lack of research which explores the role of NDIS funded support workers in universities. To the researcher's knowledge, there is a lack of studies exploring the role of NDIS funded support workers in supporting autistic students' transition to university. Further qualitative research is needed which explores the roles, responsibilities, and expectations of NDIS funded support workers supporting autistic students in the university setting. Interviews with NDIS funded support workers, students, family members, and university staff may help to expand our understanding of the role that NDIS funded support workers play in enabling university participation for autistic students. In addition, further research can help to provide an

evidence base for future recommendations, strategies, and policies related to the roles and responsibilities of NDIS funded support workers in universities.

At the exosystem level, future research should explore existing strategies and their implementation within the university setting, such as the development and use of access plans. The current research has highlighted the often vague and non-specific nature of the information included within university access plans. It has also demonstrated the need for improved strategies that support autistic students' disclosure, help seeking and communication with university staff. Given the current inconsistent, and at times inaccurate, understanding of autism by university staff reported by the current participants, it may be reasonable for Disability Services staff to not include a student's autism diagnosis in an access plan. However, further research is needed to determine the most effective information to include on a student's access plan, which supports their disclosure to academic staff and access to adjustments and support. Interviews with disability advisors and academic staff may provide further insight into these issues. Further research is also needed to confirm whether existing and emerging strategies, such as autism-specific peer mentoring programs and autism-friendly spaces on campus, provide benefits for autistic students during their transition to university. Qualitative studies seeking to understand autistic students' perspectives and experiences of these strategies are needed. Given the cost and resourcing that is required to develop and implement these strategies a strong evidence base to support their implementation is crucial.

The current research included a small number of interviews and survey responses. While the data provides insights into the experiences of autistic students from a range of universities across Australia, further research is needed to determine whether the findings can be applied across broader populations of Australian and international autistic university students and members of their support networks. Furthermore, there is a need for research which actively recruits individuals from a range of backgrounds, to ensure the findings are representative of the diverse experiences of autistic people and their families.

Finally, while the findings are specifically discussed in relation to autistic student experiences, it is likely that they will have broader implications for other neurodivergent students. As such, there is a need for future research which explores the applicability of these findings to other populations of students with disabilities such as those with ADHD, dyslexia, and other learning disabilities. Intervention studies which examine the implementation of recommendations from the current research may help to identify how these strategies impact on other neurodivergent students and students with disabilities more broadly.

12.5 Implications and Practice Recommendations

The findings of the current research highlight the importance of strategies to support the transition to university for autistic students at the individual, systemic, and cultural level. The following sections utilise the bioecological theory model as a framework to outline implications and recommendations for practice. A holistic approach is required to ensure autistic students are effectively supported during their transition to university, and throughout their university studies. A holistic approach to support should ensure students are supported at both an individual and broader whole-of-university level. It is therefore important for the following recommendations to be considered as part of an institution-wide approach to inclusion, rather than being implemented in isolation. In addition, these recommendations are unlikely to be effectively implemented without consideration of the need for policy drivers which encourage and promote inclusive practices in higher education.

12.5.1 Individual

Implement strategies that support autistic students to develop skills in help-seeking and disclosure.

At the individual level, autistic students should be supported to develop their skills in self-advocacy and help-seeking. Opportunities to develop and practice these skills during high school should be prioritised; however, universities can also support students to develop these skills in the early stages of their degree by scaffolding and supporting disclosure and help-seeking for autistic students. For example, when establishing an access plan with autistic students, disability advisors could work with the student to develop an initial email template which can be sent to academic staff to enable students to introduce themselves, provide their access plan, and outline any support needs relevant to the course they will be studying. While providing opportunities to develop self-determination, self-advocacy, help-seeking skills may support the transition experiences of autistic university students, it is unlikely to truly improve these experiences unless implemented alongside relevant microsystem and exosystem strategies. As the current research highlights, students may be hesitant to disclose their autism diagnosis in an environment where they do not feel safe and supported to do so.

12.5.2 Microsystem

Implement effective transition support programs during high school.

High schools play an important role in preparing students for their transition to post-school life. While high school transition support was not the focus of the current research project, the findings suggest that there is currently a lack of transition support practices implemented in high school, with a particular gap in support that enables the transition to university. There is a need for the development of high school transition and preparation programs and practices that recognise university as a potential pathway for autistic students and better supports autistic students who wish to pursue university studies. These programs should include opportunities for students to connect with local universities while still at school, to explore the types of support available, and the eligibility requirements for accessing support. This is particularly important for students who need to locate relevant supporting documentation to enable access to support. In the Australian context, this may require strengthening partnerships and collaboration between state and territory education departments, and National Disability Coordination Officer (NDCO) and university networks.

Develop and promote resources which inform family members about students' rights and responsibilities at university.

Most family members in the current research indicated they had limited knowledge or familiarity with the existing legislation related to disability inclusion in education. Family members also reported undertaking an advocacy role to support their child during the transition to university, while students discussed family members as providing emotional and practical support during their transition. Family members may benefit from additional information regarding relevant legislation, such as the DDA and DSE, to support them in knowing and understanding their child's rights as an autistic university student. An example of such a resource is available on the ADCET website - Tips for parents/carers to support the educational and career journeys of students with disability (ADCET, 2023). In addition, universities could consider provision of information to parents that help them to support their child during the transition to, and ongoing university studies. One example of this in current practice is the University of South Australia's resource "Guide to university for parents and friends" and webpage "information for parents" (University of South Australia, 2023), which provides information about the differences between high school and university, university expectations, and support services available. While these resources are not autism-specific, they provide valuable background information that may assist parents in supporting their

autistic child during their transition to, and first year of university. Similar resources are available through various universities in Australia and internationally; however, there is a need for ongoing funding at a national level to develop resources which provide consistent, clear, and detailed information about students' rights and responsibilities under existing legislation. In addition, these resources must be promoted and utilised widely to ensure consistency across institutions. There may also be a need for further evaluation projects which examine the benefits of using such resources to ensure they are effective.

Implement strategies that are responsive to the potentially disrupted transition experiences of autistic students.

As the current research identified, autistic students' pathways through their first year of university are often disrupted by challenges and barriers, which at times result in the need for autistic students to take leave from their studies. The findings of this research also highlight the fact that autistic students are likely to return to their studies following this period of leave. Universities should implement strategies to support autistic students who need to take leave or withdraw from their studies, to ensure that they have easy and direct access to support services if they chose to return. For example, with the student's permission, universities could identify a staff member who can be contacted by the student while they are on leave. This contact person could ensure the student is contacted prior to the end of their leave period to assist them to connect with relevant services, establish or revise their access plan, and begin preparing for their return to studies.

12.5.3 Mesosystem

Implement and promote mechanisms which enable autistic students to identify a family member or support worker as a key contact or advocate.

Institutional policies and privacy legislation can make it difficult for family members or external support providers to connect with university staff. This was not only noted in the current research project, but also in previous US research (Dymond et al., 2017; Peña & Kocur, 2013). Formal collaborative approaches should be developed that enable autistic students to determine if, how, and when they would like support from family members or other support providers. Setting up formal agreements between autistic students, their support network members, and university staff would support collaboration. Establishing formal agreements will also provide the opportunity to facilitate discussions about how the student will be supported to develop autonomy and independence as they progress through their studies.

12.5.4 Exosystem

Implement and promote strategies which enable early engagement of prospective autistic students with relevant university disability or equity services.

Ensure university disability and equity services are adequately funded and resourced to provide early and ongoing funding to support the transition needs of autistic university students.

The current research suggests that Disability Services staff require additional time to develop rapport and build effective relationships with autistic students in order to support them during their first year. Disability Services should take proactive action to ensure that autistic students can engage with their services as early as possible. Disability Services, as well as autism-specific support programs, should be visible and accessible to students prior to and in the early stages of their degree. Universities should consider mechanisms that enable students to contact Disability Services prior to enrolment and ensure these strategies are promoted effectively to prospective university students. This will also require the adequate funding and resourcing of Disability Services, student support services and autism-specific programs.

Implement strategies which support the attendance, participation, and inclusion of autistic students at orientation programs.

Universities should also consider ways to make orientation week programs and activities more inclusive or autistic students. Providing an inclusive orientation program will not only support autistic students, with and without a formal diagnosis, but also other students who may have similar experiences such as those with social anxiety, mental health conditions, or sensory processing difficulties. The following recommendations would support a more inclusive orientation program:

- Provide orientation week activities that support peer-connection for autistic students, while recognising the social and sensory challenges they may experience.
- Create an inclusive orientation week environment where all students can participate on an equal basis. This could be achieved by providing a clear schedule of activities, workshops, and other events that clearly articulates their purpose and the level of

participation or interaction required. For example, this could be implemented through an app or webpage where autistic students could plan a schedule of events and activities that they wish to participate in.

- Develop a sensory map of orientation week activities which identifies the busier, interactive activities and highlights the quieter, less busy activities and places for students to retreat to as needed. The promotion of autism/sensory-friendly spaces on campus during this time would also be beneficial.
- Provide the option of an orientation week buddy or peer for autistic students, to assist with navigating the campus and locating relevant activities.

Create an inclusive and welcoming campus culture, which celebrates neurodiversity and encourages autistic students to embrace their autistic identity.

The current research highlights the importance of strategies which create an accepting and inclusive campus for autistic students. There is a need to develop a “whole-of-university” understanding of autism, by implementing training and development that provides up-to-date, accurate information about autism. Training should be co-designed with autistic students and work to dispel existing myths and misconceptions about autism. This training also needs to be a mandated requirement across the university to ensure consistency of knowledge, awareness, and understanding of autism across all staff members.

Developing a whole-of-university approach to autism, disability, and inclusion will require support from senior leaders within the university. Institutional policies which address disability inclusion, such as Disability Action Plans, are needed to lead inclusion at all levels of the institution. However, despite the implementation of Disability Action Plans within many Australian universities (Australian Human Rights Commission [AHRC], 2021; Harpur et al., 2023), the current university outcomes of autistic students sit below those of their peers both with and without disability (Australian Bureau of Statistics, 2019; Newman et al., 2011). It may be time for universities to consider implementation of Neurodiversity Action Plans which highlight and address the specific challenges experienced by autistic students, and other neurodivergent students, while at university.

The current findings suggest that autistic students would also benefit from opportunities to develop their autistic identity. One mechanism for supporting the development of positive autistic identity may be through the implementation of campus-based autism-friendly spaces and peer networks. Providing an autism-friendly space on

campus not only provides an opportunity for students to take a break from the sensory overwhelm that they often experience on university campuses, but also provides opportunities for peer and social connection with other students with similar experiences.

Adopt Universal Design for Learning approaches and inclusive teaching and learning practices.

To support the learning, engagement and participation of autistic students, universities should consider the following recommendations:

- Implement Universal Design for Learning (UDL) and inclusive practice principles to ensure students with and without a formal diagnosis are supported to engage and participate in their learning in a way that suits their learning needs. In addition, UDL principles enable learning and participation for all students, regardless of ability.
- Reconsider the meaning of individualised support to recognise the diversity of autistic students' experience. Individualised support plays an important role in ensuring equitable access for autistic students. However, it does not need to be seen as "special" or "unique" support which requires staff to go above and beyond. Instead, it should be seen as enabling reasonable and necessary adjustments to ensure access and participation. Individualised supports should work alongside inclusive practices to ensure that barriers to effective transition and participation can be addressed and reduced as soon as possible.

Develop and implement transition strategies which support a holistic approach to orientation and transition, such as the Five Senses of Success model.

The findings of the current research highlight the importance of effective transition strategies that support students to develop a range of skills and capabilities during their transition to, and first year of university. While not specifically designed to address the support needs of autistic students, the Five Senses of Success (Griffith University, 2017; Lizzio, 2006; Lizzio, 2011) model provides an effective framework for supporting the transition of autistic students, by highlighting a range of critical areas that are particularly important for autistic students during their transition. Universities should consider how each of these senses apply to autistic students' experiences, paying particular attention to areas which may require additional support and structure to address. For example, autistic

students may experience challenges developing a sense of resourcefulness or connectedness due to difficulties social-communication or help-seeking difficulties they experience. As such, these should be a particular area of focus for supporting the transition to university for autistic students. As discussed earlier, implementation of the Five Senses model should also consider ways in which the sense of autistic identity can be developed or supported for autistic students to improve their transition experiences.

12.5.5 Macrosystem

Shift the societal and cultural narrative on autism and disability to one of inclusion and acceptance.

Change at a societal level is complex and takes time. The current research was undertaken at a time when significant improvements have been made in the inclusion and participation of students with disabilities in higher education, as the result of the widening participation movement. Yet, further work is still needed. Improving societal and cultural attitudes towards autism will require work at a systemic and policy level to reframe the narrative and dispel existing myths and misconceptions associated with autism and disability more broadly. The researcher hopes that this thesis will go some way towards shifting the focus from how autistic people can change to fit society's expectations, to how society can adapt to be more accommodating to the needs of autistic people.

12.6 Conclusion

The aim of this research was to explore the facilitators and barriers to transition to university for autistic students in Australia, using the bioecological theory model as a lens for examining individual and contextual factors. This previously underexplored area is critical to understanding ways in which we can better support the university experiences of autistic students. Understanding the experiences of transition to, and first year of university for autistic students provides an opportunity to identify and develop strategic and effective transition support programs and strategies that will enable the effective engagement and participation of autistic university students.

There is an increasing focus on research exploring the experiences of autistic students in university. However, much of the existing research has focused on individual supports and strategies as opposed to broader systemic changes that could improve the inclusion of autistic students at university. Additionally, transition is often identified as a key issue within literature which explores these the experiences of autistic university students but is less often the primary focus of the research itself, particularly within the Australian context.

The current research addressed this gap in existing knowledge by focusing specifically on the experiences of autistic students and their support networks during the transition to, and first year of university.

Semi-structured interviews were conducted with eight autistic students from universities across Australia, to explore their experiences of transition to university. To understand the contextual factors that may influence this transition, semi-structured interviews were also conducted with five members of these students' support networks. Finally, survey responses from eight family members and 24 university staff were analysed to provide additional insight into the role and experiences of support network members in supporting autistic students during this transition.

The initial systematic review (Nuske et al., 2019) undertaken for this thesis identified a range of individual characteristics and needs of autistic students that impact on their transition to university. Six studies examined in the review identified core characteristics of autism, including executive functioning difficulties, sensory processing difficulties, and social communication difficulties, as significant challenges to transition for autistic university students. However, the results of the current research challenge these findings. While difficulties associated with autistic characteristics were mentioned by autistic participants, and did contribute to their transition experience, they were not the only or most prominent challenge students discussed.

Participants in the current research also described transition challenges and barriers that may in fact be similar to those experienced by non-autistic students during their transition to university. Like non-autistic students, university transition was experienced as a period of adjustment, with students needing to adjust to new people, environments, roles, and expectations. Autistic students also expressed feeling anxiety before and during the transition period, which may not be dissimilar to experiences of non-autistic students during their first year of university. However, autistic students emphasised the added anxiety they experienced during the transition, which they perceived as higher than that of their non-autistic peers. It was this anxiety that students suggested made their transition experience different to that of other students.

The transition experiences of autistic students differed from those of non-autistic students in the ways in which they needed to approach their learning and university experience to accommodate the difficulties they experienced. For example, autistic students needed to manage the process of disclosure, deciding when and who to disclose their diagnosis to in order to access reasonable and necessary adjustments that enabled them to participate on the same basis as their non-autistic peers. Autistic students also reported

relying on self-developed coping skills and strategies to overcome the challenges they faced. For some autistic students in the current research, this took the form of masking, in an attempt to fit in and not make their difficulties apparent to others.

Uniquely, this research highlighted the persistence and resilience of autistic university students as being more than just completion of degrees. Students demonstrated persistence and resilience in the way they found strategies to address difficulties and overcome challenges. For some students this involved withdrawing from their studies and returning later, while others decreased their study load to enable them to continue to progress with their studies. This has been potentially over-looked in much of the previous literature, and it is important for universities to consider mechanisms for providing support to autistic students who are considering returning to their studies after a period of leave.

This research contributes new knowledge to our understanding of autistic experiences in higher education by examining, in detail, the experiences of autistic students during their transition to university. Notably, this research project also makes a unique contribution to the field by utilising the bioecological theory model for the first time (to the author's knowledge) as a framework for understanding not only the individual factors which impact this transition period, but the systemic and cultural factors that affect it as well. By utilising this theoretical framework as a lens through which the transition experiences of autistic students were explored, this research has also highlighted the complex interrelationships between elements across all levels of the bioecological theory model.

This research also privileges the voices of autistic students by exploring their individual experiences in-depth, as described by the students themselves. The research also included an autistic co-analyst to further enhance the inclusive research approach. Additional data was also sought from support network members, not to validate autistic student experiences, but to add to our understanding of the broader support network that surrounds the student during their transition. By exploring these experiences in detail this research has not only identified what is currently working to support transition to university for autistic students, but also provides an evidence base for improvements to transition strategies and programs in the future.

By identifying facilitators and barriers across each level of the bioecological theory model framework the research has demonstrated the interrelationships between various factor which impact on the transition experiences of autistic students. In doing so, these findings have highlighted the importance of a holistic approach to supporting autistic students during the transition to, and first year of university.

Findings from this research also demonstrate the importance of whole-of-university approaches to awareness and inclusion, which have implications not only for autistic students, but for other neurodivergent students and students with disabilities more broadly. In addition, implementing strategies which create and maintain a university-wide culture of inclusivity will also have benefits for both students and staff with disabilities.

Overall, this research has been identified a range of facilitators and barriers to transition to university for autistic students, by exploring the experiences of autistic students and members of their support network. Successful first year experiences are crucial for the retention and success of all students, but this appears to be particularly important for autistic students, as highlighted in the current research. The findings outlined in this thesis provide a strong evidence base to support the implementation of strategies to support the transition of autistic students, at both an individual and broader institutional level. In addition, recommendations and suggestions outlined in this thesis provide clear direction for future research, along with changes to practice and policy which can create a more inclusive university experience for students both in Australia and internationally. It is time to shift the narrative from one of deficit, requiring students to do the heavy lifting, and instead look to how universities can create more inclusive environments that enable autistic students to not only participate and engage, but thrive!

REFERENCES

- Accardo, A. L., Kuder, S. J., & Woodruff, J. (2019). Accommodations and support services preferred by college students with autism spectrum disorder. *Autism*, 23(3), 574-583. <https://doi.org/10.1177/1362361318760490>
- ADCET. (2023). *Tips for parents/carers to support the educational and career journeys of students with disability*. <https://www.adcet.edu.au/resource/11292/file/14>
- Adreon, D., & Durocher, J. S. (2007). Evaluating the college transition needs of individuals with high-functioning autism spectrum disorders. *Intervention in School and Clinic*, 42(5), 271-279.
- Alase, A. (2017). The interpretative phenomenological analysis (IPA): A guide to a good qualitative research approach. *International Journal of Education and Literacy Studies*, 5(2), 9-19. <https://doi.org/10.7575/aiac.ijels.v.5n.2p.9>
- Alverson, C. Y., Lindstrom, L. E., & Hirano, K. A. (2015). High school to college: Transition experiences of young adults with autism. *Focus on Autism and Other Developmental Disabilities*, 1-13. <https://doi.org/10.1177/1088357615611880>
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). <https://doi.org/10.1176/appi.books.9780890425596>
- Anderson-Chavarria, M. (2022). The autism predicament: models of autism and their impact on autistic identity. *Disability & Society*, 37(8), 1321-1341. <https://doi.org/10.1080/09687599.2021.1877117>
- Anderson, A. H., Carter, M., & Stephenson, J. (2018). Perspectives of university students with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 48(3), 651-665. <https://doi.org/10.1007/s10803-017-3257-3>
- Anderson, A. H., Carter, M., & Stephenson, J. (2019). An on-line survey of university students with autism spectrum disorder in Australia and New Zealand: Characteristics, support satisfaction, and advocacy. *Journal of Autism and Developmental Disorders*, 50, 440–454. <https://doi.org/10.1007/s10803-019-04259-8>
- Anderson, A. H., Stephenson, J., & Carter, M. (2017). A systematic literature review of the experiences and supports of students with autism spectrum disorder in post-secondary education. *Research in Autism Spectrum Disorders*, 39, 33-53. <https://doi.org/10.1016/j.rasd.2017.04.002>

- Anderson, A. H., Stephenson, J., & Carter, M. (2020). Perspectives of former students with ASD from Australia and New Zealand on their university experience. *Journal of Autism and Developmental Disorders*, 50, 2886–2901.
<https://doi.org/10.1007/s10803-020-04386-7>
- Anderson, C., & Butt, C. (2017). Young adults on the autism spectrum at college: Successes and stumbling blocks. *Journal of Autism and Developmental Disorders* 47(10), 3029–3039. <https://doi.org/10.1007/s1080>
- ASPECT. (n.d). *How do we describe autism?* <https://www.autismspectrum.org.au/about-autism/what-is-autism>
- Australian Bureau of Statistics. (2019). *Survey of disability, ageing and carers Australia: Summary of findings*. <https://www.abs.gov.au/statistics/health/disability/disability-ageing-and-carers-australia-summary-findings/latest-release>
- Australian Government. (2005). *Disability Standards for Education 2005 (Cth)*.
<https://www.legislation.gov.au/Details/F2005L00767>
- Australian Government. (2013). *National Disability Insurance Scheme Act 2013*.
<https://www.legislation.gov.au/Details/C2022C00206>
- Australian Government. (2018). *Disability Discrimination Act 1992, Act No. 135 of 992 as amended*. <https://www.legislation.gov.au/Details/C2018C00125>
- Australian Government. (2021). *Tertiary collection of student information*.
<https://www.tcsisupport.gov.au/element/615>
- Australian Human Rights Commission [AHRC]. (2021). *Disability Action Plan Guide (Framework)*.
https://humanrights.gov.au/sites/default/files/document/publication/ahrc_disability_action_plan_guide_2021_0.pdf
- Australian Institute of Health and Welfare. (2014). *Towards a performance measurement framework for equity in higher education* (Cat. no. IHW 129).
<http://www.aihw.gov.au/publication-detail/?id=60129547958>
- Autism SA. (2021). *What is Autism?* <https://autismsa.org.au/wp-content/uploads/2022/04/Autism-SA-What-is-autism-Flyer.pdf>
- Autism&Uni. (2014). *Overview*. <https://www.autism-uni.org/overview/>

- Baczewski, L. M., Pizzano, M., Kasari, C., & Sturm, A. (2022). Adjustment across the first college year: A matched comparison of autistic, attention-deficit/hyperactivity disorder, and neurotypical students. *Autism in Adulthood*, 4(1), 12-21.
<https://doi.org/10.1089/aut.2021.0012>
- Bailey, K. M., Frost, K. M., Casagrande, K., & Ingersoll, B. (2020). The relationship between social experience and subjective well-being in autistic college students: A mixed methods study. *Autism*, 24(5), 1081–1092.
<https://doi.org/10.1177/1362361319892457>
- Baio, J. (2018). Prevalence of autism spectrum disorder among children aged 8 years — Autism and developmental disabilities monitoring network, 11 sites, United States, 2014. *MMWR. Surveillance Summaries*, 67(6), 1–23.
<https://doi.org/10.15585/mmwr.ss6706a1>
- Bakker, T., Krabbendam, L., Bhulai, S., & Begeer, S. (2019). Background and enrollment characteristics of students with autism in higher education. *Research in Autism Spectrum Disorders*, 67, 1-12. <https://doi.org/10.1016/j.rasd.2019.101424>
- Bakker, T., Krabbendam, L., Bhulai, S., Meeter, M., & Begeer, S. (2023). Predicting academic success of autistic students in higher education. *Autism*, 27(6), 1803–1816. <https://doi.org/10.1177/13623613221146439>
- Baldwin, S., Costley, D., & Warren, A. (2014). Employment activities and experiences of adults with high-functioning autism and Asperger's disorder. *Journal of Autism and Developmental Disorders*, 44(10), 2440-2449. <https://doi.org/10.1007/s10803-014-2112-z>
- Baric, V. B., Hemmingsson, H., Hellberg, K., & Kjellberg, A. (2017). The occupational transition process to upper secondary school, further education and/or work in Sweden: As described by young adults with Asperger syndrome and attention deficit hyperactivity disorder. *Journal of Autism and Developmental Disorders*, 47, 667-679.
<https://doi.org/10.1007/s10803-016-2986-z>
- Barnhill, G. P. (2016). Supporting students with Asperger syndrome on college campuses: Current practices. *Focus on Autism and Other Developmental Disabilities*, 31(1), 3-15. <https://doi.org/10.1177/1088357614523121>
- Bearman, M., Smith, C. D., Carbone, A., Slade, S., Baik, C., Hughes-Warrington, M., & Neumann, D. L. (2012). Systematic review methodology in higher education. *Higher*

Education Research & Development, 31(5), 625-640.

<https://doi.org/10.1080/07294360.2012.702735>

Bell, S., Devecchi, C., Mc Guckin, C., & Shevlin, M. (2017). Making the transition to post-secondary education: Opportunities and challenges experienced by students with ASD in the Republic of Ireland. *European Journal of Special Needs Education*, 32(1), 54-70. <https://doi.org/10.1080/08856257.2016.1254972>

Bergen, D. (2008). *Human development: Traditional and contemporary theories*. Pearson Prentice Hall.

Boshoff, K., Gibbs, D., Phillips, R., Wiles, L., & Porter, L. (2016). Parents' voices: 'why and how we advocate'. A meta-synthesis of parents' experiences of advocating for their child with autism spectrum disorder. *Child: Care, Health and Development*, 42(6), 784-797. <https://doi.org/10.1111/cch.12383>

Botha, M., Dibb, B., & Frost, D. M. (2022). "Autism is me": An investigation of how autistic individuals make sense of autism and stigma. *Disability & Society*, 37(3), 427-453. <https://doi.org/10.1080/09687599.2020.1822782>

Bottema-Beutel, K., Kapp, S. K., Lester, J. N., Sasson, N. J., & Hand, B. N. (2021). Avoiding ableist language: Suggestions for autism researchers. *Autism in Adulthood*, 3(1), 18-29. <https://doi.org/10.1089/aut.2020.0014>

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77-101. <https://doi.org/10.1191/1478088706qp063oa>

Braun, V., & Clarke, V. (2013). *Successful qualitative research: A practical guide for beginners*. SAGE.

Braun, V., & Clarke, V. (2021a). Can I use TA? Should I use TA? Should I not use TA? Comparing reflexive thematic analysis and other pattern-based qualitative analytic approaches. *Counselling and Psychotherapy Research*, 21(1), 37-47. <https://doi.org/10.1002/capr.12360>

Braun, V., & Clarke, V. (2021b). To saturate or not to saturate? Questioning data saturation as a useful concept for thematic analysis and sample-size rationales. *Qualitative Research in Sport, Exercise and Health*, 13(2), 201-216. <https://doi.org/10.1080/2159676X.2019.1704846>

Braun, V., & Clarke, V. (2022). *Thematic analysis: A practical guide*. SAGE.

- Braun, V., Clarke, V., Boulton, E., Davey, L., & McEvoy, C. (2020). The online survey as a qualitative research tool. *International Journal of Social Research Methodology*, 24(6), 641-654. <https://doi.org/10.1080/13645579.2020.1805550>
- Brett, M. (2016). Disability and Australian higher education: Policy drivers for increasing participation. In A. Harvey, C. Burnheim, & M. Brett (Eds.), *Student Equity in Australian Higher Education* (pp. 87-108). Springer. https://doi.org/10.1007/978-981-10-0315-8_6
- Bronfenbrenner, U. (1979). *The ecology of human development: Experiments by nature and design*. Harvard University Press.
- Bronfenbrenner, U., & Morris, P. A. (2006). The bioecological model of human development. In R. M. Lerner & W. Damon (Eds.), *Handbook of child psychology: Theoretical models of human development* (pp. 793–828). John Wiley & Sons Inc.
- Brooker, A., Brooker, S., & Lawrence, J. (2017). First year students' perceptions of their difficulties. *Student Success*, 8(1), 49-62. <https://doi.org/10.5204/ssj.v8i1.352>
- Brown, K. R., & Coomes, M. D. (2015). A spectrum of support: Current and best practices for students with autism spectrum disorder (ASD) at community colleges. *Community College Journal of Research and Practice*, 40(6), 465-479. <https://doi.org/10.1080/10668926.2015.1067171>
- Brugha, T. S., McManus, S., Bankart, J., Scott, F., Purdon, S., Smith, J., Bebbington, P., Jenkins, R., & Meltzer, H. (2011). Epidemiology of autism spectrum disorders in adults in the community in England. *Archives of General Psychiatry*, 68(5), 459-465. <https://doi.org/10.1001/archgenpsychiatry.2011.38>
- Brugha, T. S., Spiers, N., Bankart, J., Cooper, S.-A., McManus, S., Scott, F. J., Smith, J., & Tyrer, F. (2016). Epidemiology of autism in adults across age groups and ability levels. *The British Journal of Psychiatry*, 209, 498–503. <https://doi.org/10.1192/bjp.bp.115.174649>
- Bury, S. M., Jellett, R., Spoor, J. R., & Hedley, D. (2023, Feb). "It defines who I am" or "It's something I have": What language do [Autistic] Australian adults [on the autism spectrum] prefer? *Journal of Autism and Developmental Disorders*, 53(2), 677-687. <https://doi.org/10.1007/s10803-020-04425-3>

- Bush, K. L., & Tassé, M. J. (2017). Employment and choice-making for adults with intellectual disability, autism, and down syndrome. *Research in Developmental Disabilities*, 65, 23-34. <https://doi.org/10.1016/j.ridd.2017.04.004>
- Cage, E., De Andres, M., & Mahoney, P. (2020). Understanding the factors that affect university completion for autistic people. *Research in Autism Spectrum Disorders*, 72, Article 101519. <https://doi.org/10.1016/j.rasd.2020.101519>
- Cage, E., & Howes, J. (2020). Dropping out and moving on: A qualitative study of autistic people's experiences of university. *Autism*, 24(7), 1664-1675. <https://doi.org/10.1177/1362361320918750>
- Cage, E., & Troxell-Whitman, Z. (2019). Understanding the reasons, contexts and costs of camouflaging for autistic adults. *Journal of Autism and Developmental Disorders*, 49(5), 1899-1911. <https://doi.org/10.1007/s10803-018-03878-x>
- Cai, R. Y., & Richdale, A. L. (2016). Educational experiences and needs of higher education students with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 46(1), 31-41. <https://doi.org/10.1007/s10803-015-2535-1>
- Campbell, F. (2009). *Contours of ableism: The production of disability and abledness*. Springer.
- Campbell, F. K. (2019). Precision ableism: A studies in ableism approach to developing histories of disability and abledment. *Rethinking History*, 23(2), 138-156. <https://doi.org/10.1080/13642529.2019.1607475>
- Centre for Applied Special Technology. (2015). *About Universal Design for Learning*. <https://www.cast.org/impact/universal-design-for-learning-udl>
- Chown, N., Robinson, J., Beardon, L., Downing, J., Hughes, L., Leatherland, J., Fox, K., Hickman, L., & MacGregor, D. (2017). Improving research about us, with us: a draft framework for inclusive autism research. *Disability & Society*, 32(5), 720-734. <https://doi.org/10.1080/09687599.2017.1320273>
- Christensen, D. L., Braun, K. V. N., Baio, J., Bilder, D., Charles, J., Constantino, J. N., Daniels, J., Durkin, M. S., Fitzgerald, R. T., & Kurzius-Spencer, M. (2018). Prevalence and characteristics of autism spectrum disorder among children aged 8 years — Autism and developmental disabilities monitoring network, 11 sites, United States, 2012. *MMWR Surveillance Summaries*, 65(13), 1-23. <https://doi.org/10.15585/mmwr.ss6503a1>

- Clouder, L., Karakus, M., Cinotti, A., Ferreyra, M. V., Fierros, G. A., & Rojo, P. (2020). Neurodiversity in higher education: A narrative synthesis. *Higher Education*, 80(4), 757-778. <https://doi.org/10.1007/s10734-020-00513-6>
- Cooperative Research Centre for Living with Autism. (2016). *Inclusive research practice guides and checklists for autism research: Version 2*. Autism CRC Ltd,.
- Cox, B. E., Thompson, K., Anderson, A., Mintz, A., Locks, T., Morgan, L., Edelstein, J., & Wolz, A. (2017). College experiences for students with autism spectrum disorder: Personal identity, public disclosure, and institutional support. *Journal of College Student Development*, 58(1), 71-87. <https://doi.org/10.1353/csd.2017.0004>
- Creswell, J. W., & Poth, C. N. (2018). *Qualitative inquiry and research design: Choosing among five approaches* (4th ed.). Sage.
- Cumming, T. M., & Rose, M. C. (2022). Exploring universal design for learning as an accessibility tool in higher education: A review of the current literature. *The Australian Educational Researcher*, 49(5), 1025-1043. <https://doi.org/10.1007/s13384-021-00471-7>
- Cunninghame, M. I., Costello, D., & Trinidad, S. (2016). *Issues and trends for students with disability*. National Centre for Student Equity in Higher Education, Curtin University.
- Cuthbertson, L., Robb, Y., & Blair, S. (2020). Theory and application of research principles and philosophical underpinning for a study utilising interpretative phenomenological analysis. *Radiography*, 26(2), e94-e102. <https://doi.org/10.1016/j.radi.2019.11.092>
- Davidson, J. (2008). Autistic culture online: Virtual communication and cultural expression on the spectrum. *Social & Cultural Geography*, 9(7), 791-806. <https://doi.org/10.1080/14649360802382586>
- Davis, M. T., Watts, G. W., & López, E. J. (2021). A systematic review of firsthand experiences and supports for students with autism spectrum disorder in higher education. *Research in Autism Spectrum Disorders*, 84, 1-12. <https://doi.org/10.1016/j.rasd.2021.101769>
- Dawkins, J. S. (1990). *A fair chance for all: National and institutional planning for equity in higher education: A discussion paper*. Australian Government Publishing Service.
- den Houting, J. (2019). Neurodiversity: An insider's perspective. *Autism*, 23(2), 271-273. <https://doi.org/10.1177/1362361318820762>

- den Houting, J. (2021). Participatory and Inclusive Autism Research Practice Guides. Brisbane. *Autism CRC*.
- den Houting, J., & Pellicano, E. (2019). A portfolio analysis of autism research funding in Australia, 2008–2017. *Journal of Autism and Developmental Disorders*, 49(11), 4400–4408. <https://doi.org/10.1007/s10803-019-04155-1>
- Department of Children, Equality, Disability, Integration and Youth. (2023). *Autism Innovation Strategy Analysis of Initial Public Consultation Submissions*. Government of Ireland. <https://aim.gov.ie/app/uploads/2023/04/Autism-Innovation-Strategy-Report-April-2023.pdf>
- Dickson, E., & Cumming, J. (2018). Reasonable adjustment in assessment: The Australian experience. In K. Trimmer, R. Dixon, & Y. Findlay (Eds.), *The Palgrave handbook of education law for schools* (pp. 315–333). https://doi.org/10.1007/978-3-319-77751-1_14
- Dijkhuis, R., de Sonnevile, L., Ziermans, T., Staal, W., & Swaab, H. (2020). Autism symptoms, executive functioning and academic progress in higher education students. *Journal of Autism and Developmental Disorders*, 50, 1353–1363. <https://doi.org/10.1007/s10803-019-04267-8>
- Disability Awareness. (2023). *External Support Workers*. <https://disabilityawareness.com.au/elearning/external-support-workers/>
- Duerksen, K., Besney, R., Ames, M., & McMorris, C. A. (2021). Supporting autistic adults in postsecondary settings: A systematic review of peer mentorship programs. *Autism in Adulthood*, 3(1), 85–99. <https://doi.org/10.1089/aut.2020.0054>
- Dwyer, P., Mineo, E., Mifsud, K., Lindholm, C., Gurba, A., & Waisman, T. C. (2023). Building neurodiversity-inclusive postsecondary campuses: Recommendations for leaders in higher education. *Autism in Adulthood*, 5(1), 1–14. <https://doi.org/10.1089/aut.2021.0042>
- Dymond, S. K., Meadan, H., & Pickens, J. L. (2017). Postsecondary education and students with autism spectrum disorders: Experiences of parents and university personnel. *Journal of Developmental and Physical Disabilities*, 29(5), 809–825. <https://doi.org/10.1007/s10882-017-9558-9>
- Eatough, V., & Smith, J. (2017). Interpretative phenomenological analysis. In C. Willig & W. Stainton-Rogers (Eds.), *Handbook of qualitative psychology* (2nd ed.). Sage.

- Ebersold, S. (2008). Adapting higher education to the needs of disabled students: Developments, challenges and prospects. In OECD (Ed.), *Higher education to 2030: Demography* (Vol. 1, pp. 221-240). OECD Publishing.
<https://doi.org/10.1787/9789264040663-en>
- Elias, R., & White, S. W. (2017). Autism goes to college: Understanding the needs of a student population on the rise. *Journal of Autism and Developmental Disorders*, 48(3), 732-746. <https://doi.org/10.1007/s10803-017-3075-7>
- Emery, A., & Anderman, L. H. (2020). Using interpretive phenomenological analysis to advance theory and research in educational psychology. *Educational Psychologist*, 55(4), 220-231. <https://doi.org/10.1080/00461520.2020.1787170>
- Evans, D., Granson, M., Langford, D., & Hirsch, S. (2023). Autism spectrum disorder: Reconceptualising support for neurodiverse students in higher education. *Journal of Higher Education Policy and Management*, 45(2), 243-257.
<https://doi.org/10.1080/1360080X.2023.2180168>
- Evans, J. R., & Mathur, A. (2005). The value of online surveys. *Internet Research*, 15(2), 195-219. <https://doi.org/10.1108/10662240510590360>
- Fabri, M., Andrews, P.C.S., Pukki, H.K., Aavikko, A., Quantock, P., de Bra, P., Stash, N., Montes Garcia, A., Merino, M., Lancho, M., Garcia, C., Szukalska, A., Modrzejewska, D. (2016, March 7-9). Widening access to higher education for students on the autism spectrum - The European Autism&Uni project. International Technology, Education and Development Conference (INTED), Valencia, Spain.
<https://www.autism-uni.org/wp-content/uploads/2015/10/2283-Autism-Uni-LBU.pdf>
- Fabri, M., Fenton, G., Andrews, P., & Beaton, M. (2022). Experiences of higher education students on the autism spectrum: Stories of low mood and high resilience. *International Journal of Disability, Development and Education*, 69(4), 1411-1429.
<https://doi.org/10.1080/1034912X.2020.1767764>
- Farahar, C. (2022). Autistic identity, culture, community, and space for well-being. In D. Milton & S. Ryan (Eds.), *The Routledge international handbook of critical autism studies* (pp. 229-241). Routledge. <https://doi.org/10.4324/9781003056577-23>

- Farahar, C., & Foster, A. (2021). # AutisticsInAcademia. In N. Brown (Ed.), *Lived Experiences of Ableism in Academia* (pp. 197-216). Cambridge University Press.
<https://doi.org/10.46692/9781447354123.016>
- Flegenheimer, C., & Scherf, K. S. (2022). College as a developmental context for emerging adulthood in autism: A systematic review of what we know and where we go from here. *Journal of Autism and Developmental Disorders*, 52(5), 2075-2097.
<https://doi.org/10.1007/s10803-021-05088-4>
- Fletcher-Watson, S., & Happé, F. (2019). *Autism: A new introduction to psychological theory and current debate*. Routledge.
- Flower, R. L., Richdale, A. L., & Lawson, L. P. (2021). Brief report: What happens after school? Exploring post-school outcomes for a group of autistic and non-autistic Australian youth. *Journal of Autism and Developmental Disorders*, 51, 1385–1391.
<https://doi.org/10.1007/s10803-020-04600-6>
- Fossey, E., Chaffey, L., Venville, A., Ennals, P., Douglas, J., & Bigby, C. (2017). Navigating the complexity of disability support in tertiary education: Perspectives of students and disability service staff. *International Journal of Inclusive Education*, 21(8), 822-832.
<https://doi.org/10.1080/13603116.2017.1278798>
- Freixa-Niella, M., Dorio-Alcaraz, I., & Corti, F. (2019). First year students' perceptions in transition to university: The students' experience. *Multidisciplinary Journal of School Education*, 16(2), 25-56. <https://doi.org/10.14632/mjse.2019.16.25>
- Gale, T., & Parker, S. (2014). Navigating change: A typology of student transition in higher education. *Studies in Higher Education*, 39(5), 734-753.
<https://doi.org/10.1080/03075079.2012.721351>
- Gelbar, N. W., Smith, I., & Reichow, B. (2014). Systematic review of articles describing experience and supports of individuals with autism enrolled in college and university programs. *Journal of Autism and Developmental Disorders*, 44(10), 2593-2601.
<https://doi.org/10.1007/s10803-014-2135-5>
- Geurts, H. M., de Vries, M., & van den Bergh, S. F. (2014). Executive functioning theory and autism. In S. Goldstein & J. A. Naglieri (Eds.), *Handbook of executive functioning* (pp. 121-141). Springer.

- Gibson, S. (2012). Narrative accounts of university education: Socio-cultural perspectives of students with disabilities. *Disability & Society*, 27(3), 353-369.
<https://doi.org/10.1080/09687599.2012.654987>
- Gillespie-Lynch, K., Bisson, J. B., Saade, S., Obeid, R., Kofner, B., Harrison, A. J., Daou, N., Tricarico, N., Delos Santos, J., & Pinkava, W. (2022). If you want to develop an effective autism training, ask autistic students to help you. *Autism*, 26(5), 1082-1094.
<https://doi.org/10.1177/13623613211041006>
- Gillespie-Lynch, K., Daou, N., Obeid, R., Reardon, S., Khan, S., & Goldknopf, E. J. (2021). What contributes to stigma towards autistic university students and students with other diagnoses? *Journal of Autism and Developmental Disorders*, 51, 459-475.
<https://doi.org/10.1007/s10803-020-04556-7>
- Gobbo, K., & Shmulsky, S. (2016). Autistic identity development and postsecondary education. *Disability Studies Quarterly*, 36(3).
<https://doi.org/10.18061/dsq.v36i3.5053>
- Goddard, H., & Cook, A. (2022). “I spent most of freshers in my Room” — A qualitative study of the social experiences of university students on the autistic spectrum. *Journal of Autism and Developmental Disorders*, 52(6), 2701-2716.
<https://doi.org/10.1007/s10803-021-05125-2>
- Government of Canada. (2023). *Autism: National autism strategy*.
<https://www.canada.ca/en/public-health/services/diseases/autism-spectrum-disorder-asd/national-strategy.html>
- Gowen, E., Taylor, R., Bleazard, T., Greenstein, A., Baimbridge, P., & Poole, D. (2019). Guidelines for conducting research studies with the autism community. *Autism Policy & Practice*, 2(1 A new beginning), 29-45.
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7099931/>
- Grant, A., & Kara, H. (2021). Considering the Autistic advantage in qualitative research: The strengths of Autistic researchers. *Contemporary Social Science*, 16(5), 589-603.
<https://doi.org/10.1080/21582041.2021.1998589>
- Grant, C., & Osanloo, A. (2016). Understanding, selecting, and integrating a theoretical framework in dissertation research: Creating the blueprint for your “house”. *Administrative Issues Journal: Connecting Education, Practice, and Research*, 4(2), 12-26. <https://doi.org/10.5929/2014.4.2.9>

- Griffith University. (2017, July 14). *5 Senses of Success* [Video].
<https://www.youtube.com/watch?v=1YrU6Aj1YX0>
- Gurbuz, E., Hanley, M., & Riby, D. M. (2019). University students with autism: The social and academic experiences of university in the UK. *Journal of Autism and Developmental Disorders*, 49, 617-631. <https://doi.org/10.1007/s10803-018-3741-4>
- Harpur, P., Szucs, B., & Willox, D. (2023, 2023/01/02). Strategic and policy responses to intersectionality in higher education. *Journal of Higher Education Policy and Management*, 45(1), 19-35. <https://doi.org/10.1080/1360080X.2022.2144790>
- Hewitt, L. E. (2011). Perspectives on support needs of individuals with autism spectrum disorders: Transition to college. *Topics in Language Disorders*, 31(3), 273-285.
<https://doi.org/10.1097/TLD.0b013e318227fd19>
- Huang, Y., Hwang, J., Arnold, S., Lawson, L., Richdale, A., & Trollor, J. (2022). Autistic Adults' Experiences of Diagnosis Disclosure. *Journal of Autism and Developmental Disorders*, 52, 5301–5307. <https://doi.org/10.1007/s10803-021-05384-z>
- Hubble, S., & Bolton, P. (2021). Support for disabled students in higher education in England. <https://commonslibrary.parliament.uk/research-briefings/cbp-8716/>
- Hull, L., Petrides, K., Allison, C., Smith, P., Baron-Cohen, S., Lai, M.-C., & Mandy, W. (2017). “Putting on my best normal”: Social camouflaging in adults with autism spectrum conditions. *Journal of Autism and Developmental Disorders*, 47, 2519-2534. <https://doi.org/10.1007/s10803-017-3166-5>
- Hutchison, P., Lord, J., & Salisbury, B. (2006). North American approaches to individualised planning and direct funding. In J. Leece & J. Bornat (Eds.), *Developments in direct payments* (pp. 49-62). <https://doi.org/10.51952/9781847421470.ch004>
- Interagency Autism Coordinating Committee (IACC). (2023). *2021-2023 Strategic Plan for Autism Research, Services, and Policy*. https://iacc.hhs.gov/meetings/iacc-meetings/2023/full-committee-meeting/january18/strategic_plan_draft.pdf?ver=2
- Järkestig Berggren, U., Rowan, D., Bergbäck, E., & Blomberg, B. (2016). Disabled students' experiences of higher education in Sweden, the Czech Republic, and the United States – a comparative institutional analysis. *Disability & Society*, 31(3), 339-356.
<https://doi.org/10.1080/09687599.2016.1174103>

- Jóhannsdóttir, Á., Egilson, S. Þ., & Haraldsdóttir, F. (2022). Implications of internalised ableism for the health and wellbeing of disabled young people. *Sociology of Health & Illness*, 44(2), 360-376. <https://doi.org/10.1111/1467-9566.13425>
- Jones, S. C., Akram, M., Gordon, C. S., Murphy, N., & Sharkie, F. (2021, 2021/10/01). Autism in Australia: Community knowledge and autistic people's experiences. *Journal of Autism and Developmental Disorders*, 51(10), 3677-3689. <https://doi.org/10.1007/s10803-020-04819-3>
- Katsiyannis, A., Zhang, D., Landmark, L., & Reber, A. (2009). Postsecondary education for individuals with disabilities: Legal and practice considerations. *Journal of Disability Policy Studies*, 20(1), 35-45. <https://doi.org/10.1177/1044207308324896>
- Kauffman, J. M., Anastasiou, D., Felder, M., Lopes, J., Hallenbeck, B. A., Hornby, G., & Ahrbeck, B. (2023). Trends and issues involving disabilities in higher education. *Trends in Higher Education*, 2(1), 1-15. <https://doi.org/10.3390/higheredu2010001>
- Kenny, L., Hattersley, C., Molins, B., Buckley, C., Povey, C., & Pellicano, E. (2016). Which terms should be used to describe autism? Perspectives from the UK autism community. *Autism*, 20(4), 442-462. <https://doi.org/10.1177/1362361315588200>
- Kift, S. (2008). *The next, great first year challenge: Sustaining, coordinating and embedding coherent institution-wide approaches to enact the FYE as "everybody's business"*. 11th International Pacific Rim First Year in Higher Education Conference, An Apple for the Learner: Celebrating the First Year Experience, 2008, Hobart, 16. http://www.fyhe.com.au/past_papers/papers08/FYHE2008/content/pdfs/Keynote%20-%20Kift.pdf
- Kift, S. (2009). *Articulating a transition pedagogy to scaffold and to enhance the first year student learning experience in Australian higher education: Final report for ALTC senior fellowship program*. Citeseer.
- Kift, S. (2015). A decade of transition pedagogy: A quantum leap in conceptualising the first year experience. *HERDSA Review of Higher Education*, 2, 51-86. <http://www.hersda.org.au/herdsa-review-higher-education-vol-2/51-86>
- Kift, S. (2021). Whole-of-institution transformation for first year learning and success. In H. Huijser, M. Kek, & F. F. Padró (Eds.), *Student support services* (pp. 1-22). Springer Singapore. https://doi.org/10.1007/978-981-13-3364-4_34-1

- Kilpatrick, S., Johns, S., Barnes, R., Fischer, S., McLennan, D., & Magnussen, K. (2017). Exploring the retention and success of students with disability in Australian higher education. *International Journal of Inclusive Education*, 21(7), 747-762. <https://doi.org/10.1080/00131911.2017.1379472>
- Kim, S. Y., & Crowley, S. (2021). Understanding perceptions and experiences of autistic undergraduate students toward disability support offices of their higher education institutions. *Research in Developmental Disabilities*, 113, 103956. <https://doi.org/10.1016/j.ridd.2021.103956>
- Kim, S. Y., Crowley, S., & Bottema-Beutel, K. (2021). Autistic undergraduate students' transition and adjustment to higher education institutions. *Research in Autism Spectrum Disorders*, 89, 101883. <https://doi.org/10.1016/j.rasd.2021.101883>
- Kimball, E. W., & Thoma, H. S. (2019). College experiences for students with disabilities: An ecological synthesis of recent literature. *Journal of College Student Development*, 60(6), 674-693. <https://doi.org/10.1353/csd.2019.0062>
- Kirchner, J., Ruch, W., & Dziobek, I. (2016). Brief report: Character strengths in adults with autism spectrum disorder without intellectual impairment. *Journal of Autism and Developmental Disorders*, 46(10), 3330-3337. <https://doi.org/10.1007/s10803-016-2865-7>
- Kivunja, C. (2018). Distinguishing between theory, theoretical framework, and conceptual framework: A systematic review of lessons from the field. *International Journal of Higher Education*, 7(6), 44-53. <https://doi.org/10.5430/ijhe.v7n6p44>
- Knott, F., & Taylor, A. (2014). Life at university with Asperger syndrome: A comparison of student and staff perspectives. *International Journal of Inclusive Education*, 18(4), 411-426. <https://doi.org/10.1080/13603116.2013.781236>
- Kogan, M. D., Vladutiu, C. J., Schieve, L. A., Ghandour, R. M., Blumberg, S. J., Zablotsky, B., Perrin, J. M., Shattuck, P., Kuhlthau, K. A., Harwood, R. L., & Lu, M. C. (2018). The prevalence of parent-reported autism spectrum disorder among US children. *Pediatrics*, 142(6), e20174161. <https://doi.org/10.1542/peds.2017-4161>
- Koro-Ljungberg, M., Yendol-Hoppey, D., Smith, J. J., & Hayes, S. B. (2009). (E)pistemological awareness, instantiation of methods, and uninformed methodological ambiguity in qualitative research projects. *Educational Researcher*, 38(9), 687-699. <https://doi.org/10.3102/0013189X09351980>

- Kuder, S. J., & Accardo, A. (2018). What works for college students with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 48(3), 722-731.
<https://doi.org/10.1007/s10803-017-3434-4>
- Kuzminski, R., Netto, J., Wilson, J., Falkmer, T., Chamberlain, A., & Falkmer, M. (2019). Linking knowledge and attitudes: Determining neurotypical knowledge about and attitudes towards autism. *PLOS one*, 14(7), e0220197.
<https://doi.org/10.1371/journal.pone.0220197>
- Lai, M.-C., & Baron-Cohen, S. (2015). Identifying the lost generation of adults with autism spectrum conditions. *The Lancet Psychiatry*, 2(11), 1013-1027.
[https://doi.org/10.1016/S2215-0366\(15\)00277-1](https://doi.org/10.1016/S2215-0366(15)00277-1)
- Lai, M.-C., Kasse, C., Besney, R., Bonato, S., Hull, L., Mandy, W., Szatmari, P., & Ameis, S. H. (2019). Prevalence of co-occurring mental health diagnoses in the autism population: A systematic review and meta-analysis. *The Lancet Psychiatry*, 6(10), 819-829. [https://doi.org/10.1016/S2215-0366\(19\)30289-5](https://doi.org/10.1016/S2215-0366(19)30289-5)
- Lambe, S., Russell, A., Butler, C., Fletcher, S., Ashwin, C., & Brosnan, M. (2018). Autism and the transition to university from the student perspective. *Autism*, 23(6), 1531–1541. <https://doi.org/10.1177/1362361318803935>
- Lang, L. (2015). Responsibility and participation in transition to university – voices of young people with disabilities. *Scandinavian Journal of Disability Research*, 17(2), 130-143.
<https://doi.org/10.1080/15017419.2013.817355>
- Larkin, M., Watts, S., & Clifton, E. (2006). Giving voice and making sense in interpretative phenomenological analysis. *Qualitative Research in Psychology*, 3(2), 102-120.
<https://doi.org/10.1191/1478088706qp062oa>
- Larsen, A., Horvath, D., & Bridge, C. (2020). 'Get ready': Improving the transition experience of a diverse first year cohort through building student agency. *Student Success*, 11(2), 14-27. <https://doi.org/10.5204/ssj.v11i3.1144>
- Lei, J., Brosnan, M., Ashwin, C., & Russell, A. (2020). Evaluating the role of autistic traits, social anxiety, and social network changes during transition to first year of university in typically developing students and students on the autism spectrum. *Journal of Autism and Developmental Disorders*, 50, 1-20. <https://doi.org/10.1007/s10803-020-04391-w>

- Lei, J., & Russell, A. (2021). Understanding the role of self-determination in shaping university experiences for autistic and typically developing students in the United Kingdom. *Autism*, 25(5), 1262-1278. <https://doi.org/10.1177/1362361320984897>
- Lester, J. N. (2014). Young adulthood, transitions, and dis/ability. In C. A. Davis & J. S. Olson (Eds.), *Meeting the transitional needs of young adult learners : New directions for adult and continuing education* (Vol. 143, pp. 39-49). <https://ebookcentral-proquest-com.ezproxy.flinders.edu.au>
- Letts, L., Wilkins, S., Law, M., Stewart, D., Bosch, J., & Westmorland, M. (2007). Guidelines for critical review form: Qualitative studies (Version 2.0). *McMaster University Occupational Therapy Evidence-Based Practice Research Group*.
- Lewis, L. F. (2017, 2017/08/01). A mixed methods study of barriers to formal diagnosis of autism spectrum disorder in adults. *Journal of Autism and Developmental Disorders*, 47(8), 2410-2424. <https://doi.org/10.1007/s10803-017-3168-3>
- Lizzio, A. (2006). *Designing an orientation and transition strategy for commencing students: A conceptual summary of research and practice (First year experience project)* Griffith University,
- Lizzio, A. (2011). *The student lifecycle: An integrative framework for guiding practice*. Brisbane: Griffith University.
- Loomes, R., Hull, L., & Mandy, W. P. L. (2017). What is the male-to-female ratio in autism spectrum disorder? A systematic review and meta-analysis. *Journal of the American Academy of Child & Adolescent Psychiatry*, 56(6), 466-474. <https://doi.org/10.1016/j.jaac.2017.03.013>
- Lubin, J., & Brooks, J. (2021). College students with autism: Navigating the bumpy road. *College Student Journal*, 55(3), 318-324. <https://www.ingentaconnect.com/content/prin/csj/2021/00000055/00000003/art00007>
- MacLennan, K., Woolley, C., @ 21andsensory, E., Heasman, B., Starns, J., George, B., & Manning, C. (2022). "It is a big spider web of things": Sensory experiences of autistic adults in public spaces. *Autism in Adulthood*, Ahead of print. <https://doi.org/10.1089/aut.2022.0024>
- Madriaga, M., & Goodley, D. (2010). Moving beyond the minimum: Socially just pedagogies and Asperger's syndrome in UK higher education. *International Journal of Inclusive Education*, 14(2), 115-131. <https://doi.org/10.1080/13603110802504168>

- Mayoh, J., & Onwuegbuzie, A. J. (2015). Toward a conceptualization of mixed methods phenomenological research. *Journal of Mixed Methods Research*, 9(1), 91-107.
<https://doi.org/10.1177/1558689813505358>
- Meadows, K. A. (2003). So you want to do research? 5: Questionnaire design. *British Journal of Community Nursing*, 8(12), 562-570.
<https://doi.org/10.12968/bjcn.2003.8.12.11854>
- Miller, D., Rees, J., & Pearson, A. (2021). "Masking is life": Experiences of masking in autistic and nonautistic adults. *Autism in Adulthood*, 3(4), 330-338.
<https://doi.org/10.1089/aut.2020.0083>
- Mitchell, W., & Beresford, B. (2014). Young people with high-functioning autism and Asperger's syndrome planning for and anticipating the move to college: what supports a positive transition? *British Journal of Special Education*, 41(2), 151-171.
<https://doi.org/10.1111/1467-8578.12064>
- Moher, D., Liberati, A., Tetzlaff, J., Altman, D. G., & The PRISMA Group. (2009). Preferred reporting items for systematic reviews and meta-analyses: The PRISMA statement. *PLoS med*, 6(7), e1000097. <https://doi.org/10.1371/journal.pmed.1000097>
- Monk, R., Whitehouse, A. J., & Waddington, H. (2022). The use of language in autism research. *Trends in Neurosciences*, 45(11), 791-793.
<https://doi.org/10.1016/j.tins.2022.08.009>
- Moriña, A. (2015). Inclusive university settings? An analysis from the perspective of students with disabilities [Review]. *Cultura y Educacion*, 27(3), 669-694.
<https://doi.org/10.1080/11356405.2015.1072361>
- Moriña, A. (2017). Inclusive education in higher education: challenges and opportunities. *European Journal of Special Needs Education*, 32(1), 3-17.
<https://doi.org/10.1080/08856257.2016.1254964>
- Morris, I. F., Matta, C., & Fung, L. K. (2022). A scoping review of peer mentoring programs for autistic college students. *Review Journal of Autism and Developmental Disorders*, 1-18. <https://doi.org/10.1007/s40489-022-00325-7>
- Mulder, A. M., & Cashin, A. (2014). The need to support students with autism at university. *Issues in Mental Health Nursing*, 35(9), 664-671.
<https://doi.org/10.3109/01612840.2014.894158>

- National Health and Medical Research Council [NHMRC]. (2007, updated 2018). *National statement on ethical conduct in human research*. Canberra: Australian Government. <https://www.nhmrc.gov.au/about-us/publications/national-statement-ethical-conduct-human-research-2007-updated-2018#block-views-block-file-attachments-content-block-1>
- NDIS. (2022). *What can we fund if you're in university or other training?* <https://ourguidelines.ndis.gov.au/supports-you-can-access-menu/social-and-community-participation/work-and-study-supports/what-can-we-fund-if-youre-university-or-other-training>
- Neubauer, B. E., Witkop, C. T., & Varpio, L. (2019). How phenomenology can help us learn from the experiences of others. *Perspectives on Medical Education*, 8(2), 90-97. <https://doi.org/10.1007/s40037-019-0509-2>
- Newman, L., Wagner, M., Knokey, A.-M., Marder, C., Nagle, K., Shaver, D., & Wei, X. (2011). The Post-High School Outcomes of Young Adults with Disabilities up to 8 Years after High School: A Report from the National Longitudinal Transition Study-2 (NLTS2). NCSER 2011-3005. *National Center for Special Education Research*. <https://eric.ed.gov/?id=ED524044>
- Nicholas, D. B., & Klag, M. (2020). Critical reflections on employment among autistic adults. *Autism in Adulthood*, 2(4), 289-295. <https://doi.org/10.1089/aut.2020.0006>
- Nuske, A., Brett, M., & Knight, E. (In press). Disability services in higher education: An Australian perspective. In J. W. Madaus & L. L. Dukes III (Eds.), *Handbook of Higher Education and Disability*. Elgar.
- Nuske, A., Rillotta, F., Bellon, M., & Richdale, A. (2019). Transition to higher education for students with autism: A systematic literature review. *Journal of Diversity in Higher Education*, 12(3), 280-295. <https://doi.org/10.1037/dhe0000108>
- Ohl, A., Grice Sheff, M., Small, S., Nguyen, J., Paskor, K., & Zanjirian, A. (2017). Predictors of employment status among adults with autism spectrum disorder. *Work*, 56(2), 345-355. <https://doi.org/10.3233/WOR-172492>
- Oredipe, T., Kofner, B., Riccio, A., Cage, E., Vincent, J., Kapp, S. K., Dwyer, P., & Gillespie-Lynch, K. (2023). Does learning you are autistic at a younger age lead to better adult outcomes? A participatory exploration of the perspectives of autistic university students. *Autism*, 27(1), 200-212. <https://doi.org/10.1177/13623613221086700>

- Ortlipp, M. (2008). Keeping and using reflective journals in the qualitative research process. *The Qualitative Report*, 13(4), 695-705. <https://nsuworks.nova.edu/tqr/vol13/iss4/8/>
- Osborne, T. (2019, 2019/02/07). Not lazy, not faking: Teaching and learning experiences of university students with disabilities. *Disability & Society*, 34(2), 228-252. <https://doi.org/10.1080/09687599.2018.1515724>
- Parliament of Canada. (2023). *Federal Framework on Autism Spectrum Disorder Act*. <https://www.parl.ca/legisinfo/en/bill/44-1/s-203>
- Patton, M. Q. (2002). *Qualitative research and evaluation methods*. Sage.
- Pearson, C. (2012). Independent living. In N. Watson, Roulstone, A. and Thomas, C (Ed.), *Routledge companion to disability studies* (pp. 240-252). Routledge.
- Pedler, M. L., Willis, R., & Nieuwoudt, J. E. (2022). A sense of belonging at university: Student retention, motivation and enjoyment. *Journal of Further and Higher Education*, 46(3), 397-408. <https://doi.org/10.1080/0309877X.2021.1955844>
- Pellicano, E., & Stears, M. (2011, Aug). Bridging autism, science and society: Moving toward an ethically informed approach to autism research. *Autism Research*, 4(4), 271-282. <https://doi.org/10.1002/aur.201>
- Peña, E. V., & Kocur, J. (2013). Parents' experiences in the transition of students with autism spectrum disorders to community college. *Journal of Applied Research in the Community College*, 20(2), 25-32. http://works.bepress.com/edlyn_pena/11/
- Pinder-Amaker, S. (2014). Identifying the unmet needs of college students on the autism spectrum. *Harvard Review of Psychiatry*, 22(2), 125-137. <https://doi.org/10.1097/HRP.0000000000000032>
- Poulsen, R., Brownlow, C., Lawson, W., & Pellicano, E. (2022). Meaningful research for autistic people? Ask autistics! , 26(1), 3-5. <https://doi.org/10.1177/13623613211064421>
- Pumfrey, P. D. (2008). Moving towards inclusion? The first-degree results of students with and without disabilities in higher education in the UK: 1998-2005. *European Journal of Special Needs Education*, 23(1), 31-46. <https://doi.org/10.1080/08856250701791229>

Redulski, E. (2020). *Neurodiversity toolkit*.

https://opal.latrobe.edu.au/articles/educational_resource/Neurodiversity_toolkit/13322981

Richdale, A., Dissanayake, C., & Cai, R. (2012). *DHS final report*. Olga Tennison Autism Research Centre, La Trobe University.

Riddell, S., Pearson, C., Jolly, D., Barnes, C., Priestley, M., & Mercer, G. (2005). The development of direct payments in the UK: Implications for social justice. *Social Policy and Society*, 4(1), 75-85. <https://doi.org/10.1017/S1474746404002209>

Rocco, T. S. (2001). Helping adult educators understand disability disclosure. *Adult Learning*, 12(2), 10-12. <https://doi.org/10.1177/104515950101200204>

Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability. (2023). *Executive summary, our vision for an inclusive Australia and recommendations*. Commonwealth of Australia.
<https://disability.royalcommission.gov.au/publications/final-report-executive-summary-our-vision-inclusive-australia-and-recommendations>

Russell, G., Kapp, S. K., Elliott, D., Elphick, C., Gwernan-Jones, R., & Owens, C. (2019). Mapping the autistic advantage from the accounts of adults diagnosed with autism: A qualitative study. *Autism in Adulthood*, 1(2), 124-133.
<https://doi.org/10.1089/aut.2018.0035124>

Sarrett, J. C. (2018). Autism and accommodations in higher education: Insights from the autism community. *Journal of Autism and Developmental Disorders*, 48(3), 679-693.
<https://doi.org/10.1007/s10803-017-3353-4>

Schembri-Mutch, T. M., McCrimmon, A. W., & Zwiers, M. L. (2023). Understanding the needs of autistic post-secondary students. *Journal of Autism and Developmental Disorders*, 1-15. <https://doi.org/10.1007/s10803-023-06010-w>

Schlossberg, N. K. (2011). The challenge of change: The transition model and its applications. *Journal of Employment Counseling*, 48(4), 159-162.
<https://doi.org/10.1002/j.2161-1920.2011.tb01102.x>

Shakes, P., & Cashin, A. (2019). Identifying language for people on the autism spectrum: A scoping review. *Issues in Mental Health Nursing*, 40(4), 317-325.
<https://doi.org/10.1080/01612840.2018.1522400>

- Shattuck, P. T., Steinberg, J., Yu, J., Wei, X., Cooper, B. P., Newman, L., & Roux, A. M. (2014). Disability identification and self-efficacy among college students on the autism spectrum. *Autism Research and Treatment*, 2014, 924182.
<https://doi.org/10.1155/2014/924182>
- Shea, G., & Derry, S. (2019, 2019/07/01/). Academic libraries and autism spectrum disorder: What do we know? *The Journal of Academic Librarianship*, 45(4), 326-331.
<https://doi.org/https://doi.org/10.1016/j.acalib.2019.04.007>
- Shpigelman, C.-N., Mor, S., Sachs, D., & Schreuer, N. (2022). Supporting the development of students with disabilities in higher education: Access, stigma, identity, and power. *Studies in Higher Education*, 47(9), 1776-1791.
<https://doi.org/10.1080/03075079.2021.1960303>
- Simmeborn Fleischer, A. (2012). Support to students with Asperger syndrome in higher education — The perspectives of three relatives and three coordinators. *International Journal of Rehabilitation Research*, 35(1), 54-61.
<https://doi.org/10.1097/MRR.0b013e32834f4d3b>
- Sims, T. (2016). Transition to university for young adults on the autism spectrum. *The Journal of Inclusive Practice in Further and Higher Education*, 7, 64-69.
- Sischka, P. E., Décieux, J. P., Mergener, A., Neufang, K. M., & Schmidt, A. F. (2022). The impact of forced answering and reactance on answering behavior in online surveys. *Social Science Computer Review*, 40(2), 405-425.
<https://doi.org/10.1177/089443932090706>
- Smith, J. A., Flowers, P., & Larkin, M. (2009). *Interpretative phenomenological analysis: Theory, method and research*. SAGE.
- Smith, J. A., Flowers, P., & Larkin, M. (2022). *Interpretative phenomenological analysis: Theory, method and research* (2nd ed.). SAGE.
- Smith, J. A., & Shinebourne, P. (2012). Interpretative phenomenological analysis. In H. Cooper, P. M. Camic, D. L. Long, A. T. Panter, D. Rindskopf, & K. J. Sher (Eds.), *APA handbooks in psychology®. APA handbook of research methods in psychology, Vol. 2. Research designs: Quantitative, qualitative, neuropsychological, and biological*. American Psychological Association. <https://doi.org/10.1037/13620-005>
- Sue, V. M., & Ritter, L. A. (2012). *Conducting online surveys* (2nd ed.). Sage.
<https://doi.org/10.4135/9781506335186>

- Swart, E., & Greyling, E. (2011). Participation in higher education: Experiences of students with disabilities. *Acta Academica*, 43(4), 81-110.
http://scholar.ufs.ac.za:8080/xmlui/bitstream/handle/11660/2833/academ_v43_n4_a4.pdf?sequence=1
- Thomas, A. J. (2020). Examining the neurodiverse postsecondary experience. *Journal of Disability Studies*, 6(1), 18-25.
<http://pubs.iscience.in/journal/index.php/jds/article/view/1049>
- Thompson-Hodgetts, S. (2023). Reflections on my experiences as a non-autistic autism researcher. *Autism*, 27(1), 259-261. <https://doi.org/10.1177/13623613221121432>
- Toepoel, V. (2015). *Doing surveys online*. SAGE.
- Tong, A., Sainsbury, P., & Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*, 19(6), 349-357.
<https://doi.org/10.1093/intqhc/mzm042>
- Toor, N., Hanley, T., & Hebron, J. (2016). The facilitators, obstacles and needs of individuals with autism spectrum conditions accessing further and higher education: A systematic review. *Journal of Psychologists & Counsellors in Schools*, 26(2), 166-190. <https://doi.org/10.1017/jqc.2016.21>
- Treweek, C., Wood, C., Martin, J., & Freeth, M. (2019). Autistic people's perspectives on stereotypes: An interpretative phenomenological analysis. *Autism*, 23(3), 759-769.
<https://doi.org/10.1177/1362361318778286>
- Turnock, A., Langley, K., & Jones, C. R. (2022). Understanding stigma in autism: A narrative review and theoretical model. *Autism in Adulthood*, 4(1), 76-91.
<https://doi.org/10.1089/aut.2021.0005>
- UK Government. (2009). *Autism Act*. <https://www.legislation.gov.uk/ukpga/2009/15/contents>
- UK Government. (2021). *The national strategy for autistic children, young people and adults: 2021 to 2026*.
https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1004528/the-national-strategy-for-autistic-children-young-people-and-adults-2021-to-2026.pdf

Convention on the Rights of Persons with Disabilities. (2006).

<http://www.un.org/disabilities/convention/conventionfull.shtml>

University of South Australia. (2023). *information for parents*.

<https://study.unisa.edu.au/services-for-schools/resources-and-support/information-for-parents/>

US Government. (2019). *Autism, Collaboration, Accountability, Research, Education, and Support Act of 2019*. <https://www.congress.gov/116/plaws/publ60/PLAW-116publ60.pdf>

Usher, W. (2020). Living in quiet desperation: The mental health epidemic in Australia's higher education. *Health Education Journal*, 79(2), 138-151.
<https://doi.org/10.1177/0017896919867438>

Van Hees, V., Moyson, T., & Roeyers, H. (2015). Higher education experiences of students with autism spectrum disorder: Challenges, benefits and support needs. *Journal of Autism and Developmental Disorders*, 45(6), 1673-1688.
<https://doi.org/10.1007/s10803-014-2324-2>

Van Manen, M. (1990). *Researching lived experience: Human science for an action sensitive pedagogy*. SUNY.

VanBergeijk, E., Klin, A., & Volkmar, F. (2008). Supporting more able students on the autism spectrum: College and beyond. *Journal of Autism and Developmental Disorders*, 38(7), 1359-1370. <https://doi.org/10.1007/s10803-007-0524-8>

Volkmar, F. R., Reichow, B., & McPartland, J. C. (2014). *Adolescents and adults with autism spectrum disorders*. Springer. <https://doi.org/10.1007/978-1-4939-0506-5>

Walker, N. (2021). *Neuroqueer heresies: Notes on the neurodiversity paradigm, autistic empowerment, and postnormal possibilities*. Autonomous Press.
<https://books.google.com.au/books?id=xG6izgEACAAJ>

Ward, D., & Webster, A. (2018). Understanding the lived experiences of university students with autism spectrum disorder (ASD): A phenomenological study. *International Journal of Disability, Development and Education*, 65(4), 373-392.
<https://doi.org/10.1080/1034912X.2017.1403573>

- Warner, G., Cooper, H, Cusack, J. . (2019). *A review of the autism research funding landscape in the United Kingdom*. Autistica.
<https://urn.kb.se/resolve?urn=urn:nbn:se:uu:diva-397692>
- Western Sydney University. (2023). *Disclosure During Study*.
<https://www.westernsydney.edu.au/choosingyourpath/disclosure-during-study>
- White, D., Hillier, A., Frye, A., & Makrez, E. (2019). College students' knowledge and attitudes towards students on the autism spectrum. *Journal of Autism and Developmental Disorders*, 49, 2699-2705. <https://doi.org/10.1007/s10803-016-2818-1>
- Widman, C. J., & Lopez-Reyna, N. A. (2020). Supports for postsecondary students with autism spectrum disorder: A systematic review. *Journal of Autism and Developmental Disorders*, 50, 3166–3178. <https://doi.org/10.1007/s10803-020-04409-3>
- Yardley, L. (2000). Dilemmas in qualitative health research. *Psychology and Health*, 15(2), 215-228. <https://doi.org/10.1080/08870440008400302>
- Zeedyk, S. M., Tipton, L. A., & Blacher, J. (2016). Educational supports for high functioning youth with ASD: the postsecondary pathway to college. *Focus on Autism and Other Developmental Disabilities*, 31(1), 37-48. <https://doi.org/10.1177/1088357614525435>
- Zeidan, J., Fombonne, E., Scolah, J., Ibrahim, A., Durkin, M. S., Saxena, S., Yusuf, A., Shih, A., & Elsabbagh, M. (2022). Global prevalence of autism: A systematic review update. *Autism Research*, 15(5), 778-790. <https://doi.org/10.1002/aur.2696>
- Zener, D. (2019). Journey to diagnosis for women with autism. *Advances in Autism*, 5(1), 2-13. <https://doi.org/10.1108/aia-10-2018-0041>

APPENDICES

Appendix A: Published systematic literature review



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1938-8926/19/\$12.00

NADOHE
National Association of Diversity Officers in Higher Education

Journal of Diversity in Higher Education

2019, Vol. 12, No. 3, 280–295
<http://dx.doi.org/10.1037/dhe0000108>

Transition to Higher Education for Students With Autism: A Systematic Literature Review

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This study is a systematic literature review of the experiences of individuals with autism spectrum disorder (ASD) and their family members in higher education, with a particular focus on transition. Systematic searches were conducted across six databases: Medline, CINAHL, ProQuest, PsycINFO, Scopus, and Informit. Published articles ($n = 11$) describing the experiences of transition to higher education, from the perspectives of individuals with ASD and their family members, were reviewed. The biocological theory model was used as a framework for examining the complex interactions between elements at the individual, microsystem, mesosystem, exosystem, macrosystem, and chronosystem levels, and how they impact on the student's experience of transition to higher education. Findings showed that individuals with ASD experience challenges associated with: core and associated characteristics of ASD, self-disclosure and awareness, and mental health and wellbeing. Family members reported significant challenges associated with systemic policies, which impacted on their ability to support their family member with ASD. It is highlighted that an individual and flexible approach to transition support, and increased academic and professional staff awareness and understanding of ASD, are critical to the transition experience of students with ASD in higher education.

Keywords: autism spectrum disorder, higher education, postsecondary education, transition, university

Autism spectrum disorder (ASD) is characterized by difficulties with social communication skills, and a pattern of restricted or repetitive behavior, interests, or activities (American Psychiatric Association, 2013). Most recent prevalence rates suggest approximately 1 in 68 children have ASD and an increase in this prevalence rate has been reported in the United States over the past 20 to 30 years (Christensen et al., 2016). The prevalence of ASD in adults has been reported in two English studies as approximately 1 in 100 (Brugha et al., 2011; Brugha et al., 2016). ASD is the current diagnostic category outlined in the *Diagnostic and Statistical Manual of Mental Disorders-Fifth Edition (DSM-5)*; American Psychiatric Association, 2013); however, other terminology such as autism, Asperger's syndrome, high functioning autism, autism spectrum condition, and pervasive developmental disorder not otherwise specified (PDDNOS) have also been used to describe individuals with characteristics along this spectrum. For the purposes of this review, the term ASD will be used throughout.

Inclusion of students in higher education from diverse backgrounds, including those with disabilities, has been increasing (Brett, 2016; Katsiyannis, Zhang, Landmark, & Reber, 2009; Swart & Greyling, 2011). Changes to education and disability legislation internationally, have resulted in a significant shift toward promoting increased opportunities for individuals with a disability, including ASD, to engage in higher education (Brett, 2016; Ebersold, 2008; Katsiyannis et al., 2009). The introduction of legislation such as the Disability Discrimination Act 1992 (Cth) in Australia, the Americans with Disabilities Act (1990) in the United States, and the Disability Discrimination Act (1995) in the United Kingdom has been a driving force behind changes to higher education policy and increased focus on inclusive practice over the past three decades (Brett, 2016; Järkestig Berggren, Rowan, Bergbäck, & Blomberg, 2016; Katsiyannis et al., 2009; Pumfrey, 2008; VanBergeijk, Klin, & Volkmar, 2008). The Convention on the Rights of Persons with Disabilities (UNCPRD), adopted by the United Nations in 2006, has also played a significant role in influencing disability legislation internationally. The UNCPRD highlights the importance of improved educational opportunities for individuals with disabilities (Järkestig Berggren et al., 2016; Morley & Croft, 2011).

It has been reported that the number of individuals with ASD enrolling in higher education has been increasing (Barnhill, 2016; Bell, Devecchi, Mc Guckin, & Shevlin, 2017). This may be because of the increasing inclusion of individuals with disabilities within higher education (Brett, 2016; Ebersold, 2008; Katsiyannis et al., 2009), as well as the increase in prevalence of ASD over the past 20 to 30 years (Cox et al., 2017; Gelbar, Smith, & Reichow, 2014). It is also predicted that the number of individuals with ASD

This article was published Online First February 25, 2019.

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seeking to enroll in higher education is likely to continue to rise (Kuder & Accardo, 2018; Pinder-Amaker, 2014; Thierfeld Brown & Wolf, 2014). Thus, it is necessary to further examine and synthesize the literature available across existing studies to better understand the experiences of students with ASD and their family members during the transition to higher education. Further research is also needed to explore the experiences of these students to develop appropriate and effective support strategies during their transition to higher education.

Difficulties with social communication skills; a preference for structure and difficulty managing changes to routines; difficulties with executive functioning skills, such as planning and problem solving; and sensory sensitivities, associated with ASD often create significant challenges in primary and secondary educational settings (Fleury et al., 2014). These same difficulties can also create unique challenges in the higher education setting, where routine and structure is often lacking, educational spaces are often much larger and overwhelming, and access to support requires an increased level of self-awareness, and a reliance on a student's ability and willingness to self-disclose (Adreon & Durocher, 2007; Knott & Taylor, 2014) and to seek support.

There is a wide range of literature on the barriers to, and facilitators for individuals with ASD while undertaking studies in higher education (Barnhill, 2016; Brown & Coomes, 2016; Knott & Taylor, 2014; Kuder & Accardo, 2018; VanBergeijk et al., 2008); however, there is a paucity of research that has focused specifically on the transition period. In addition, there are limited studies that explore the experiences of individuals with ASD in higher education directly (Alverson, Lindstrom, & Hirano, 2015; C. Anderson & Butt, 2017; Baric, Hemmingsson, Hellberg, & Kjellberg, 2017; Bell et al., 2017; Cai & Richdale, 2016; Madriaga & Goodley, 2010; Mitchell & Beresford, 2014; Van Hees, Moyson, & Roeyers, 2015).

Literature investigating the experiences of students with disabilities in higher education has highlighted a range of difficulties and barriers. For students with ASD, many of these difficulties relate to the need for self-disclosure, self-awareness and a desire to "fit in," often resulting in a delay in seeking or accessing disability support services (Adreon & Durocher, 2007; Bell et al., 2017; Cox et al., 2017). As Hewitt (2011) highlights, this may in fact be the first time that the student has been required to advocate for themselves to access supports or accommodations. Disclosure to disability services is the first step in successfully accessing services and supports (Rocco, 2001); however, research has shown that some students may be reluctant to disclose their disability (Adreon & Durocher, 2007; A. H. Anderson, Carter, & Stephenson, 2018; Shattuck et al., 2014), and this may result in delayed access to services. For this reason, a broad definition of "transition" has been considered for this review, to encompass the transition into and the first year of studies in higher education.

Family members, in particular parents, play a significant role in supporting and advocating for an individual with ASD, especially during their primary and secondary educational years (Volkmar, Reichow, & McPartland, 2014). Previous studies exploring needs and facilitators for individuals with ASD attending higher education have also highlighted the importance of family support in the pursuit of higher education (Zeedyk, Tipton, & Blacher, 2016). However, research exploring the experiences of parents or other family members during the transition to higher education for

students with ASD is lacking (C. Anderson & Butt, 2017; Bell et al., 2017; Cai & Richdale, 2016; Dymond, Meadan, & Pickens, 2017; Simmeborn Fleischer, 2012; Peña & Kocur, 2013). Therefore, studies that have examined the perspectives of family members during this transition have also been included within this review.

The experiences of students with disabilities in higher education have been an expanding area of focus in educational research in recent years (Lang, 2015). There has also been an increase in the number of studies focused on the experiences of students with ASD enrolled in higher education. A number of systematic reviews into these experiences have been conducted over the past 5 years (A. H. Anderson, Stephenson, & Carter, 2017; Gelbar et al., 2014; Toor, Hanley, & Hebron, 2016; Zeedyk et al., 2016), with varying focus and purpose. In particular the study conducted by Toor et al. (2016), examined the literature on the experiences of students with ASD, their family members and staff in the higher education setting. This review identified the facilitators, obstacles, and needs of individuals with ASD in accessing higher education. While not specifically focused on transition itself, it highlights the transition period as a significant aspect of students' successful participation in higher education. The latest article reviewed by Toor and colleagues, was published in 2015. Since this time, a number of additional studies have been conducted exploring these experiences for students with ASD and their family members. In addition, the study conducted by Toor et al. (2016) excluded studies with a quantitative or mixed methods design. While the purpose of only including studies with a qualitative design was to ensure that all included studies had directly explored the experiences of individuals with ASD in this transition process, exclusion of mixed methods studies may have resulted in relevant qualitative data being excluded from their evaluation. To gather a wide range of literature on the subject, the current review has, therefore, included articles with a qualitative or mixed methods approach to ensure qualitative discussion of experiences are not overlooked.

Another review, conducted by Sims (2016), was geographically limited, only including research conducted within the United Kingdom. While differences in educational practice between the United Kingdom and other countries was cited as the reason for this limited geographical scope, one can argue that, given the paucity of literature on the subject, a systematic review of studies conducted with an international perspective is warranted. Regardless of systemic differences between various countries' higher education systems, the needs and experiences of individuals with ASD and their families are likely to be similar across international boundaries. This in turn can assist in the development of recommendations for best practice globally and identification of areas for future research.

As a result of the increase in the number of students with ASD likely to be enrolling in higher education, and the growing research being undertaken in this area, it is critical for higher education institutions (HEIs) to develop an in depth understanding of the experiences of these students to implement best practice transition support strategies. Systematic review methodology is designed to do just this; provide an analysis and synthesis of current available knowledge within a specific area. Bearman et al. (2012) highlight the benefits of systematic review methodology, in particular as it relates to the higher education sector and acknowledges the limited uptake of this methodology within this setting. While Bearman et

al. (2012) recognize the challenges in undertaking this methodology, they also identify the importance of the systematic review in potentially increasing the quality of future research conducted in the field.

Aim

The first aim of this review is to provide an update of current research, with a focus on the transition experiences of students with ASD, and the experiences of their family members during this time.

An additional aim was to further understand the experiences of individuals with ASD and their family members in their transition to higher education, to inform best practice strategies for supporting students with ASD in their first year in higher education. The review question is: What are the experiences of individuals with autism spectrum disorder and/or their family members regarding transition to higher education?

From the available literature on transition to higher education for students with ASD, there does not appear to be a standard practice or approach to transition or orientation to university for students with ASD. In policy development and implementation, it is important to consider the views of those effected by these decisions; therefore, the goal of this systematic literature review is to provide an analysis and synthesis of available studies that have investigated the experiences of students with ASD and/or their family members. This will provide an important insight into these experiences, which in turn can help to inform future policy and intervention decisions in relation to this complex transition process. To better understand the complex systems and interactions involved in this transition process, a bioecological systems theory (Bronfenbrenner, 1979) framework has been adopted to explore and describe the outcomes of the studies reviewed.

Method

A systematic review was conducted following the PRISMA guidelines (Moher, Liberati, Tetzlaff, & Altman, 2009). Systematic searches were conducted across six databases during August of 2017: Medline, CINAHL, ProQuest limited to articles only, PsycINFO, Scopus, and Informit.

Searches were conducted using a combination of free text and subject headings terms (such as MeSH terms) and were combined using Boolean operators. Examples of subject heading terms are provided in Table 1 and Table 2. The free text search terms used

included synonyms for each keyword such as: Autism spectrum disorder OR Asperger; higher education OR further education OR tertiary education OR postsecondary education OR university OR college; transition.

The primary focus of this review was on studies that included a qualitative component to their investigation of the experiences of individuals with ASD or their family members in their transition to higher education. For this reason, mixed-methods studies were included to ensure that relevant articles or experiences were not overlooked. Articles were excluded if they contained less than 10% qualitative data on the experiences of individuals or their family members in the transition to higher education. Articles were also excluded if less than 10% of the participants had ASD or were the family member of an individual with ASD. Articles in which less than 10% of the data described transition experiences (i.e., commencing in higher education, first year of higher education) were also excluded.

References returned through the search strategy outlined above were downloaded into the systematic review software Covidence. Using this software, articles were screened by title and abstract, by two independent reviewers (AN and MB) Where there was uncertainty about whether a specific article met the eligibility criteria, the full article was included for detailed review against the inclusion criteria. Conflicts were resolved through discussion between the two reviewers and an agreement was made as to the inclusion of these articles.

The same reviewers conducted an autonomous review of the full text versions of potentially relevant studies using the eligibility criteria outlined above. Reviewers recorded reasons for exclusion using the Covidence software. Any disagreements in determining eligibility of an article was resolved by discussion between the two reviewers. Reference lists of all articles selected were also hand searched to identify additional articles for inclusion. Hand searches were conducted in two key journals in ASD and in disability and diversity in higher education: *Focus on Autism and Developmental Disabilities*; *Journal of Autism and Developmental Disorders*; *Journal of Diversity in Higher Education*; and *Journal of Further and Higher Education*.

Bioecological Theory and Transition to Higher Education

Previous literature reviews conducted within this area have not used a theoretical framework in analyzing study findings; however, given the complex elements involved in the transition to

Table 1
Medline Search Terms

1. Exp Autistic Disorder/
2. Exp Autism Spectrum Disorder/ or exp Asperger Syndrome/
3. (autis* or asperger* or ASD or ASC).tw.
4. 1 or 2 or 3
5. Exp Universities/
6. Exp Vocational Education/
7. (universit* or college* or higher education or postsecondary education or postsecondary education or postsecondary education or tertiary education or TAFE or vocational education).tw.
8. 5 or 6 or 7
9. (transition* or prepar*).tw.
10. 4 and 8 and 9

Table 2
PsycINFO Search Terms

1. Exp Autism Spectrum Disorders/
2. (autis* or asperger* or ASD or ASC).tw.
3. 1 or 2
4. Exp COMMUNITY COLLEGES/ or exp COLLEGES/
5. exp Higher Education/
6. (universit* or college* or higher education or further education or post-secondary education or postsecondary education or postsecondary education or tertiary education or TAFE or vocational education).tw.
7. 4 or 5 or 6
8. Exp SCHOOL TRANSITION/ or exp TRANSITION PLANNING/
9. (transition* or prepar*).tw.
10. 8 or 9
11. 3 and 7 and 10

higher education for individuals with ASD, the bioecological theory model provides a useful framework for exploring these experiences in more depth. Therefore, studies examined in the current systematic review will be discussed using the bioecological theory model as a framework to consider the impact of the complex and interrelated systems within which the student engages.

Bioecological theory was originally developed by Urie Bronfenbrenner to explore the ecology of human development (Bergen, 2008). Bronfenbrenner arranges the ecological environment within which an individual exists into four systems. At the center of these systems is the individual themselves, surrounded by the people and settings within which they directly interact (microsystem), while the mesosystem describes the complex interactions between two or more of these people or settings (Bergen, 2008; Bronfenbrenner, 1979). The exosystem refers to the settings not directly related to the individual, but within which events may occur that affect the individual's development (Bergen, 2008; Bronfenbrenner, 1979). More broadly, at the macrosystem level, cultural or societal factors may also impact on the individual's development (Bergen, 2008; Bronfenbrenner, 1979). Bronfenbrenner later added a fifth system, the chronosystem, that includes historical contexts and events that may impact on the individual's situation (Bergen, 2008). In revising the bioecological theory, Bronfenbrenner sought to emphasize the interactive and dynamic nature of human development and place a greater emphasis on the individual component (Bergen, 2008).

Ecological transitions occur throughout the life span, whenever the person's position is altered because of a change of "role, setting, or both" (Bronfenbrenner, 1979, p. 26). The transition to higher education involves not only a significant change in setting, but also a significant shift in role, with increased expectations. Within higher education settings, the individual with ASD is now required to self-advocate, request support, and in many cases, live independently or away from home for the first time (Zeedyk et al., 2016).

As Pinder-Amaker (2014) highlights, a complex interaction occurs in the student's educational environment, between the individual, family members, educational staff, and other professionals (*mesosystem*); relevant policies and legislation (*exosystem*); and cultural and societal beliefs about the inclusion of individuals with ASD (*macrosystem*), which may impact directly on outcomes for the individual when they commence higher education. In addition, these factors may be influenced by significant changes in history during the individual's life span (*chronosystem*), for ex-

ample, the adoption of the UN Conventions on the Rights of Persons with Disabilities (United Nations, 2006).

Adapted from Pinder-Amaker's (2014) example of the bioecological theory model of development applied to individuals with ASD in education, Figure 1 illustrates specific elements of each of these systems as they apply to individuals with ASD, in the higher education setting.

Findings

Database searching resulted in the identification of 587 studies after duplicate removal and screening (see Figure 2). An additional 10 studies were identified through hand searching reference lists and journal indexes. After title and abstract screening, 526 articles were excluded as they did not meet inclusion criteria. A further 60 articles were excluded during full-text article review for the following reasons: not primary research study (32); not focused on transition (10); not focused on higher education (5); no or less than 10% qualitative component (4); no or less than 10% inclusion of individual or family perspectives (4); wrong population (i.e., less than 10% of participants were individuals with ASD or family members) (3); focus on pretransition expectations (1). After independent review and consensus by AN and MB, 11 articles were agreed upon for inclusion within this review.

Quality of Study Methodology

Using the McMasters Critical Review form: Qualitative Studies (Letts et al., 2007), articles that met the inclusion criteria were assessed for methodological quality by two reviewers (AN and MB). The studies reviewed ranged in quality score from 11 to 19 points (maximum possible score 21), on the McMasters critical appraisal tool (see Table 3). Of these 11 studies, the highest score (19), was achieved by two studies (Baric et al., 2017; Dymond et al., 2017), with one study scoring only 11 points (Peña & Kocur, 2013).

Two studies had evidence of a clearly described decision trail supporting auditability of the studies (Baric et al., 2017; Dymond et al., 2017). Only three studies clearly identified a theoretical perspective within which their studies were framed (Alverson et al., 2015; Baric et al., 2017; Madriaga & Goodley, 2010) and only three studies clearly identified the assumptions and biases of the researcher (Baric et al., 2017; Dymond et al., 2017; Madriaga & Goodley, 2010). The two studies with the lowest quality scores

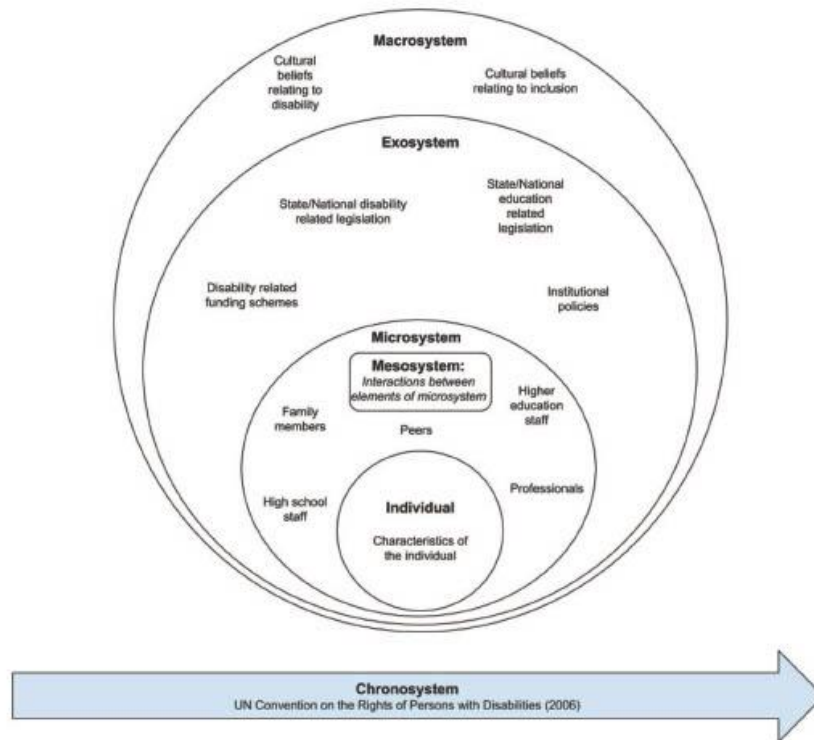


Figure 1. Bioecological theory model of transition to higher education. Adapted from Pinder-Amaker (2014). See the online article for the color version of this figure.

(Madruga & Goodley, 2010; Peña & Kocur, 2013) did not address rigor in data collection strategies and demonstrated limited evidence of trustworthiness.

Study Characteristics

Articles within this review were all published between 2010 and 2017. Four studies were conducted in the United States, 2 in the United Kingdom, 2 in Sweden, 1 in Belgium, 1 in the Republic of Ireland, and 1 in Australia. An overview of the studies is presented in Table 4.

Study designs included grounded theory (C. Anderson & Butt, 2017; Madruga & Goodley, 2010; Van Hees et al., 2015), phenomenology (Alverson et al., 2015; Baric et al., 2017), naturalistic inquiry (Peña & Kocur, 2013), and case study (Simmeborn Fleischer, 2012). Data were collected using interviews in 10 of the studies and by focus groups in one study. Four studies did not specifically state a study design (Bell et al., 2017; Cai & Richdale, 2016; Dymond et al., 2017; Mitchell & Beresford, 2014).

Participant characteristics are outlined in Table 5. There were a total of 180 participants across the 11 studies, of these a total of

158 participants were individuals with ASD or family members of individuals with ASD. Other participants included staff; individuals with a diagnosis other than ASD; or individuals who were not attending a HEI. These participants have not been discussed in this review. A total of 92 individuals with ASD ($M = 71$, $F = 21$) participated in the studies reviewed. Parents made up a total of 64 participants, across 10 of the studies, with one study (Alverson et al., 2015) including an unclear number of family members as participants. Only two studies included a sibling of an individual with ASD as a participant.

Key findings from each of the studies were categorized according to the bioecological theory model discussed earlier and are presented in Table 6. Results indicate the experiences of transition to higher education by individuals with ASD and their family members are complex and varied and are now examined within the framework of the bioecological theory model.

Individual.

Challenges related to the characteristics of ASD. Six studies described issues related directly to the core characteristics of ASD. Challenges reported during the transition to higher education included: social communication difficulties (Bell et al., 2017; Cai &

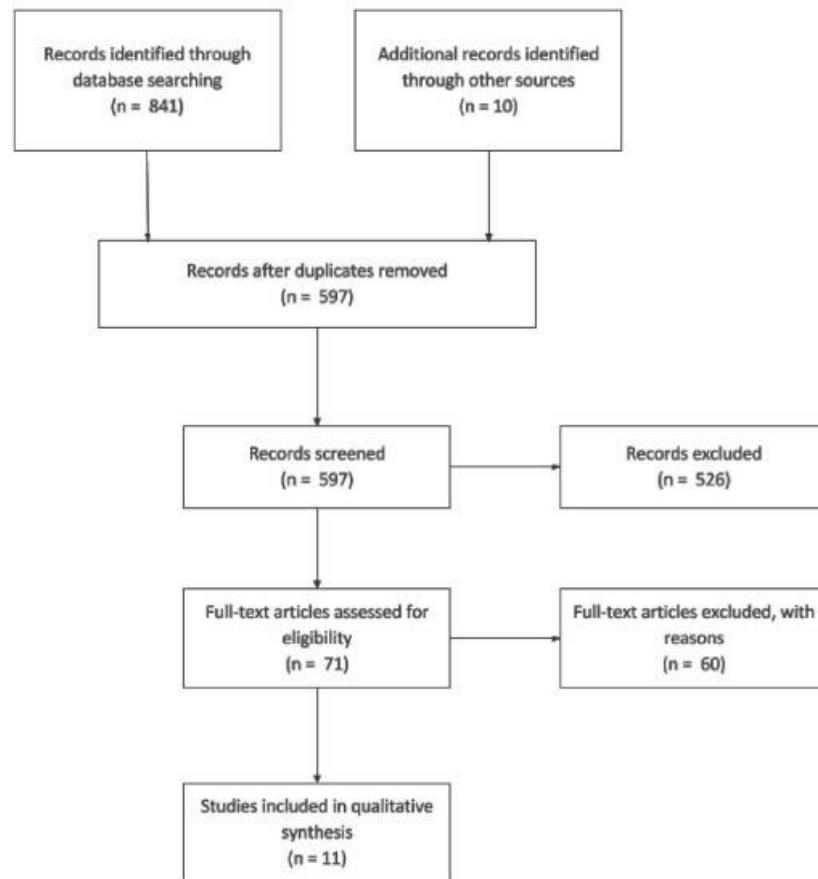


Figure 2. PRISMA flow diagram for articles identified through database searches.

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Richdale, 2016; Dymond et al., 2017; Mitchell & Beresford, 2014; Van Hees et al., 2015); sensory processing difficulties (Cai & Richdale, 2016; Simmeborn Fleischer, 2012; Van Hees et al., 2015); and the need for structure and routine (Cai & Richdale, 2016; Van Hees et al., 2015). Difficulties related to characteristics associated with ASD included: executive functioning difficulties (Cai & Richdale, 2016; Dymond et al., 2017; Simmeborn Fleischer, 2012; Van Hees et al., 2015); and difficulties with independent living skills (Dymond et al., 2017; Mitchell & Beresford, 2014; Simmeborn Fleischer, 2012).

While challenges experienced by students with ASD were similar across a number of studies, two studies also highlighted the importance of considering the difference in manifestation of these core characteristics of ASD for each individual (Alverson et al., 2015; Madriaga & Goodley, 2010). Strengths and unique skills associated with the core characteristics of ASD, such as strong

memory, dedication, focus, and an eye for detail were also highlighted by Van Hees et al. (2015).

Self-awareness/disclosure. Self-awareness and disclosure were also identified as key requirements for transition to higher education and were highlighted across five studies (Alverson et al., 2015; Cai & Richdale, 2016; Dymond et al., 2017; Peña & Kocur, 2013; Van Hees et al., 2015). Alverson et al. (2015) found that levels of self-awareness varied significantly among participants. Issues relating to disclosure across the studies reviewed included: doubts about the benefits of disclosing (Van Hees et al., 2015), deficits in self-determination skills or initiative to seek help (Dymond et al., 2017; Peña & Kocur, 2013), or a lack of acceptance to seek support until a crisis or significant challenge had arisen (Cai & Richdale, 2016; Van Hees et al., 2015).

Mental health and emotional wellbeing. Experiences of increased levels of stress and anxiety were reported by participants

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Table 3
McMaster University Critical Review Form—Qualitative Studies

Criteria (McMaster University Critical Review Form)	Alverson, Lindstrom, and Hume (2015)	Anderson and Butt (2017)	Bark, Hemmingson, Heilberg, and Kjelberg (2017)	Bell, Deseschi, Mc Cackin, and Shelin (2017)	Cai and Richdale (2016)	Dymand, McAdams, and Pickens (2017)	Malangu and Goodley (2010)	Michell and Bensford (2014)	Rein and Kocur (2013)	Simmehum Fleischer (2012)	Van Hees, Moysen, and Rogers (2015)
Was the purpose and/or research question stated clearly?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Was relevant background literature reviewed?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Was a theoretical perspective identified?	Y	N	Y	N	N	N	Y	N	N	N	N
Was the process of purposeful selection described?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Was sampling done until saturation was reached?	NA	NA	NA	NA	NA	Y	NA	NA	NA	N	NA
Was informed consent obtained?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Clear & complete description of participants?	Y	Y	Y	Y	Y	Y	N	Y	Y	N	Y
Role of researcher & relationship with participants?	N	N	N	N	N	N	N	N	N	N	N
Identification of assumptions and biases of researcher?	N	N	Y	N	N	Y	Y	N	N	N	N
Procedural rigor was used in data collection strategies?	Y	Y	Y	Y	Y	Y	NA	Y	NA	Y	Y
Data analyses were inductive?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Findings were consistent with & reflective of data?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Decision trail developed?	NA	NA	Y	NA	NA	Y	NA	NA	NA	NA	NA
Process of analyzing the data was described adequately?	Y	Y	Y	Y	Y	Y	NA	Y	Y	Y	Y
Did a meaningful picture of the phenomenon under study emerge?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Credibility	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Transferability	Y	Y	Y	Y	Y	Y	N	Y	Y	Y	Y
Dependability	Y	Y	Y	Y	Y	Y	N	Y	Y	N	Y
Confirmability	Y	Y	Y	Y	Y	Y	Y	Y	N	Y	Y
Conclusions were appropriate given the study findings?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Findings contributed to theory development & future practice/research?	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Total	17	16	19	14	16	19	12	15	11	14	16

Table 4
Overview of Studies Included in Review

Study (design)	Method(s)	Future research recommendations	Limitations
Alverson et al. (2015) (Phenomenology)	Semi-structured interviews (twice, 6–12 months apart) (protocol derived from special education, transition and ASD literature) Family background questionnaire + field notes	More extensive longitudinal and experimental studies.	Small sample size. Sample selection represents only one portion of those with ASD (before 2013 diagnostic criteria change). Participants from narrow demographic. No longitudinal data to explore college completion.
Anderson and Butt (2017) (grounded theory)	Unstructured interviews Open-ended questions	Larger, more diverse samples. Investigate practices, policies and programs associated with success.	Small convenience sample. Only included white, high income. Limited number of young adults with ASD (7) included.
Baric et al. (2017) (hermeneutical)	Semi-structured interviews Open-ended questions	To understand preparatory transitional activities and services during compulsory school which support move to employment or enrolling in HE.	Limited number of participants with ASD in university studies setting. All participants from community-based vocational training centers. Only individual view (parents, teachers not included). Limited scope
Bell et al. (2017) (not stated)	Semi-structured interviews (twice, pretransition and posttransition)	Tracking students through postsecondary education to identify quality of transition process, appropriateness of support, and whether students become socially integrated.	
Cai and Richdale (2016) (not stated)	Semi-structured focus groups (9 with students, 6 with family members) (themes derived from literature relating to needs of students with ASD in higher education) Questionnaire	Research into providing appropriate educational support and into social supports.	
Dymond et al. (2017) (not stated)	Semi-structured interviews (questions derived from literature relating to postsecondary students with disabilities and information gathered from university support staff)	Explore whether experience of parents (and university personnel) consistent with experiences of students with ASD. Case studies of specific students + parents + university personnel + support providers. Examine perspective through lens of students with ASD themselves. Examine relationship between university experience and postuniversity outcomes.	One large public research university with a history of providing disability accommodations. Only parents of students registered with Disability Services eligible to participate. Small sample size Unable to include students with ASD due to insufficient number of participants. Researchers undertaking study affiliated with the university being investigated.
Madriaga and Goodley (2010) (grounded theory/dialectical and cyclical)	Interviews (over 12 month period)		
Mitchell and Beresford (2014) (not stated)	Semi-structured interviews. (topic guides piloted with young people with ASD)	Explore cost effectiveness of school/ college links, extended visits to college campus.	Self-selecting sample. Presence of parents/carer during approx. half of interviews.
Peña and Kocur (2013) (naturalistic inquiry/emergent design)	Semi-structured interviews.	Include voice of students with ASD to understand transition from their point of view.	Sample only included highly educated, middle-class families from one county. Did not include voice of students with ASD. Small sample size.
Simmeborn Fleischer (2012) (case study)	Interviews. (interview guides based on interviews with young people with ASD participating in main study)		

(table continues)

Table 4 (continued)

Study (design)	Method(s)	Future research recommendations	Limitations
Van Hees et al. (2015) (grounded theory)	Semi-structured interviews	Examine perspectives of parents, disability service providers, informal support networks. Parent's potential role in student transition to HE. Use of standardized measures of anxiety and stress. Development of intervention services which are evidence based and can moderate impact of mental health issues.	Possible selection bias. Self-report qualitative data.

Note. ASD = autism spectrum disorder.

across five studies (C. Anderson & Butt, 2017; Baric et al., 2017; Cai & Richdale, 2016; Mitchell & Beresford, 2014; Van Hees et al., 2015). In addition, preparation for transition, and timely, appropriate support was recommended to minimize negative impacts on mental health and wellbeing (Baric et al., 2017; Cai & Richdale, 2016; Van Hees et al., 2015).

Microsystem. At the microsystem level, individuals with ASD described within these studies had support from family members, as well as professionals and staff within both the secondary school and postsecondary education settings.

Family support. All 11 studies addressed the significant role played by parents during the transition period. Family members were reported as playing a significant role in providing emotional and psychosocial support to individuals with ASD during this transition period (Baric et al., 2017; Cai & Richdale, 2016; Dymond et al., 2017; Mitchell & Beresford, 2014; Van Hees et al., 2015). Three studies also described parents taking on an active role in supporting their son or daughter with disclosing or initiating access to support services (Bell et al., 2017; Cai & Richdale, 2016; Peña & Kocur, 2013).

Professional support. Participants in three studies described positive experiences associated with professionals involved in the transition process (Bell et al., 2017; Cai & Richdale, 2016; Mitchell & Beresford, 2014). Participants who took part in the study conducted by Mitchell and Beresford (2014) described professionals as undertaking two specific roles: (a) supporting and engaging with planning, and (b) providing information. The participants reportedly valued support provided by professionals who were honest, reliable, provided information that was clear and easy to understand (written and verbal), and who had a knowledge and understanding of ASD. The importance of professional's knowledge of ASD was also echoed by parents in Peña and Kocur's (2013) study. Parents within this study reported feeling that faculty members were unprepared for students with ASD and lacked awareness or knowledge of the disability.

Mesosystem. At the mesosystem level, studies demonstrated the importance of effective collaboration between all elements of the microsystem, including family members, professionals, and educational staff.

Collaboration. Six studies highlighted the importance of secondary schools, families and higher education staff working collaboratively together (Alverson et al., 2015; C. Anderson & Butt, 2017; Baric et al., 2017; Cai & Richdale, 2016; Dymond et al.,

2017; Simmeborn Fleischer, 2012) to support the transition process.

Exosystem. Issues related to the exosystem level were noted in six studies (Alverson et al., 2015; C. Anderson & Butt, 2017; Cai & Richdale, 2016; Dymond et al., 2017; Peña & Kocur, 2013; Van Hees et al., 2015). These issues predominantly revolved around the impact of legislation relating to transition and higher education.

Issues related to the influence of policy and legislation were most commonly present in U.S. studies. Difficulties were associated with the implementation of transition support programs or services as outlined within the Individuals with Disabilities Act (IDEA; 2004). While it is a requirement of IDEA to implement a formal postsecondary transition plan (VanBergeijk et al., 2008), experiences of these processes varied greatly (Alverson et al., 2015; C. Anderson & Butt, 2017; Dymond et al., 2017). Where participants experienced effective formal transition support they developed clear postsecondary goals, eventually leading to successful adaptation and adjustment to higher education (Alverson et al., 2015; Dymond et al., 2017). However, some participants described transition services that did not provide this same level of coordination, experiencing a lack of formal planning, or effective follow up of goals and plans (C. Anderson & Butt, 2017; Dymond et al., 2017). Australian participants reported similarly varied experiences (Cai & Richdale, 2016). Where formal transition planning was not evident, students consequently felt unprepared for the transition to higher education (Cai & Richdale, 2016). In Ireland, where formal transition planning is not mandated, formal transition planning was lacking (Bell et al., 2017). Transition to higher education or work was not specifically included in the participant's individual education plans, and in some cases this resulted in students needing to find alternative pathways into higher education as the result of undertaking courses that did not lead directly to higher education opportunities.

Another exosystem element, which affected the experiences of students and family members within three of these studies, was that of privacy legislation (Cai & Richdale, 2016; Dymond et al., 2017; Peña & Kocur, 2013). A number of parents reported barriers presented by the implementation of privacy and confidentiality policies within higher education settings in response to legislative requirements. While these policies are implemented to protect the individual's privacy and confidentiality, it is also evident that individuals with ASD rely heavily on support from family mem-

Table 5
Overview of Participant Characteristics

Study	Location	Number of participants				Characteristics of individuals with ASD ^a				
		Total	Individuals with ASD in higher education		Family member		Age (mean)	Gender	Diagnosis	Confirmation of diagnosis
					Parent	Sibling				
Alverson et al. (2015)	U.S.	5	5	0	unclear	0	21	M = 5	ASD = 1 AS = 4	Medical diagnosis
Anderson and Butt (2017)	U.S.	25	7	0	18	0	22.9	M = 14	Autism = 1 AS = 13 PDDNOS = 2 ASD (other) = 2	Parent report, no medical confirmation
Baric et al. (2017)	Sweden	15	2	0	0	0	25.5	M = 1 F = 1	AS = 2	Formal diagnosis
Bell et al. (2017)	Republic of Ireland	8	6	0	2	0	18	M = 6	ASD	Not stated
Cia and Richdale (2016)	Australia	38	23	1	14	0	26	M = 16 F = 7	ASD	Formal diagnosis
Dymond et al. (2017)	U.S.	16	0	0	10 (2 fathers, 6 mothers, 1 mother + father pair)	0	Not stated	M = 9	ASD	Registered with university disability services
Madriga and Goodley (2010)	U.K.	8	8	0	0	0	between 18 and 30	M = 5 F = 3	AS	Registered with university disability services
Mitchell and Beesford (2014)	U.K.	18	18	0	0	0	18.6 years	M = 14 F = 4	HF autism/AS	Self-reported
Patin and Kocur (2013)	U.S.	18	0	0	18 (2 fathers, 16 mothers)	0	Not stated	Not stated	AS Autism PDDNOS	Not stated
Simeonova Plischer (2012)	Sweden	6	0	1	2 (1 father, 1 mother)	0	Not stated	M = 3	Not stated	Not stated
Van Hees et al. (2015)	Belgium	23	23	0	0	0	between 18 and 25	M = 17 F = 6	Autism AS PDDNOS	Medical diagnosis
										University = 1 University colleges = 2

^a Characteristics of individual with autism spectrum disorder (ASD) whose experience is being explored within the study (includes individuals with ASD as participants, and individuals about whose experience family members had reported on).

Table 6
Overview of Key Concepts Within Each Study Categorized Using the Bioecological Theory Model

Study	Individual			Microsystem		Mesocosystem	Exocosystem		Macrosystem
	Characteristics of ASD	Self-awareness and disclosure	Mental health and wellbeing	Family support	Professional support	Collaboration	Transition prog/ planning	Privacy legislation	Not addressed
Alverson et al. (2015)		x		x		x	x		x
Anderson and Butt (2017)			x	x		x	x		x
Baric et al. (2017)			x	x		x			x
Bell et al. (2017)	x			x	x				x
Cai and Richdale (2016)	x	x	x	x	x	x	x	x	x
Dymond et al. (2017)	x	x		x		x	x	x	x
Madriaga and Goodley (2010)				x					x
Mitchell and Beresford (2014)	x		x	x	x				x
Peña and Kocur (2013)		x		x	x			x	x
Simmeborn Fleischer (2012)	x			x		x			x
Van Hees et al. (2015)	x	x	x	x			x		x

Note. ASD = autism spectrum disorder.

bers, in many cases to assist them in the process of disclosure, as required to access necessary supports and reasonable adjustments (Bell et al., 2017; Cai & Richdale, 2016; Peña & Kocur, 2013). In addition, Mitchell and Beresford (2014) found no evidence that support provided by family members was unwelcome, which raises the question of whether this legislation may in fact be creating unnecessary barriers for students with ASD transitioning to higher education.

Macrosystem and chronosystem. Discussion of macrosystem and chronosystem elements of student experiences was absent in these studies. Only three studies included within this review were from the United Kingdom or Australia, where individualized payment systems are already in place, it is interesting that none of the participants described experiences associated with supports accessed through these systems.

Methodological limitations of studies reviewed. Scores on the McMaster Critical Review Form: Qualitative Studies (Letts et al., 2007) varied significantly. A clearly defined theoretical perspective was missing from all but three of the included studies, and only two studies clearly identified assumptions and potential bias of the researcher conducting the study. Further research using a clearly defined theoretical perspective and acknowledgment of existing assumptions or bias may help to improve the quality and interpretability of the research conducted.

The studies included in this review all had relatively small sample sizes, which while appropriate to the case study methodology used in most, provided only a limited snapshot of the experiences of individuals with ASD transitioning to higher education. Participants in a number of studies were also recruited from relatively narrow demographic groups (e.g., White, high income, and middle class), which significantly limited the generalizability of the results. In over half of the studies, participants were only eligible if they could provide evidence of a formal diagnosis or if they had already registered with their institution's disability service. Therefore, individuals who identified as having ASD but had not received a formal diagnosis were not represented in these studies. The majority of studies also only explored the perspectives of one group (individual, family, or staff/professionals), and did not compare these perspectives simultaneously. Only three studies included perspectives of both the individual and family members concurrently (C. Anderson & Butt, 2017; Bell et al., 2017; Cai &

Richdale, 2016). Concurrent exploration of these perspectives may have helped to clarify the issues experienced and determine whether the perspectives of individuals with ASD and other members of their support network are in fact similar. The inclusion of siblings was also minimal, with only two studies including a sibling when exploring perspectives of family members (Cai & Richdale, 2016; Simmeborn Fleischer, 2012).

Discussion

This study extends upon previous research into the experiences of individuals with ASD in higher education. In addition, this review utilized the bioecological theory model to examine in detail, the experiences of individuals with ASD, and their family members, during the transition to higher education. The following discussion will explore these findings in more detail, with consideration of the ways in which the various elements of the bioecological theory model within which this transition exists, interact to impact on the experiences of the individual and their family member/s.

Bioecological Theory and Experiences of Higher Education

Findings from these studies suggest the core and associated characteristics of ASD may create additional challenges for students with ASD when transitioning to higher education. In particular, difficulties associated with social-communication skills, executive functioning skills, and independent living skills may result in students needing supports and accommodations beyond those typically provided within higher education. In addition, the differences in manifestation of these characteristics of ASD for each individual (Alverson et al., 2015; Madriaga & Goodley, 2010) will necessitate an individualized approach to supports provided.

Regardless of diagnosis, no two individuals will have the same difficulties, experiences or needs. This is particularly the case for individuals with ASD who may exhibit the core and associated characteristics of ASD across a broad spectrum. Students with ASD are often provided with traditional adjustments such as additional time in exams or tests, or an alternative setting within which to sit these assessments, yet these adjustments may be

inappropriate or may not effectively address the specific needs of this population (Barnhill, 2016; Brown & Coomes, 2016; VanBergeijk et al., 2008). For higher education to be truly inclusive, institutions need to go beyond providing these traditional adjustments, and consider the needs of the individual, to ensure all students can participate fully within their educational setting. The need for individualized approaches to support strategies was also noted in the studies included within this review. For example, in the study conducted by Madriaga and Goodley (2010) not all participants felt that accommodations provided, were necessary or appropriate. Some participants felt that the accommodations they received benefited them, for example having a separate location for sitting their exams or tests, allowed them to access adjustments without having to disclose or explain their reasons for accessing these to their peers; however, others felt that these arrangements resulted in feelings of segregation.

Similar to recommendations made by Kuder and Accardo (2018), this review highlighted the importance of the provision of adjustments and supports which are individualized and address the nonacademic needs of individuals with ASD. To appropriately address the diverse needs of individuals with ASD, early engagement with relevant disability service staff within the HEI is critical to identify and implement effective and relevant adjustments and supports in a timely manner. However, as studies within this review have identified there are a number of individual and systemic (exosystem) barriers that may make this process more challenging for individuals with ASD.

To access supports and accommodations within higher education, a student must first identify and acknowledge their need for these supports. Students must then disclose their disability to relevant staff in order for supports and adjustments to be identified and implemented (Adreon & Durocher, 2007; Rocco, 2001; Zeedyk et al., 2016), yet some students with ASD may not identify as having a disability (Shattuck et al., 2014). Consistent with the findings of A. H. Anderson et al. (2018), some participants within the studies reviewed, delayed disclosing their disability to academic or professional staff within their HEI. Whether the decision to delay disclosure is made because of difficulties with understanding or navigating the process, or is a conscious choice by the individual, the delay in disclosing and accessing support may impact on the individual's overall higher education experience (A. H. Anderson et al., 2018). The need to develop skills in self-advocacy and self-disclosure before commencing higher education has been highlighted in previous literature (Barnhill, 2016; Elias & White, 2018). However, it appears these difficulties continue to pose challenges, and there remains a gap between the skills of individuals with ASD in disclosing and self-advocating, and the expectations of the HEIs within which they are enrolling. While emphasis should continue to be placed on developing effective self-advocacy skills before commencing higher education, perhaps HEIs should consider new strategies for engaging with students with ASD who are transitioning into higher education, to provide a more effective mechanism for self-disclosure and consequently accessing relevant support and accommodations they may require. Providing online mechanisms for disclosure and registration with disability support services within HEIs or developing formal processes that allow for effective parental support in the early stages of transition, may help to address some of these disclosure related difficulties.

As Pinder-Amaker (2014) suggests, the transitional years moving from secondary to postsecondary education, are a "peak period of onset of major psychiatric illnesses" in typically developing individuals (p. 126). The transition to higher education has also been associated with an increase in stress and anxiety levels for students with ASD (VanBergeijk et al., 2008). Therefore, it is not surprising that the mental health and wellbeing of students, was highlighted within a number of the studies reviewed. Cai and Richdale (2016) suggest effective early preparation and planning, which ensures timely access to supports, is important in minimizing the increases to stress and anxiety, which are commonly reported by individuals with ASD during this transition period. This was a recommendation also supported by Baric et al. (2017) and Van Hees et al. (2015). It appears that formal transition planning is linked to better adjustment and wellbeing in the transition to higher education, however, even in the United States, where this was mandated through legislation, it was not always implemented consistently or effectively. This demonstrates a significant gap between legislation (exosystem) and implementation (individual/microsystem). As such, there is clearly a need for further investigation of how this legislation is being implemented, with the aim of developing more effective links between the legislative requirements and implementation of these programs to improve the transition and adjustment of students with ASD to higher education.

Support from family members, in particular parents, was by far the most common microsystem element described by participants within these studies. Parents were seen to be providing supports such as "coaching" and "encouraging" (Peña & Kocur, 2013). Other supports provided by parents included coordination of the transition process, help with organization, and financial support (Alverson et al., 2015; Cai & Richdale, 2016; Dymond et al., 2017; Mitchell & Beresford, 2014). These findings further demonstrate the complex interaction between the individual and their support networks, which exist within the microsystem level, to support effective transition to higher education.

In addition to family members, participants also reported receiving support from professionals in roles across both the secondary school (e.g., career guidance, teaching staff) and higher education settings (e.g., disability services staff, counseling, and faculty staff). In some situations, participants also described support provided by other external support services (e.g., therapists, psychologists, or counselors).

Similar to disclosure, collaboration can only occur when the student has acknowledged and accepted the need for assistance (Simmeborn Fleischer, 2012). Collaboration between family members and HEI staff was also made more difficult as the result of barriers imposed by relevant privacy legislation and institutional policies (Cai & Richdale, 2016; Dymond et al., 2017; Peña & Kocur, 2013). Elements such as these, at the exosystem level appear relatively distant from the individual, yet their impact on the individual and their support networks can be significant. As Lester (2014) points out limited research has been conducted into how individuals view and make sense of the relevant policies and programs that have been developed to support their post school transitions. Therefore, this is a key area for further consideration in future studies.

Pinder-Amaker (2014) noted, societal beliefs about inclusion and resulting emphasis placed on inclusive practice within higher

education may impact on individuals with ASD at the macrosystem level. However, experiences related to macrosystem elements were not discussed in the studies reviewed. While historical events, such as the adoption of the UNCRPD may have influenced the experiences of students with disabilities in higher education in recent years, these chronosystem elements were also not discussed by participants within the studies reviewed; therefore, warranting further exploration.

Strengths and Limitations

This study included five major strengths. For the first time it: (a) included an examination of the perspectives of both students with ASD and their family members; (b) included a purposive focus on the experience of transition to higher education; (c) included qualitative data from mixed methods studies; (d) was conducted within a theoretical framework, the bioecological theory model (Bronfenbrenner, 1979); and (e) used the McMasters Critical Review form: Qualitative Studies (Letts et al., 2007) to evaluate the quality of the studies reviewed.

This review also extended upon the studies included in the systematic review by Toor et al. (2016), with five articles in the current review published since 2016. The focus on transition experiences specifically and the inclusion of family members were also unique to the present review.

Nevertheless, there are some limitations, which should be acknowledged. While the critical appraisal tool used to evaluate the included studies provided a valuable method of assessing the quality of the studies, it did not necessarily allow for more in depth consideration of methodological differences among studies. The review was also limited to an exploration of published, peer reviewed research articles. Additional, potentially relevant data from theses and published reports, were excluded from this review. Given this is a rapidly expanding area of investigation these additional sources may have provided additional, valuable information.

Recommendations for Future Research

Recommendations for future research identified within the included studies are outlined in Table 4. Recommendations focused on conducting longitudinal studies to explore outcomes of transition support and social integration; investigating the experiences of individuals with ASD during their transition and studies in higher education; and exploring the concurrent experiences of students, staff, and family members. Given these recommendations, and the limitations of these studies, future research should consider a larger and more diverse participant group, exploring experiences across a broad range of HEIs. Longitudinal studies should also be considered, to further explore strategies and experiences that are related to successful outcomes for students with ASD transitioning into higher education. The lack of research providing data on outcomes for students with ASD in higher education is also highlighted in recent reviews conducted by Kuder and Accardo (2018) and Zeedyk et al. (2016). Future research may need to examine the impact of transition processes, support and accommodations on longer-term outcomes for students with ASD in higher education. It should also explore the perspectives of individuals, family members, professionals, and educational staff to develop a deeper

understanding of the needs and experiences of individuals with ASD during this transition process. Given the complex nature of this transition experience, the bioecological theory model provides a valuable framework for further exploration of these experiences.

While a number of studies identified challenges directly linked to the core characteristics of ASD; interestingly, there was limited use of comparison groups within these studies. Further exploration and comparison to other commencing student cohorts may help to more clearly identify those experiences unique to students with ASD. Van Hees et al. (2015) also suggested further exploration of the impact of mental health issues using standardized measures would provide the opportunity for further examination of the impact of comorbid conditions such as anxiety and depression on the transition process for individuals with ASD. Studies comparing the experiences of students with ASD to those of students without ASD, both with and without anxiety may provide additional clarification concerning the contribution of these co-occurring conditions.

Implications for Practice

It is important for those who work to support students with disabilities in the higher education setting to be aware of the complex interaction of elements, which affect the transition experiences for individuals with ASD. Consideration needs to be given to the challenges faced by individuals with ASD and their family members during this transition process. For individuals with ASD these challenges may relate to the core characteristics and associated characteristics of, and comorbid conditions associated with, ASD; however, it is important to also acknowledge the unique strengths and skills that these students also possess. It is imperative that an individualized approach is taken, to ensure accommodations provided are effective and appropriate to meeting the specific needs of each student (A. H. Anderson et al., 2018; Barnhill, 2016; Brown & Coomes, 2016; Cai & Richdale, 2016; Madriaga & Goodley, 2010; Van Hees et al., 2015). While traditional supports and accommodations available for students with disabilities may benefit some students with ASD, others may find these to be unnecessary or irrelevant to their specific needs. This may require consideration of implementing social communication and organizational support strategies beyond those typically provided to commencing students in higher education. This finding reiterates previous recommendations that suggest students with ASD in higher education may require supports beyond those typically provided for students with disabilities that consider both academic and nonacademic skills (Gelbar et al., 2014; Kuder & Accardo, 2018). An individualized approach may not only apply to the accommodations made for students once they have enrolled and commenced their studies. Individualized and targeted transition support opportunities may also be beneficial for individuals and their family members when preparing for and undertaking the transition to higher education.

Ideally, staff who provide disability support and services within HEIs should provide a first point of contact for students with ASD who are seeking adjustments or accommodations to engage with their studies. These staff should have a sound knowledge and understanding of ASD and the needs of these students, and should provide information in a clear and easy to understand format. The provision of this information in a written format may provide

students with a valuable opportunity to discuss this information with their relevant support networks such as family members or professionals to better identify and voice their needs for support within the higher education setting. Implementing these strategies and providing the opportunity for simple and effective disclosure to occur, is likely to lead to supports and strategies being implemented in a timely and efficient manner. However, as Cai and Richdale (2016) point out, this may require the provision of additional staff and, thus, an increase in funding for disability support services within higher education.

As highlighted in this review, consideration must be given to the difficulties students with ASD may experience in expressing and discussing the challenges they face or the supports they require when commencing higher education studies. Disability service staff within HEIs may need to consider developing an alternative approach to providing assistance to students with ASD during this transition period. This approach must be a careful balance between the student's right to privacy, confidentiality, and self-determination, and the identified need for additional parental or family support in accessing services to manage difficulties they may experience during their transition to higher education. Ways in which family members of students with ASD can be involved in the transition process without interfering with the growth and development of the student as an adult learner within the higher education setting also need to be addressed. Developing a new approach may appear challenging when faced with institutional policies and privacy legislation; however, delays in seeking the required support and adjustments to successfully engage in higher education may have a detrimental effect on these students' higher education experience.

The varied experiences of transition support programs described by participants within these studies highlights the need for effective programs to facilitate the transition of students with ASD into higher education. Further exploration of existing transition support programs and identification of key stakeholders in this area may help to define and improve future transition support practices. Transition programs developed collaboratively between the secondary education and higher education setting, may also be beneficial.

Conclusion

The present review updates our insights into a rapidly expanding and significant area of research investigating the experiences of students with ASD who are transitioning to higher education. Additionally, this review explored the experiences of family members, in supporting students with ASD during this period. By examining the perspectives of individuals and their family members using the bioecological theory model, this review demonstrates the complex interactions, which impact on the experiences of students with ASD in their transition to higher education. A deeper understanding of the experiences of individuals with ASD and their families during this transition period to higher education, will allow HEIs to consider more targeted and effective approaches to transition for these students. This will lead to more effective and successful transition experiences for individuals with ASD who are commencing their studies in the higher education setting, and inform more inclusive practices for supporting these students.

References

- Adreon, D., & Durocher, J. S. (2007). Evaluating the college transition needs of individuals with high-functioning autism spectrum disorders. *Intervention in School and Clinic*, 42, 271–279. <http://dx.doi.org/10.1177/10534512070420050201>
- Alverson, C. Y., Lindstrom, L. E., & Hirano, K. A. (2015). High school to college: Transition experiences of young adults with autism. *Focus on Autism and Other Developmental Disabilities*. Advance online publication. <http://dx.doi.org/10.1177/1088357615611880>
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Washington, DC: APA.
- Americans With Disabilities Act of 1990, Pub. L. No. 101-336, 104 Stat. 328 (1990).
- Anderson, A. H., Carter, M., & Stephenson, J. (2018). Perspectives of university students with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 48, 651–665. <http://dx.doi.org/10.1007/s10803-017-3257-3>
- Anderson, A. H., Stephenson, J., & Carter, M. (2017). A systematic literature review of the experiences and supports of students with autism spectrum disorder in post-secondary education. *Research in Autism Spectrum Disorders*, 39, 33–53. <http://dx.doi.org/10.1016/j.rasd.2017.04.002>
- Anderson, C., & Butt, C. (2017). Young adults on the autism spectrum at college: Successes and stumbling blocks. *Journal of Autism and Developmental Disorders*, 47, 3029–3039. <http://dx.doi.org/10.1007/s10803-017-3218-x>
- Baric, V. B., Hemmingsson, H., Hellberg, K., & Kjellberg, A. (2017). The occupational transition process to upper secondary school, further education and/or work in Sweden: As described by young adults with Asperger syndrome and attention deficit hyperactivity disorder. *Journal of Autism and Developmental Disorders*, 47, 667–679. <http://dx.doi.org/10.1007/s10803-016-2986-z>
- Barnhill, G. P. (2016). Supporting students with Asperger syndrome on college campuses: Current practices. *Focus on Autism and Other Developmental Disabilities*, 31, 3–15. <http://dx.doi.org/10.1177/1088357614523121>
- Bearman, M., Smith, C. D., Carbone, A., Slade, S., Baik, C., Hughes-Warrington, M., & Neumann, D. L. (2012). Systematic review methodology in higher education. *Higher Education Research & Development*, 31, 625–640. <http://dx.doi.org/10.1080/07294360.2012.702735>
- Bell, S., Devecchi, C., McGuckin, C., & Shevlin, M. (2017). Making the transition to post-secondary education: Opportunities and challenges experienced by students with ASD in the Republic of Ireland. *European Journal of Special Needs Education*, 32, 54–70. <http://dx.doi.org/10.1080/08856257.2016.1254972>
- Bergen, D. (2008). *Human development: Traditional and contemporary theories*. Upper Saddle River, NJ: Pearson Prentice Hall.
- Brett, M. (2016). Disability and Australian higher education: Policy drivers for increasing participation. In A. Harvey, C. Burnheim, & M. Brett (Eds.), *Student equity in Australian higher education* (pp. 87–108). Singapore: Springer. http://dx.doi.org/10.1007/978-981-10-0315-8_6
- Bronfenbrenner, U. (1979). *The ecology of human development: Experiments by nature and design*. Cambridge, MA: Harvard University Press.
- Brown, K. R., & Coomes, M. D. (2016). A spectrum of support: Current and best practices for students with autism spectrum disorder (ASD) at community colleges. *Community College Journal of Research and Practice*, 40, 465–479. <http://dx.doi.org/10.1080/10668926.2015.1067171>
- Brugha, T. S., McManus, S., Bankart, J., Scott, F., Purdon, S., Smith, J., . . . Meltzer, H. (2011). Epidemiology of autism spectrum disorders in adults in the community in England. *Archives of General Psychiatry*, 68, 459–465. <http://dx.doi.org/10.1001/archgenpsychiatry.2011.38>
- Brugha, T. S., Spiers, N., Bankart, J., Cooper, S.-A., McManus, S., Scott, F. J., . . . Tyrer, F. (2016). Epidemiology of autism in adults across age

- groups and ability levels. *The British Journal of Psychiatry*, 209, 498–503. <http://dx.doi.org/10.1192/bjp.bp.115.174649>
- Cai, R. Y., & Richdale, A. L. (2016). Educational experiences and needs of higher education students with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 46, 31–41. <http://dx.doi.org/10.1007/s10803-015-2535-1>
- Christensen, D. L., Baio, J., Braun, K., Bilder, C. J., Constantino, J., Daniels, J., . . . Yeargin-Allsopp, M. (2016). Prevalence and characteristics of autism spectrum disorder among children aged 8 years—Autism and developmental disabilities monitoring network, 11 sites, United States, 2012. *MMWR. Surveillance Summaries* 2016, 65(No. SS-3), 1–23. <http://dx.doi.org/10.15585/mmwr.ss6503a1>
- Cox, B. E., Thompson, K., Anderson, A., Mintz, A., Locks, T., Morgan, L., . . . Wolz, A. (2017). College experiences for students with autism spectrum disorder: Personal identity, public disclosure, and institutional support. *Journal of College Student Development*, 58, 71–87. <http://dx.doi.org/10.1353/csd.2017.0004>
- Disability Discrimination Act 1992, Act No. 135 of 1992 as amended. Commonwealth of Australia, Attorney-General's Department: Canberra, (2018). Retrieved from <https://www.legislation.gov.au/Details/C2018C00125>
- Disability Discrimination Act 1995, United Kingdom (1995). Retrieved from <http://www.legislation.gov.uk/ukpga/1995/50/resources>
- Dymond, S. K., Meadan, H., & Pickens, J. L. (2017). Postsecondary education and students with autism spectrum disorders: Experiences of parents and university personnel. *Journal of Developmental and Physical Disabilities*, 29, 809–825. <http://dx.doi.org/10.1007/s10882-017-9558-9>
- Ebersold, S. (2008). Adapting higher education to the needs of disabled students: Developments, challenges and prospects. In OECD. (Ed.), *Higher education to 2030: Demography* (Vol. 1, pp. 221–240). Paris: OECD Publishing. <http://dx.doi.org/10.1787/9789264040663-9-en>
- Elias, R., & White, S. W. (2018). Autism goes to college: Understanding the needs of a student population on the rise. *Journal of Autism and Developmental Disorders*, 48, 732–746.
- Fleischer, A. S. (2012). Support to students with Asperger syndrome in higher education—The perspectives of three relatives and three coordinators. *International Journal of Rehabilitation Research*, 35, 54–61. <http://dx.doi.org/10.1097/MRR.0b013e32834f4d3b>
- Fleury, V. P., Hedges, S., Hume, K., Browder, D. M., Thompson, J. L., Fallin, K., . . . Vaughn, S. (2014). Addressing the academic needs of adolescents with autism spectrum disorder in secondary education. *Remedial and Special Education*, 35, 68–79. <http://dx.doi.org/10.1177/0741932513518823>
- Gelbar, N. W., Smith, I., & Reichow, B. (2014). Systematic review of articles describing experience and supports of individuals with autism enrolled in college and university programs. *Journal of Autism and Developmental Disorders*, 44, 2593–2601. <http://dx.doi.org/10.1007/s10803-014-2135-5>
- Hewitt, L. E. (2011). Perspectives on support needs of individuals with autism spectrum disorders: Transition to college. *Topics in Language Disorders*, 31, 273–285. <http://dx.doi.org/10.1097/TLD.0b013e328227fd19>
- Järkestig Berggren, U., Rowan, D., Berghück, E., & Blomberg, B. (2016). Disabled students' experiences of higher education in Sweden, the Czech Republic, and the United States—A comparative institutional analysis. *Disability & Society*, 31, 339–356. <http://dx.doi.org/10.1080/09687599.2016.1174103>
- Katsiyannis, A., Zhang, D., Landmark, L., & Reber, A. (2009). Postsecondary education for individuals with disabilities: Legal and practice considerations. *Journal of Disability Policy Studies*, 20, 35–45. <http://dx.doi.org/10.1177/1044207308324896>
- Knott, F., & Taylor, A. (2014). Life at university with Asperger syndrome: A comparison of student and staff perspectives. *International Journal of Inclusive Education*, 18, 411–426. <http://dx.doi.org/10.1080/13603116.2013.781236>
- Kuder, S. J., & Accardo, A. (2018). What works for college students with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 48, 722–731. <http://dx.doi.org/10.1007/s10803-017-3434-4>
- Lang, L. (2015). Responsibility and participation in transition to university—Voices of young people with disabilities. *Scandinavian Journal of Disability Research*, 17, 130–143. <http://dx.doi.org/10.1080/15017419.2013.817355>
- Lester, J. N. (2014). Young adulthood, transitions, and dis/ability. In C. A. Davis & J. S. Olson (Eds.), *Meeting the transitional needs of young adult learners: new directions for adult and continuing education, number 143*. (pp. 39–49). Somerset, NJ: John Wiley & Sons, Incorporated.
- Letts, L., Wilkins, S., Law, M., Stewart, D., Bosch, J., & Westmorland, M. (2007). Guidelines for critical review form: Qualitative studies (Version 2.0). *McMaster University Occupational Therapy Evidence-Based Practice Research Group*. Retrieved from <https://srs-mcmaster.ca/wp-content/uploads/2015/04/Critical-Review-Form-Qualitative-Studies-Version-2-English.doc>
- Madriaga, M., & Goodley, D. (2010). Moving beyond the minimum: Socially just pedagogies and Asperger's syndrome in U. K. higher education. *International Journal of Inclusive Education*, 14, 115–131. <http://dx.doi.org/10.1080/13603110802504168>
- Mitchell, W., & Beresford, B. (2014). Young people with high-functioning autism and Asperger's syndrome planning for and anticipating the move to college: What supports a positive transition? *British Journal of Special Education*, 41, 151–171. <http://dx.doi.org/10.1111/1467-8578.12064>
- Moher, D., Liberati, A., Tetzlaff, J., & Altman, D. G., & the PRISMA Group. (2009). Preferred reporting items for systematic reviews and meta-analyses: The PRISMA statement. *PLoS Medicine*, 6, e1000097. <http://dx.doi.org/10.1371/journal.pmed.1000097>
- Morley, L., & Croft, A. (2011). Agency and advocacy: Disabled students in higher education in Ghana and Tanzania. *Research in Comparative and International Education*, 6, 383–399. <http://dx.doi.org/10.2304/rcie.2011.6.4.383>
- Peña, E. V., & Kocur, J. (2013). Parents' experiences in the transition of students with autism spectrum disorders to community college. *Journal of Applied Research in the Community College*, 20, 25–32. Retrieved from http://works.bepress.com/edlyn_pena/11/
- Pinder-Amaker, S. (2014). Identifying the unmet needs of college students on the autism spectrum. *Harvard Review of Psychiatry*, 22, 125–137. <http://dx.doi.org/10.1097/HRP.0000000000000032>
- Pumfrey, P. D. (2008). Moving towards inclusion? The first-degree results of students with and without disabilities in higher education in the U. K.: 1998–2005. *European Journal of Special Needs Education*, 23, 31–46. <http://dx.doi.org/10.1080/08856250701791229>
- Rocco, T. S. (2001). Helping adult educators understand disability disclosure. *Adult Learning*, 12, 10–12. <http://dx.doi.org/10.1177/104515950101200204>
- Shattuck, P. T., Steinberg, J., Yu, J., Wei, X., Cooper, B. P., Newman, L., & Roux, A. M. (2014). Disability identification and self-efficacy among college students on the autism spectrum. *Autism Research and Treatment*, 2014, 924182. Advance online publication. <http://dx.doi.org/10.1155/2014/924182>
- Sims, T. (2016). Transition to university for young adults on the autism spectrum. *The Journal of Inclusive Practice in Further and Higher Education*, 7, 64–69. Retrieved from <http://eprints.brighton.ac.uk/15099/1/transition%20to%20HE.pdf>
- Swart, E., & Greyling, E. (2011). Participation in higher education: Experiences of students with disabilities. *Acta Academica*, 43, 81–110. Retrieved from http://scholar.ufs.ac.za:8080/xmlui/bitstream/handle/11660/2833/academ_v43_n4_a4.pdf?sequence=1
- Thierfeld Brown, J., & Wolf, L. (2014). Transition to higher education for

- students with Autism spectrum disorder. In J. C. K. McPartland, A. Klin, & F. Volkmar (Eds.), *Asperger syndrome: Assessing and treating high-functioning autism spectrum disorders* (2nd ed., pp. 367–393). New York: Guilford Press.
- Toor, N., Hanley, T., & Hebron, J. (2016). The facilitators, obstacles and needs of individuals with autism spectrum conditions accessing further and higher education: A systematic review. *Journal of Psychologists and Counsellors in Schools*, 26, 166–190. <http://dx.doi.org/10.1017/jps.2016.21>
- United Nations. (2006). *Convention on the rights of persons with disabilities*. Retrieved from <http://www.un.org/disabilities/convention/conventionfull.shtml>
- VanBergeijk, E., Klin, A., & Volkmar, F. (2008). Supporting more able students on the autism spectrum: College and beyond. *Journal of Autism and Developmental Disorders*, 38, 1359–1370. <http://dx.doi.org/10.1007/s10803-007-0524-8>
- Van Hees, V., Moyson, T., & Roeyers, H. (2015). Higher education experiences of students with autism spectrum disorder: Challenges, benefits and support needs. *Journal of Autism and Developmental Disorders*, 45, 1673–1688. <http://dx.doi.org/10.1007/s10803-014-2324-2>
- Volkmar, F. R., Reichow, B., & McPartland, J. C. (2014). *Adolescents and adults with autism spectrum disorders*. New York, NY: Springer Science + Business Media. <http://dx.doi.org/10.1007/978-1-4939-0506-5>
- Zedyk, S. M., Tipton, L. A., & Blacher, J. (2016). Educational supports for high functioning youth with ASD: The postsecondary pathway to college. *Focus on Autism and Other Developmental Disabilities*, 31, 37–48. <http://dx.doi.org/10.1177/1088357614525435>

Received April 20, 2018

Revision received August 23, 2018

Accepted December 21, 2018 ■

Appendix B: Co-authorship approval form



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Co-authorship Approvals for Higher Degree by Research Thesis for Examination

In accordance with Clause 5, 7 and 8 in the [HDR Thesis Rules](#), a student must sign a declaration that the thesis does not contain any material previously published or written by another person except where due reference is made in the text or footnotes. There can be no exception to this rule.

a. Publications or significant sections of publications (whether accepted, submitted or in manuscript form) arising out of work conducted during candidature may be included in the body of the thesis, or submitted as additional evidence as an appendix, on the following conditions:

- i. they contribute to the overall theme of the work, are conceptually linked to the chapters before and after, and follow a logical sequence
- ii. they are formatted in the same way as the other chapters (i.e. not presented as reprints unless as an appendix), whether included as separate chapters or integrated into chapters
- iii. they are in the same typeface as the rest of the thesis (except for reprints included as an appendix)
- iv. published and unpublished sections of a chapter are clearly differentiated with appropriate referencing or footnotes, and
- v. unnecessary repetition in the general introduction and conclusion, and the introductions and conclusions of each published chapter, is avoided.

b. Multi-author papers may be included within a thesis, provided:

- i. the student is the primary author
- ii. there is a clear statement in prose for each publication at the front of each chapter, recording the percentage contribution of each author to the paper, from conceptualisation to realisation and documentation, in accordance with the [Research Publication, Authorship and Peer Review Policy](#), and
- iii. each of the other authors provides permission for use of their work to be included in the thesis on the [Submission of Thesis Form](#) below.

c. Papers where the student is not the primary author may be included within a thesis if a clear justification for the paper's inclusion is provided, including the circumstances relating to production of the paper and the student's position in the list of authors. However, it is preferable to include such papers as appendices, rather than in the main body of the thesis.

A. STUDENT'S DETAILS (to be completed by the Student)

Name: Alison Louise Nuske Student ID: 2009062
Degree: PhD College: CNHS
Title of Thesis: Transition to university for autistic students in Australia: A phenomenological study

B. CO-AUTHORSHIP APPROVALS (To be completed by the student and co-authors)

If there are more than four co-authors (student plus 3 others), only the three co-authors with the most significant contributions are required to sign below.

Please note: A copy of this page will be provided to the Examiners.

1. Full publication Details Nuske, A., Rillotta, F., Bellon, M., & Richdale, A. (2018). Transition to higher education for students with autism: A systematic literature review. *Journal of Diversity in Higher Education*, 12(2), 200

Section of the thesis where the publication is referred to Chapter 2: Literature Review

Student's Contribution to the publication:

Research Design	<u>80</u> %
Data Collection and analysis	<u>80</u> %
Writing and editing	<u>80</u> %

Outline your (the student's) contribution to the publication:

AN contributed 80% to the research design, 80% to the data collection and analysis
and 80% to writing and editing of the manuscript. Co-authors MB, FR and AR collectively
contributed 20% to the research design, and 20% to the editing the manuscript. Co-author
MB contributed 20% to data collection and analysis.

☒ I confirm that the details above are an accurate record of the student's contribution to the work.

Name of Co-Author 1: Dr Fiona Rillotta Signed: Fiona Rillotta Digitally signed by Fiona Rillotta
Date: 2023.06.09 14:38:13 +09'30' Date: 9/6/23

☒ I confirm that the details above are an accurate record of the student's contribution to the work.

Name of Co-Author 2: Assoc. Prof. Michelle Bellon Signed: Michelle Bellon Digitally signed by Michelle Bellon
Date: 2023.06.09 14:56:05 +09'30' Date: 9/6/23

☒ I confirm that the details above are an accurate record of the student's contribution to the work.

Name of Co-Author 3: Prof. Amanda Richdale Signed: A. L. Richdale Date: 13/6/23

Appendix C: Ethics approval notice

From: [Human Research Ethics](#)
To: [Alison Nuske](#); [Fiona Rillotta](#); [Michelle Bellon](#); A.Richdale@latrobe.edu.au
Subject: 8242 ETHICS approval notice (5 March 2019)
Date: Tuesday, 5 March 2019 11:16:00 AM

Dear Alison,

Your conditional approval response for project 8242 was reviewed by the Chairperson of the Social and Behavioural Research Ethics Committee (SBREC) and was **approved**. The ethics approval notice can be found below.

APPROVAL NOTICE

Project No.:	8242		
Project Title:	Transition to and first year of university for students on the autism spectrum		
Principal Researcher:	Mrs Alison Nuske		
Email:	alison.nuske@flinders.edu.au		
Approval Date:	5 March 2019	Ethics Approval Expiry Date:	30 November 2021

The above proposed project has been **approved** on the basis of the information contained in the application, its attachments and the information subsequently provided with the addition of the following comments.

Additional comments:

1. Please ensure that copies of the correspondence granting permission to conduct the research from (i) Universities; and (ii) state-based and national autism associations are submitted to the Committee *on receipt*. Please ensure that the SBREC project number is included in the subject line of any permission emails forwarded to the Committee. Please note that data collection should not commence until the researcher has received the relevant permissions (item D8 and Conditional approval response – number 10).
 2. In the circumstance that organisations have their own ethics processes, please provide a copy of the organisations committee's ethics approval notice *on receipt*. Please note that data collection should not commence until the researcher has received ethics committee approvals where relevant (item G1 and Conditional approval response – number 11).
-

RESPONSIBILITIES OF RESEARCHERS AND SUPERVISORS

1. **Participant Documentation**
Please note that it is the responsibility of researchers and supervisors, in the case of student projects, to ensure that:

- all participant documents are checked for spelling, grammatical, numbering and formatting errors. The Committee does not accept any responsibility for the above mentioned errors.
- the Flinders University logo is included on all participant documentation (e.g., letters of Introduction, information Sheets, consent forms, debriefing information and questionnaires – with the exception of purchased research tools) and the current Flinders University letterhead is included in the header of all letters of introduction. The Flinders University international logo/letterhead should be used and documentation should contain international dialling codes for all telephone and fax numbers listed for all research to be conducted overseas.
- the SBREC contact details, listed below, are included in the footer of all letters of introduction and information sheets.

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project Number 'INSERT PROJECT No. here following approval'). For more information regarding ethics approval of the project the Executive Officer of the Committee can be contacted by telephone on 8201 3116, by fax on 8201 2035 or by email human.researchethics@flinders.edu.au.

2. Annual Progress / Final Reports

In order to comply with the monitoring requirements of the *National Statement on Ethical Conduct in Human Research (2007-Updated 2018)* an annual progress report must be submitted each year on the **5 March** (approval anniversary date) for the duration of the ethics approval using the report template available from the [Managing Your Ethics Approval](#) SBREC web page. *Please retain this notice for reference when completing annual progress or final reports.*

If the project is completed *before* ethics approval has expired please ensure a final report is submitted immediately. If ethics approval for your project expires please submit either (1) a final report; or (2) an extension of time request and an annual report.

Student Projects

The SBREC recommends that current ethics approval is maintained until a student's thesis has been submitted, reviewed and approved. This is to protect the student in the event that reviewers recommend some changes that may include the collection of additional participant data.

Your first report is due on **5 March 2020** or on completion of the project, whichever is the earliest.

3. Modifications to Project

Modifications to the project must not proceed until approval has been obtained from the Ethics Committee. Such proposed changes / modifications include:

- change of project title;
- change to research team (e.g., additions, removals, principal researcher or supervisor change);
- changes to research objectives;
- changes to research protocol;
- changes to participant recruitment methods;
- changes / additions to source(s) of participants;
- changes of procedures used to seek informed consent;
- changes to reimbursements provided to participants;
- changes / additions to information and/or documentation to be provided to potential participants;
- changes to research tools (e.g., questionnaire, interview questions, focus group questions);
- extensions of time.

To notify the Committee of any proposed modifications to the project please submit a Modification Request Form available from the [Managing Your Ethics Approval](#) SBREC web page. Download the form from the website every time a new modification request is submitted to ensure that the most recent form is used. Please note that extension of time requests should be submitted prior to the Ethics Approval Expiry Date listed on this notice.

Change of Contact Details

Please ensure that you notify the Committee if either your mailing or email address changes to ensure that correspondence relating to this project can be sent to you. A modification request is not required to change your contact details.

4. Adverse Events and/or Complaints

Researchers should advise the Executive Officer of the Ethics Committee on 08 8201-3116 or human.researchethics@flinders.edu.au immediately if:

- any complaints regarding the research are received;
- a serious or unexpected adverse event occurs that effects participants;
- an unforeseen event occurs that may affect the ethical acceptability of the project.

Kind regards
Wendy Green

On behalf of Andrea Mather

Ms Andrea Mather (formerly Fiegert) and Ms Rae Tyler
Ethics Officers and Executive Officers, Social and Behavioural Research Ethics Committee

Ms Andrea Mather Monday - Friday	T: +61 8201-3116 E: human.researchethics@flinders.edu.au
Ms Rae Tyler Monday, Wednesday and Friday mornings	T: +61 8201-7938 E: human.researchethics@flinders.edu.au
A/Prof David Hunter SBREC Chairperson	T: +61 7221-8477 E: david.hunter@flinders.edu.au
Dr Deb Agnew SBREC Deputy Chairperson	T: +61 8201-3456 E: deb.agnew@flinders.edu.au
SBREC Website	Social and Behavioural Research Ethics Committee (SBREC)

[Research Development and Support](#) | Union Building Basement
Flinders University
Sturt Road, Bedford Park | South Australia | 5042
GPO Box 2100 | Adelaide SA 5001

CRICOS Registered Provider: The Flinders University of South Australia | CRICOS Provider Number 00114A
This email and attachments may be confidential. If you are not the intended recipient, please inform the sender by reply email and delete all copies of this message.

Appendix D: Executive summary of ethics application



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Adelaide SA 5001
Tel: 08 8201 2108
fiona.rillotta@flinders.edu.au
CRICOS Provider No. 00114A

Executive Summary of the Flinders University Social and Behavioural Research Ethics Committee application (Project Number: 8242): Phase 1

Title: Transition to and first year of university for students on the autism spectrum.

Researcher

Mrs Alison Nuske (PhD Candidate)
College of Nursing and Health Sciences, Flinders University
Email: alison.nuske@flinders.edu.au

Supervisor(s)

Dr Fiona Rillotta (Primary)
College of Nursing and Health Sciences, Flinders University
Email: fiona.rillotta@flinders.edu.au
Tel: +61 8 8201 2108

Dr Michelle Bellon (Associate)
College of Nursing and Health Sciences, Flinders University

A/Prof Amanda Richdale (Adjunct)
Olga Tennison Autism Research Centre, School of Psychology and Public Health,
La Trobe University

Aim:

The aim of this study is to explore the experiences of students on the autism spectrum in their transition to university (preparation for university and first year of university). The primary research question is: What are the barriers and facilitators to successful transition to university for students on the autism spectrum?

The research objectives are:

1. To explore the experiences of transition to university and first year of university for students on the autism spectrum from the perspectives of students on the autism spectrum, and their family members.
2. To explore the experiences, knowledge and understanding of ASD of university staff, in supporting students on the autism spectrum in their transition to university and first year of university.

Project Value and Benefits:

Through better understanding of the experiences and needs of students on the autism spectrum at Australian universities, their family members and staff supporting them during their university transition period, it is expected that the study findings will indicate their support needs, leading to improvements in provision of transition support and services for student on the autism spectrum, when commencing university studies.

Project Information and Data Type:

This study will use both qualitative and quantitative methods of data collection via an online survey. We intend to publish the results in a thesis and other academic journal publications.

Research Method

WHO will be recruited? (e.g., students, staff, CEOs, children, members of public, doctors, nurses etc)

Group A: Individuals on the autism spectrum

Inclusion criteria:

- have a diagnosis of ASD as outlined in the DSM-5; or autism or Asperger's syndrome as outlined in the DSM-IV TR
- commenced an undergraduate degree at university within the previous 4 years
- have completed at least one semester (6 months) of university study at an undergraduate level

Group B: Family members of individuals on the autism spectrum

Inclusion criteria:

- family member or carer (e.g., parent, sibling, grandparent, aunt/uncle, carer) of individual on the autism spectrum who meets the criteria for group A
- provided direct support to the individual during their transition to and first year at university

Group C: Academic and professional university staff

Inclusion criteria:

- currently working in a professional or academic role at an Australian university
- have had interactions with first year students on the autism spectrum at their university

Research Method – (what will participation involve for each participant group?)

Group A.

Participants in Group A (students on the autism spectrum) will be asked to complete a series of qualitative and quantitative questions via an online survey tool (Qualtrics). It is expected that the survey will take approximately 30-45 minutes to complete. In keeping with an inclusive approach to research in the area of ASD (Cooperative Research Centre for Living with Autism, 2016), the

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questions will be reviewed by students on the autism spectrum who have undertaken tertiary studies at an Australian university, to provide feedback on the wording, structure or format of the questions. It is not anticipated that this will change to content of the questions.

Group B.

Participants in group B (family members/carers of individuals on the autism spectrum) will also be asked to complete a short series of qualitative questions (using Qualtrics) relating to their experience supporting their family member with their transition to and first year at university. It is expected that the survey will take approximately 30 minutes to complete.

Group C.

Participants in group C (university staff – professional and academic) will be asked to complete a short online survey (using Qualtrics). It is expected that the survey will take approximately 30 minutes to complete.

A preview of the survey questions is available online:

Student survey preview - https://qualtrics.flinders.edu.au/CP/File.php?F=F_3INQmMjldgXs30F

Staff survey preview - https://qualtrics.flinders.edu.au/CP/File.php?F=F_0jo5XPQ7AYtYHOd

Family survey preview - https://qualtrics.flinders.edu.au/CP/File.php?F=F_cPd1wQE8wS9vTcF

Remuneration

Participants will not receive any remuneration from their participation; however, those who are eligible and complete the survey may also choose to enter a draw to win one of three gift vouchers worth \$100 each. Details collected to enter the draw will be stored separately to your survey so that participant information cannot be cross-referenced with information provided for the prize draw.

Management of burdens and/or risks

The researcher anticipates few risks from participation in this study, however, given the nature of the project, some participants could experience emotional discomfort. Individuals who undertake the survey will be advised to contact their university counselling service or lifeline on 13 11 14 if they are experiencing any emotional discomfort or distress in undertaking the online survey or online focus groups.

If you wish to discuss any of the details of this study further please do not hesitate to contact me via email alison.nuske@flinders.edu.au or phone (08) 8201 5449.

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project Number: 8242). For more information regarding ethical approval of the project only, the Executive Officer of the Committee can be contacted by telephone on (08) 8201 3116, by fax on (08) 8201 2035, or by email to human.researchethics@flinders.edu.au

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Appendix E: Full survey previews – Student, Staff, and Family



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Students - Transition to and first year of university for students on the autism spectrum

Information and Consent

This survey is being conducted in partial fulfilment of a PhD (PhD Candidate: Alison Nuske)

Thank you for your interest in participating in our survey. The aim of this study is to explore the experiences of transition to university and first year of university for students on the autism spectrum* and their family members. We hope that your responses will help us to improve the provision of transition support services for students on the autism spectrum when commencing university studies.

Eligibility

You will be eligible to participate in this study if you:

- are on the autism spectrum
- have completed at least one semester (6 months) of undergraduate study at an Australian university

You will be asked to complete an online survey about your experiences of transition to university. This survey should take approximately 30 - 45 minutes to complete.

Participation is entirely voluntary.

Anonymity and confidentiality

Your responses for each page of the online survey will be anonymously saved when you click "Next". A "Back" button has also been included to allow you to go back and edit your responses if needed. If you close your browser prior to clicking "Next", your responses for that page will not be saved. Once you have clicked "Next" on the final question, all responses will be submitted, and you will not be able to return to the survey. Once information has been submitted it will be stored anonymously and will not be able to be withdrawn from the study. If you need to take a break from the survey, you will be able to return to complete your survey later. You can continue on with the survey using the link you have already been provided. Please note, you will need to open the survey using the same browser on the same computer each time. You will have 1 month from the commencement of the survey to complete all of the questions.

At the completion of the survey you will be asked if you would like to provide your name and contact details for a future focus group. Details collected to register interest in the focus groups



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will be stored separately to your survey so that participant information cannot be cross-referenced with information provided within this survey.

All information and results obtained in this study will be stored securely for at least five years following publication of this research, with access restricted to relevant researchers (PhD student: Alison Nuske and her supervisors). Data collected may also appear in publications in peer reviewed journals and may be presented in conference presentations and talks about this study. A summary of the results will be made available on the following Facebook page: <https://fb.me/AutismTransition2Uni> or you can contact the researchers to ask for a summary of the results.

Are there any risks?

It is not anticipated that you will experience any risks or distress from participating in this study. If you do experience any concerns, distress or emotional discomfort as a result of participating in this study you can access support via your university student counselling service, or you can contact Beyondblue on Ph: 1300 224 636 or the 24-hour Lifeline Counselling Service Ph: 13 11 14, or you can speak with your medical practitioner.

Remuneration

Participants will not receive any remuneration from their participation; however, those who are eligible and complete the survey may also choose to enter a draw to win one of three gift vouchers worth \$100 each. Details collected to enter the draw will be stored separately to your survey so that participant information cannot be cross-referenced with information provided for the prize draw.

How do I agree to take part in this study?

Participation is entirely voluntary; you are not obliged to participate. Refusing to participate will not affect your current or future enrolment. If you agree to participate, please click "I agree" below to progress with this survey.

**Please note the term "student/individual on the autism spectrum" has been used with the intention of being inclusive, we do not intend any offense by the use of this terminology.*

☐ I agree

☐ I do not agree



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Thank you for agreeing to take part in our survey. Completing the following questions will help to determine whether you are eligible to participate in this study.

Do you have a diagnosis of one of the following?

- ☐ Autism
- ☐ Asperger's syndrome (or disorder)
- ☐ Autism spectrum disorder (ASD)
- ☐ Autism Spectrum Condition
- ☐ Autistic Disorder
- ☐ PDD-NOS
- ☐ None of the above

Have you completed at least one semester (6 months) of undergraduate study at an Australian university?

- ☐ Yes
- ☐ No



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Thank you. Please answer the following questions to provide us with some demographic information about yourself.

How old are you?

Which gender identity do you most identify with?

- ☐ Male
- ☐ Female
- ☐ Other

In what year did you receive your autism diagnosis?

▼ 2019 (1) ... Prior to 1970

In what year did you leave high school?

▼ 2018 (1) ... Prior to 1970

What year did you start your undergraduate degree at university?

▼ 2019 (1) ... prior to 2006

Are you still studying at university?

- ☐ Yes, in the same degree
- ☐ Yes, but in a different degree
- ☐ No, I have left university
- ☐ No, I have graduated from my degree

Did you complete any post-secondary studies, prior to enrolling in your undergraduate university degree?

- ☐ Yes
- ☐ No

Please tick all that apply

- ☐ Certificate III
- ☐ Certificate IV
- ☐ Diploma
- ☐ Advanced Diploma
- ☐ other _____

The following questions relate to your first year of university.

What undergraduate degree did you enrol into?

Did you enrol full time or part time:

- ☐ Full time
- ☐ Part time

Was your degree:

- ☐ Online (distance education)
- ☐ On-campus
- ☐ Combination

In which state or territory is your university located?

▼ Australian Capital Territory ... Unsure

Are you a participant with the National Disability Insurance Scheme (NDIS)?

- ☐ Yes
- ☐ No

Did you receive any NDIS funded support to assist you with your transition to university?

- ☐ Yes
- ☐ No

Question will only appear if "Yes" selected for: Are you a participant with the National Disability Insurance Scheme (NDIS)?

Please describe your experiences of NDIS funded support during your transition to university. (e.g. What did you use this support for? Who provided this support? How helpful or unhelpful did you find this? Why?)

Question will only appear if "Yes" selected for: Did you receive any NDIS funded support to assist you with your transition to university?

Were there any reasons why you did not receive any NDIS funded support?

Question will only appear if "No" selected for: Are you a participant with the National Disability Insurance Scheme (NDIS)?

In the following questions we would like to find out a little more information about your preparation and planning for university, your transition to university and your first year as a university student. Please provide as much detail as possible about your experiences.

What were your experiences of planning and preparing for university?

- ☐ Very bad
☐ Bad
☐ Somewhat good
☐ Good

Please provide as much information about your experiences of planning and preparation for university as possible, including what you found helpful, or unhelpful.

Did you attend any orientation programs run by your university?

- ☐ Yes
☐ No

How helpful did you find the orientation program/s?

- ☐ Not at all helpful
☐ Somewhat helpful
☐ Helpful
☐ Very helpful

Question will only appear if "Yes" selected for: Did you attend any orientation programs run by your university?

Please describe your experiences of attending your university's orientation program, including what you found helpful or unhelpful.

Question will only appear if "Yes" selected for: Did you attend any orientation programs run by your university?

Were there any reasons you did not attend your university's orientation program?

Question will only appear if "No" selected for: Did you attend any orientation programs run by your university?

- ☐ My university did not have an orientation program
☐ I was not aware of my university's orientation program
☐ Other _____

What were your experiences of your first few weeks of university?

- ☐ Very bad
☐ Bad
☐ Somewhat good
☐ Good

Please tell us more about your experiences of the first few weeks of university, including what you found helpful or unhelpful.

Overall, what were your experiences of your first year at university?

- ☐ Very bad
☐ Bad
☐ Somewhat good
☐ Good

Please provide as much detail about your experiences of your first year of university as possible, including what you found helpful or unhelpful.

Please describe what supports were most helpful for you during your transition to and first year at university? Why?

Please describe what would have been helpful for you during your transition to and first year at university that you did not receive during this time?

How aware are you of the Disability Discrimination Act (1992) and how it applies to your university studies?

- ☐ Never heard of it
☐ Heard of it, but don't know much about it
☐ I know a little about it
☐ Very familiar with it

What impact (if any) do you think the Disability Discrimination Act had on your transition to university?

How aware are you of the Disability Standards for Education (2005) and how it applies to your university studies?

- ☐ Never heard of it
☐ Heard of it, but don't know much about it
☐ I know a little about it
☐ Very familiar with it



What impact (if any) do you think the Disability Standards for Education had on your transition to university?

Thank you for your contribution so far. We really appreciate it.
In the following section, we would like to find out more about the supports you may have received from family members and friends during your transition to and first year of university. Please provide as much detail as possible.

Did you receive help/support from any of the following during your transition to university?
(please tick all that apply)

- ☐ Mother
☐ Father
☐ Sibling
☐ Friends
☐ other _____
☐ None

Were there any reasons that you did not receive support from family or friends? Please describe below.

Please describe the ways in which your **family members** supported you during your transition to and first year at university, including how helpful or unhelpful you found this support and why.



Please describe the ways in which your **friends or peers** supported you during your transition to and first year at university, including how helpful or unhelpful you found this support and why.

Were there any other people that assisted you during your transition to university?

- ☐ Yes
☐ No

Please describe the roles these people played in your transition to university and the support that they provided to you, including how helpful or unhelpful you found this support and why.

Question will only appear if "Yes" selected for: Were there any other people that assisted you during your transition to university?

The following questions relate to your first year at university. Please provide as much detail as possible about the supports and services that you accessed during your first year at university.

Did you make contact with your university's disability support/equity and diversity services?

- ☐ Yes
☐ No

Were there any reasons why you **did not** choose to make contact with your university's disability support/equity and diversity services?

Question will only appear if "No" selected for: Did you make contact with your university's disability support/equity and diversity services?

Please rate how helpful you found the support you received from your university's disability support/equity and diversity services:

Question will only appear if "Yes" selected for: Did you make contact with your university's disability support/equity and diversity services?

- ☐ Not at all helpful
☐ Somewhat helpful
☐ Helpful
☐ Very helpful

Please provide additional details about why you found this support helpful or unhelpful.

Question will only appear if "Yes" selected for: Did you make contact with your university's disability support/equity and diversity services?

Did you develop an access plan/learning support plan or other documented plan related to the impacts of your autism within the first year of your university studies?

- ☐ Yes
☐ No
☐ Don't know what this is

Were there any reasons why you **did not** set up an access plan/support plan related to your autism?

Question will only appear if "No" selected for: Did you develop an access plan/learning support plan or other documented plan related to the impacts of your autism within the first year of your university studies?

When did you develop this access/support plan?

Question will only appear if "Yes" selected for: Did you develop an access plan/learning support plan or other documented plan related to the impacts of your autism within the first year of your university studies?

- ☐ Prior to starting university
- ☐ within the first 6 weeks of university
- ☐ within the first 6 months of university
- ☐ within the first year of university (after 6 months)

Please rate how helpful you found this access/support plan during your first year at university:

Question will only appear if "Yes" selected for: Did you develop an access plan/learning support plan or other documented plan related to the impacts of your autism within the first year of your university studies?

- ☐ Not at all helpful
- ☐ Somewhat helpful
- ☐ Helpful
- ☐ Very helpful

Please describe the process and experiences of setting up your access/support plan.

Question will only appear if "Yes" selected for: Did you develop an access plan/learning support plan or other documented plan related to the impacts of your autism within the first year of your university studies?

Did you use the university student counselling services?

- ☐ Yes
- ☐ No

Please rate how helpful you found your university's student counselling services:

- ☐ Not at all helpful
- ☐ Somewhat helpful
- ☐ Helpful
- ☐ Very helpful

Question will only appear if "Yes" selected for: Did you use the university student counselling services?

Please provide additional details about why you found this support helpful or unhelpful.

Question will only appear if "Yes" selected for: Did you use the university student counselling services?

Did you use your university's student academic support services (e.g. for support with academic writing or study related skills)?

- ☐ Yes
- ☐ No

Please rate how helpful you found your university's student academic support services (e.g. for support with academic writing or study related skills):

- ☐ Not at all helpful
- ☐ Somewhat helpful
- ☐ Helpful
- ☐ Very helpful

Question will only appear if "Yes" selected for: Did you use your university's student academic support services (e.g. for support with academic writing or study related skills)?

Please provide additional details about why you found this support helpful or unhelpful.

Question will only appear if "Yes" selected for: Did you use your university's student academic support services (e.g. for support with academic writing or study related skills)?

Thanks! We would like to find out about your experiences with professional and academic staff during your first year at university.

Please indicate how helpful you found the support you received from the following:

	Not applicable	Not at all helpful	Somewhat helpful	Helpful	Very Helpful
Lecturer(s)	☐	☐	☐	☐	☐
Tutor(s)	☐	☐	☐	☐	☐
other	☐	☐	☐	☐	☐
other	☐	☐	☐	☐	☐
Administrative staff	☐	☐	☐	☐	☐
Library staff	☐	☐	☐	☐	☐
Security staff	☐	☐	☐	☐	☐
other	☐	☐	☐	☐	☐
other	☐	☐	☐	☐	☐

Please describe the ways in which **academic staff** (e.g. lecturer, tutors) within your university did or did not support you during your first year of university.

Please describe the ways in which **professional staff** (e.g. library staff, security staff, administrative staff) within your university did or did not support you during your first year of university.

What information or knowledge do you think **professional staff** (e.g. library staff, health/counselling/disability services, security staff, administrative staff) within a university require in order to support students on the autism spectrum in their first year at university effectively?

What information or knowledge do you think **academic staff** (e.g. lecturers, tutors) within a university require in order to support students on the autism spectrum in their first year at university effectively?

You are nearly finished! The questions below will ask you for some information about any additional health or mental health conditions that you may have had prior to or during your transition to university.

Did you have a diagnosis of any of the following prior to your transition to university? (please tick all that apply)

- ☐ Specific Learning Disability
- ☐ Dyslexia
- ☐ Anxiety Disorder
- ☐ Mood disorder/depression
- ☐ Obsessive Compulsive Disorder (OCD)
- ☐ other mental health condition _____
- ☐ other health condition (e.g. asthma, arthritis, diabetes) _____

Were you diagnosed with any of the following **during your first year** of university? (please tick all that apply)

- ☐ Specific Learning Disability
- ☐ Dyslexia
- ☐ Anxiety Disorder
- ☐ Mood disorder/depression
- ☐ Obsessive Compulsive Disorder (OCD)
- ☐ other mental health condition _____
- ☐ other health condition (e.g. asthma, arthritis, diabetes) _____

Do you think this/these condition(s) directly impacted on your experience of transition to or first year of university?

- ☐ Yes
- ☐ No

Please explain how this/these condition/s impacted on your experience of transition to or first year of university.

Question will only appear if "Yes" selected for: Do you think this/these condition(s) directly impacted on your experience of transition to or first year of university?

Did you develop an access plan /learning support plan or other documented plan with your university's disability service, to support you in relation to any of the above conditions during your first year at university?

- ☐ Yes – I developed a plan
- ☐ Yes – I updated a plan I already had in place
- ☐ No – I didn't feel I needed one
- ☐ No – I did not know about them
- ☐ No – I already had a plan in place for my autism
- ☐ No – other (Please provide reason) _____

Do you think your transition to university may have impacted on any of these conditions?

- ☐ Yes
- ☐ No

Please describe the ways in which you think your transition may have impacted on any of these conditions?

Question will only appear if "Yes" selected for: Do you think your transition to university may have impacted on any of these conditions?

This is the final survey question.
Would you like to provide any further information relating to your experiences of transition to university?

University staff - Transition to and first year of university for students on the autism spectrum

Information and Informed Consent

Thank you for your interest in taking part in our survey. The aim of this study is to explore the experiences of transition to and first year of university for students on the autism spectrum* and their family members. We hope that your responses will help us to improve the provision of transition support services for students on the autism spectrum when commencing university studies.

Eligibility

You will be eligible to participate in this study if you:

- are a current academic or professional staff member within an Australian university
- have had interactions with first year students on the autism spectrum at your university

You will be asked to complete an online survey about your experiences of transition to university. This survey should take approximately 30 minutes to complete.

Participation is entirely voluntary.

Anonymity and confidentiality

Your responses for each page of the online survey will be anonymously saved when you click "Next". A "Back" button has also been included to allow you to go back and edit your responses if needed. If you close your browser prior to clicking "Next", your responses for that page will not be saved. Once you have clicked "Next" on the final question, all responses will be submitted, and you will not be able to return to the survey. Once information has been submitted it will be stored anonymously and will not be able to be withdrawn from the study. If you need to take a break from the survey, you will be able to return to complete your survey later. You can continue on with the survey using the link you have already been provided. Please note, you will need to open the survey using the same browser on the same computer each time. You will have 1 month from the commencement of the survey to complete all of the questions.

Information and responses gathered during this study will remain confidential. Any identifying information will be removed, and your comments will not be linked directly to you. All information and results obtained in this study will be stored securely for at least 5 years following publication

of this research, with access restricted to relevant researchers. Data collected may also appear in publications in peer reviewed journals, and may be presented in conference presentations and talks about this study. A summary of the results will be made available on the following Facebook page: <https://fb.me/AutismTransition2Uni> or you can contact the researchers to ask for a summary of the results.

Are there any risks?

It is not anticipated that you will experience any risks or distress from participating in this study. If you do experience any concerns, distress or emotional discomfort as a result of participating you can contact Beyondblue on Ph: 1300 224 636 or the 24-hour Lifeline Counselling Service Ph: 13 11 14, or you can speak with your medical practitioner.

How do I agree to take part in this study?

Participation in this study is entirely voluntary and you are not obliged to participate. If you agree to participate, please click "I agree" below to progress with this survey.

*Please note the term "student/individual on the autism spectrum" has been used with the intention of being inclusive, we do not intend any offense by the use of this terminology.

- ☐ I agree
- ☐ I do not agree

Thank you for agreeing to take part in our survey. Completing the following questions will help to determine whether you are eligible to participate in this study.

Are you currently engaged in an academic or professional role within an Australian University?

- ☐ Yes
- ☐ No

Have you had interactions with students on the autism spectrum during their transition to and first year of university (including preparation and planning for study)?

- ☐ Yes
- ☐ No

The next questions aim to explore your experiences in providing support or services to students on the autism spectrum during their transition to and first year at university. Please provide as much detail as possible.

Please indicate which roles you are currently engaged in within the university:

- ☐ Topic/course/subject coordinator
- ☐ Degree coordinator
- ☐ Lecturer
- ☐ Tutor
- ☐ other _____
- ☐ Student academic support services
- ☐ Counselling services
- ☐ Health services
- ☐ Disability services
- ☐ Library
- ☐ Security
- ☐ Facilities
- ☐ Administrative
- ☐ other _____

How many years have you worked within the higher education setting?

- ☐ 0-1
- ☐ 1-3
- ☐ 3-5
- ☐ 6-10
- ☐ 11-15
- ☐ 15+

How aware are you of the Disability Discrimination Act (1992) and how it applies to your role in supporting students with autism spectrum disorder within your university?

- ☐ Never heard of it
- ☐ Heard of it, but don't know much about it
- ☐ Heard of it, but I don't think it applies to my role
- ☐ Familiar with it and the impact it has on my role

Experiences engaging with students on the autism spectrum

Please describe the types of support or interactions you have had with first year students on the autism spectrum. Please provide as much detail as possible (e.g., about the type of support you provided the student, your role when providing this support, your experience of the interaction, the challenges of the interaction or the benefits of providing the support).

How would you rate your confidence in supporting or interacting with students on the autism spectrum at your university?

- ☐ Very confident
- ☐ Somewhat confident
- ☐ Not very confident
- ☐ Not at all confident

Have you been provided with training to develop your understanding of autism?

- ☐ Yes
- ☐ No

Please describe your experiences of this training and its impact on your confidence/understanding of autism (e.g., the format of the training, whether you found it helpful or unhelpful, what you liked or did not like about the training).

Question will only appear if "Yes" selected for: Have you been provided with training to develop your understanding of autism?

Have you had experiences engaging with family members of students on the autism spectrum?

- ☐ Yes
- ☐ No

Please describe your experiences of engaging with family members of students on the autism spectrum (e.g. what the interaction involved, whether you found the interaction helpful or unhelpful, did the interaction involve the student?).

Question will only appear if "Yes" selected for: Have you had experiences engaging with family members of students on the autism spectrum?

This is the final question. Would you like to provide any further information relating to your experiences of supporting your students on the autism spectrum during their transition to university or first year of university?

Family - Transition to and first year of university for students on the autism spectrum

This survey is being conducted in partial fulfilment of a PhD (PhD Candidate: Alison Nuske)

Thank you for your interest in taking part in our survey. The aim of this study is to explore the experiences of transition to and first year of university for students on the autism spectrum* and their family members. We hope that your responses will help us to improve the provision of transition support services for individuals on the autism spectrum when commencing university studies.

Eligibility

You will be eligible to participate in this study if you:

- are the family member (e.g., parent, sibling, grandparent, carer) of an individual on the autism spectrum (autism, Asperger syndrome or autism spectrum disorder) who has completed at least one semester (6 months) of undergraduate studies at an Australian university and
- provided direct support to that individual during their transition to and first year at university

You will be asked to complete an online survey about your experiences of transition to university. This survey should take approximately 30 minutes to complete.

Participation is entirely voluntary.

Anonymity and confidentiality

Your responses for each page of the online survey will be anonymously saved when you click "Next!". A "Back" button has also been included to allow you to go back and edit your responses if needed. If you close your browser prior to clicking "Next!", your responses for that page will not be saved. Once you have clicked "Next" on the final question, all responses will be submitted, and you will not be able to return to the survey. Once information has been submitted it will be stored anonymously and will not be able to be withdrawn from the study. If you need to take a break from the survey, you will be able to return to complete your survey later. You can continue on with the survey using the link you have already been provided. Please note, you will need to open the survey using the same browser on the same computer each time. You will have 1 month from the commencement of the survey to complete all of the questions.

Information and responses gathered during this study will remain confidential. Any identifying information will be removed, and your comments will not be linked directly to you. All information and results obtained in this study will be stored securely for at least 5 years following publication

of this research, with access restricted to relevant researchers (PhD student: Alison Nuske and her supervisors). Data collected may also appear in publications in peer reviewed journals, and may be presented in conference presentations and talks about this study. A summary of the results will be made available on the following Facebook page: <https://fb.me/AutismTransition2Uni> or you can contact the researchers to ask for a summary of the results.

Are there any risks?

It is not anticipated that you will experience any risks or distress from participating in this study. If you do experience any concerns, distress or emotional discomfort as a result of participating in this study you can access support via your university student counselling service, or you can contact Beyondblue on Ph: 1300 224 636 or the 24-hour Lifeline Counselling Service Ph: 13 11 14, or you can speak with your medical practitioner.

How do I agree to take part in this study?

Participation in this study is entirely voluntary and you are not obliged to participate. If you agree to participate, please click "I consent" below to progress with this survey. *Please note the term "student/individual on the autism spectrum" has been used with the intention of being inclusive, we do not intend any offense by the use of this terminology.

☐ I agree

☐ I do not agree

Are you the family member of an individual on the autism spectrum who has completed at least one semester (6 months) of undergraduate study at an Australian university?

- ☐ Yes
☐ No

Did you provide direct support to this individual during their transition to and first year at university?

- ☐ Yes
☐ No

What is your relationship to this individual?

- ☐ Parent
☐ Sibling
☐ Grandparent
☐ Carer
☐ other _____

In which state or territory are you located?

▼ Australian Capital Territory ... Western Australia

What is the highest level of education you have completed?

- ☐ Less than High School Certificate
☐ High School Certificate
☐ Certificate II
☐ Certificate III
☐ Certificate IV
☐ Diploma
☐ Advanced Diploma
☐ Bachelors Degree
☐ Masters Degree
☐ Doctoral Degree

Thank you. In the following questions we would like you to provide some information about your family member on the autism spectrum.

Please indicate which diagnosis your family member has:

- ☐ Autism
☐ Asperger's syndrome (or disorder)
☐ Autism spectrum disorder (ASD)
☐ Autism Spectrum Condition
☐ Autistic Disorder
☐ PDD-NOS

How old is your family member?

In what year did your family member start their undergraduate degree at university?

- ☐ 2019
☐ 2018
☐ 2017
☐ 2016
☐ 2015

Thank you. In the following questions we would like to find out about the support you provided to your family member during their transition to university (including preparation, planning, and first 12 months). Please provide as much detail as possible.

Where you involved in transition planning meetings for your family member during their final years of high school (e.g. year 9 - 12)?

- ☐ Yes
☐ No

What were your experiences of participating in these meetings? Please provide as much information as possible, including what you found helpful or unhelpful in this experience.

Question will only appear if "Yes" selected for: Where you involved in transition planning meetings for your family member during their final years of high school (e.g. year 9 - 12)?

In what areas did you provide support to your family member on the autism spectrum during their transition to and first year of university? (please tick all that apply)

- ☐ Enrolment
☐ Independent living skills
☐ Financial
☐ Social skills
☐ Executive functioning (e.g. time management, organisation, problem solving)
☐ Health and wellbeing (e.g., emotional support)
☐ Accessing university support services
☐ Academic skills (e.g. assignment planning, writing, study skills)
☐ other _____

Overall, would you describe your experience of providing support as:

- ☐ Very positive
☐ Positive
☐ Negative
☐ Very negative

Please describe the types of support you provided for your family member during their transition to and first year of university and your experiences of providing this support.

What do you feel were the benefits of providing this support?

What do you feel were the challenges in providing this support?

Did you provide any direct support for your family member which involved communication with academic or professional university staff? (Please tick all that apply)

- ☐ Yes - Academic staff (e.g. lecturer, tutor, topic/course coordinator)
- ☐ Yes - Professional staff (e.g. student support services, administration, library staff)
- ☐ No

Overall, how would you rate this experience?

- ☐ Very positive
- ☐ Positive
- ☐ Negative
- ☐ Very negative

Question will only appear if "Yes" selected for: Did you provide any direct support for your family member which involved communication with academic or professional university staff?

Would you like to provide any additional details about your experiences interacting with university staff? (e.g. what the interaction involved, the role of the staff member, whether you found the interaction helpful or unhelpful, whether your family member on the autism spectrum was involved in the interaction)

Question will only appear if "Yes" selected for: Did you provide any direct support for your family member which involved communication with academic or professional university staff?

How aware are you of the Disability Discrimination Act (1992)?

- ☐ Never heard of it
- ☐ Heard of it, but don't know much about it
- ☐ I know a little about it
- ☐ Very familiar with it

How aware are you of the Disability Standards for Education (2005)?

- ☐ Never heard of it
- ☐ Heard of it, but don't know much about it
- ☐ I know a little about it
- ☐ Very familiar with it

This is the final question. Would you like to provide any further information relating to your experiences of providing support to your family member in transitioning to university?

Appendix F: Aust-Ed permission email

Alison Nuske

From: Jane Hawkeswood <jane.hawkeswood@utas.edu.au>
Sent: Thursday, 31 May 2018 12:09 PM
To: Alison Nuske
Subject: RE: ATEND query

Not a problem. Send through when ready.

J

From: Alison Nuske [mailto:hann0100@flinders.edu.au]
Sent: Thursday, 31 May 2018 12:36 PM
To: Jane Hawkeswood <jane.hawkeswood@utas.edu.au>
Subject: Re: ATEND query

Hi Jane,

Thanks for getting back to me. I am one of the Access and Inclusion Advisors at UniSA and I am also currently undertaking my PhD at Flinders University. I am exploring the transition to university for students with ASD and will be hoping to recruit individuals with ASD, as well as professional and academic staff from universities around Australia to complete a short online quiz. Is this something that, once Ethics has been approved, I could forward to you for distribution through the aust-ed mailing list?

Kind regards,

Alison

Alison Nuske

PhD Candidate
College of Nursing and Health Sciences
Flinders University

GPO Box 2100
Adelaide, South Australia, 5001
Room S215, South Wing, Sturt Campus

From: Jane Hawkeswood <jane.hawkeswood@utas.edu.au>
Sent: Thursday, 31 May 2018 9:34:23 AM
To: Dallas Dunn; Alison Nuske
Subject: RE: ATEND query

Morning Alison,

There are currently 26 universities with ATEND members. And yes, I maintain the aust-ed email list.

Regards,

Jane Hawkeswood

Project Coordinator

ADCET – Australian Disability Clearinghouse on Education and Training

C/- University of Tasmania

Email: Jane.Hawkeswood@utas.edu.au Tel: +61 3 6324 3615

Mail: University of Tasmania, Locked Bag 1354, Launceston 7250

CRICOS Provider Code: 005868



SUPPORTING YOU, SUPPORTING STUDENTS



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Inclusive • Innovative • Ingenuity

www.pathways.consec.com.au
Novotel Manly Pacific, Sydney, Australia
4-7 December 2018

Appendix G: Aust-Ed - Introductory email – Round one

Alison Nuske

From: Alison Nuske
Sent: Friday, 17 May 2019 8:13 AM
To: austed-list@list.utas.edu.au
Cc: Fiona Rillotta
Subject: Students on the autism spectrum – seeking experiences of transition to university
Attachments: 8242 ETHICS approval notice (5 March 2019).pdf; Modification 2 Approval Notice 10 May 2019.pdf; Information Sheet and Permission Request to Advertise Research.doc

This email is to introduce Alison Nuske who is a PhD candidate in the College of Nursing and Health Sciences at Flinders University. Alison is undertaking research leading to the production of a thesis or other publications on the subject of transition to and first year of university for students on the autism spectrum.

The purpose of this research is to help us to better understand the barriers and facilitators to transition to university for individuals on the autism spectrum in Australia.

Alison is seeking participation from individuals on the autism spectrum, as well as academic and professional staff within Australian universities who have had experience engaging with or supporting students on the spectrum in their first year at university.

This research requires participants, who meet the eligibility criteria, to complete an online survey (approximately 30-45 minutes). The surveys can be viewed at:

Student survey preview - https://qualtrics.flinders.edu.au/CP/File.php?F=F_3lNQmMjldgXs30F

Staff survey preview - https://qualtrics.flinders.edu.au/CP/File.php?F=F_0jo5XPQ7AYtYHOd

The attached Information Sheet and Permission Request to Advertise Research provides further details regarding this study.

Subject to the return of the attached Permission Request, Alison will forward you two recruitment notices via email. It would be gratefully appreciated if you could display these recruitment notices within general student spaces, and student support services within your university.

A summary of the results will be made available on the Facebook page: <https://fb.me/AutismTransition2Uni> or you can contact the researchers to ask for a summary of the results.

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project Number: 8242). For more information regarding ethical approval of the project the Executive Officer of the Committee can be contacted by telephone on 8201 3116, by fax on 8201 2035 or by email human.researchethics@flinders.edu.au

You may also be interested in our recent publication: Nuske, A., Rillotta, F., Bellon, M., & Richdale, A. (2019). Transition to higher education for students with autism: A systematic literature review. *Journal of Diversity in Higher Education*. Advance online publication. <http://dx.doi.org/10.1037/dhe0000108>

If you have any queries or concerns regarding this project, please direct them to Dr Fiona Rillotta by phone: 08 8201 2108 or e-mail fiona.rillotta@flinders.edu.au.

Thank you for your attention and assistance.

Yours sincerely,



--
Dr Fiona Rillotta, PhD
Lecturer & Honours Coordinator
Bachelor of Disability and Developmental Education
Disability & Community Inclusion
College of Nursing and Health Sciences
Flinders University
Sturt Road, Bedford Park
South Australia, 5042
Phone: (08) 82012108 (International: +61 8 82012108)
Email: fiona.rillotta@flinders.edu.au

<http://www.flinders.edu.au>

<http://www.flinders.edu.au/people/fiona.rillotta>



CRICOS Provider Number: 00114A

This email and any attachments may be confidential. If you are not the intended recipient, please inform the sender by reply email and delete all copies of this message.

Appendix H: Aust-Ed - Information sheet & permission form



College of Nursing and Health Sciences

Sturt Road, Bedford Park
South Australia, 5042

GPO Box 2100
Adelaide SA 5001

Tel: 08 8201 2108
fiona.rillotta@flinders.edu.au

CRICOS Provider No. 00114A

Information Sheet and Permission Request to Advertise Research

Title: Transition to and first year of university for students on the autism spectrum.

Researcher

Mrs Alison Nuske (PhD Candidate)
College of Nursing and Health Sciences
Flinders University
alison.nuske@flinders.edu.au

Supervisor(s)

Dr Fiona Rillotta
College of Nursing and Health Sciences
Flinders University
Tel: +61 8 8201 2108

Dr Michelle Bellon
College of Nursing and Health Sciences
Flinders University

A/Prof Amanda Richdale
Olga Tennison Autism Research Centre, School of Psychology and Public Health
La Trobe University

Purpose of the study

The purpose of this research is to help us to better understand the barriers and facilitators to transition to university for individuals on the autism spectrum in Australia. It is hoped that the findings of this study will lead to improvements in provision of transition support and services for individuals on the autism spectrum when commencing university studies.

ABN 65 524 596 200 CRICOS Provider No. 00114A

inspiring
achievement

What will participants be asked to do?

Participants who meet the eligibility criteria will be asked to complete an online survey about their experiences of transition to university (students), or their experience of supporting individuals on the autism spectrum to transition to university (staff). Participation is **entirely voluntary**. The surveys should take approximately 30-45 minutes to complete.

You can view a copy of the surveys at:

Student survey preview - https://qualtrics.flinders.edu.au/CP/File.php?F=F_3lNQmMjldgXs30F

Staff survey preview - https://qualtrics.flinders.edu.au/CP/File.php?F=F_0jo5XPQ7AYtYHOd

Will participants be identifiable by being involved in this study?

We do not require participant names in order for someone to complete the online survey and individuals will be able to remain anonymous. Any identifying information will be removed, and comments will not be linked directly to any participant. All information and results obtained in this study will be stored securely, with access restricted to relevant researchers.

Individuals on the spectrum who complete the survey will be offered the opportunity to register their interest in a future focus group (face-to-face or online). These participants will need to provide their contact details, however information they provide within the survey will not be linked directly to the individual.

Are there any risks or discomforts?

The researcher anticipates few risks from participation in this study, however, given the nature of the project, some participants could experience emotional discomfort. Students who undertake the survey will be advised to contact their university counselling service, Beyondblue on Ph: 1300 224 636 or the 24-hour Lifeline Counselling Service Ph: 13 11 14, or speak with their medical practitioner, if they are experiencing any emotional discomfort or distress in undertaking the online survey.

If you have any concerns regarding anticipated or actual risks or discomforts, please do not hesitate to contact the principal researcher, Alison Nuske (alison.nuske@flinders.edu.au)

Can participants withdraw from this study?

Participation in this study is entirely voluntary. Participants will be asked to indicate consent to participate at the beginning of the online survey, through an online information and consent form. Participant responses for each page of the online survey will be anonymously saved when they click "Next". However, if participants close their browser prior to clicking "Next" responses for that page will not be saved. Participants will have 1 month from commencement of the survey to return and complete the remaining questions. If participants do not complete all of the survey questions, their saved responses for the questions they did complete, will be submitted 1 month after they commenced the survey. Once participants click "Next" on the final question, all responses will be submitted, and participants will not be able to return to the survey. Once information has been submitted it will be stored anonymously, and the data cannot be withdrawn.

What are we asking you to do?

We are not asking for direct recruitment of participants via your service, rather we would be grateful if you could display the two recruitment notices (e.g. via notice boards or electronic communication sources) within your university campus. These notices will be provided to you once your written permission to promote the study has been received.

The first recruitment notice outlines eligibility criteria and additional information (including the survey link) for participants who are on the autism spectrum. The second outlines eligibility criteria and additional information (including the survey link) for participants who are engaged in an academic or professional position within your university who may have had experience engaging with, teaching or supporting individuals on the autism spectrum during their transition to university.

If you would be willing to advertise this study via your student noticeboards, newsletters or other general distribution methods within your university, please complete the Permission Form below and return it to alison.nuske@flinders.edu.au.

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project Number: 8242). For more information regarding ethical approval of the project only, the Executive Officer of the Committee can be contacted by telephone on (08) 8201 3116, by fax on (08) 8201 2035, or by email to human.researchethics@flinders.edu.au

I, _____ have read and understood the information above and any questions I have asked have been answered to my satisfaction. I agree to assist with the recruitment for this study, by displaying recruitment notices within general student and staff spaces, and student support services areas.

Disability Services Manager Name or nominee:

(Block letters)

Contact email:

Signature:

Date:

(To be completed by the principal researcher)

Researcher's Name:

(Block letters)

Researcher's Signature:

Date:

Appendix I: Participant recruitment flyers – Round one



Call for Research Participants

Transition to and first year of university for students on the autism spectrum.

- Are you a current academic or professional staff member within an Australian university?
- Have you had interactions with first year students on the autism spectrum at your university?

If so, you are invited to participate in an online survey to explore the barriers and facilitators to transition to university for individuals on the autism spectrum in Australia.

If you would like to find out more please go to

https://qualtrics.flinders.edu.au/jfe/form/SV_8CFbFVo0h3uEGQ5

or use the QR Code below which will take you to the survey link.



This study is being conducted to meet the requirements for the degree of Doctor of Philosophy by Alison Nuske (alison.nuske@flinders.edu.au) under the supervision of Dr Fiona Rillotta (Flinders University), Dr Michelle Bellon (Flinders University) and Associate Professor Amanda Richdale (La Trobe University).

Thank you for your interest!

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project number: 8242).

For more information regarding ethical approval of the project only, the Executive Officer of the Committee can be contacted by telephone on (08) 8201 3116, by fax on (08) 8201 2035, or by email to human.researchethics@flinders.edu.au

Transition to and first year of university for students on the autism spectrum.

- Are you autistic or on the autism spectrum?
- Have you started your undergraduate degree at an Australian university within the past 4 years?
- Have you completed at least 6 months of your studies?

If so, you are invited to participate in an online survey to explore the barriers and facilitators to transition to university for individuals on the autism spectrum in Australia.

If you would like to find out more please go to

https://qualtrics.flinders.edu.au/jfe/form/SV_3Ko0ZyBwgTP8hTv

or use the QR Code below which will take you to the survey link.



This study is being conducted to meet the requirements for the degree of Doctor of Philosophy by Alison Nuske (alison.nuske@flinders.edu.au) under the supervision of Dr Fiona Rillotta (Flinders University), Dr Michelle Bellon (Flinders University) and Associate Professor Amanda Richdale (La Trobe University).

Thank you for your interest!

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project number: 8242).

For more information regarding ethical approval of the project only, the Executive Officer of the Committee can be contacted by telephone on (08) 8201 3116, by fax on (08) 8201 2035, or by email to human.researchethics@flinders.edu.au

Call for Research Participants

Transition to and first year of university for students on the autism spectrum.

- Are you the family member (e.g. parent, sibling, grandparent) of someone on the autism spectrum who has commenced an undergraduate degree at an Australian university within the past 4 years?
- Did you provide direct support to that person during their transition to and first year at university?

If so, you are invited to participate in an online survey to explore the barriers and facilitators to transition to university for individuals on the autism spectrum in Australia.

If you would like to find out more please go to

https://qualtrics.flinders.edu.au/jfe/form/SV_87aEJCJiYj5Z3YF

or use the QR Code below which will take you to the survey link.



This study is being conducted to meet the requirements for the degree of Doctor of Philosophy by Alison Nuske (alison.nuske@flinders.edu.au) under the supervision of Dr Fiona Rillotta (Flinders University), Dr Michelle Bellon (Flinders University) and Associate Professor Amanda Richdale (La Trobe University).

Thank you for your interest!

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project number: 8242).

For more information regarding ethical approval of the project only, the Executive Officer of the Committee can be contacted by telephone on (08) 8201 3116, by fax on (08) 8201 2035, or by email to human.researchethics@flinders.edu.au

Appendix J: Aust-Ed recruitment documentation – Round two

Alison Nuske

From: austed-list <austed-list-bounces@list.utas.edu.au> on behalf of Alison Nuske <alison.nuske@flinders.edu.au>
Sent: Tuesday, 10 December 2019 9:30 AM
To: austed-list@list.utas.edu.au
Cc: Fiona Rillotta
Subject: [austed-list] Seeking experiences of supporting students on the autism spectrum to transition to university
Attachments: Letter of Introduction_Aust-Ed_R2.pdf; Infosheet_AustEd_2Staff_Dec2019.pdf

Dear Sir/Madam,

Research Project: Transition to and first year of university for students on the autism spectrum

We are seeking participants for a Doctor of Philosophy project which is being conducted at Flinders University. The purpose of this research is to help us to better understand the barriers and facilitators to transition to university for individuals on the autism spectrum in Australia. We are seeking academic and professional university staff to complete an online survey (approximately 30 minutes).

For further information please see attached Letter of Introduction, and Information Sheet and Permission Request Form.

Subject to your approval, we would be very grateful if you could assist us by promoting this study to staff across your university, using the recruitment notice which will be emailed to you.

If you can assist us, please complete the enclosed Permission Form and return it to Alison Nuske (alison.nuske@flinders.edu.au) and we will then forward the recruitment notice to you.

Thank you for your attention and assistance.

Yours sincerely,



--
Dr Fiona Rillotta, PhD
Lecturer & Honours Coordinator
Bachelor of Disability and Developmental Education
Disability & Community Inclusion
College of Nursing and Health Sciences
Flinders University
Sturt Road, Bedford Park
South Australia, 5042
Phone: (08) 82012108 (International: +61 8 82012108)
Email: fiona.rillotta@flinders.edu.au

<http://www.flinders.edu.au>

<http://www.flinders.edu.au/people/fiona.rillotta>



CRICOS Provider Number: 00114A

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flona.rilotta@flinders.edu.au
CRICOS Provider No. 00114A

Letter of Introduction

Title: Transition to and first year of university for students on the autism spectrum.

This letter is to introduce Alison Nuske who is a PhD candidate in the College of Nursing and Health Sciences at Flinders University.

Alison is undertaking research leading to the production of a thesis or other publications on the subject of transition to and first year of university for students on the autism spectrum.

The purpose of this research is to help us to better understand the barriers and facilitators to transition to university for individuals on the autism spectrum in Australia.

Alison is seeking academic and professional university staff to complete an online survey (approximately 30 minutes). The survey questions can be previewed at:

https://qualtrics.flinders.edu.au/CP/File.php?F=F_0jo5XPQ7AYtYHOd

The attached Information Sheet and Permission Request to Advertise Research provides further details regarding this study. **Subject to the return of the attached Permission Request, Alison will forward you a recruitment notice via email. It would be gratefully appreciated if you could promote this study using this recruitment notice.**

A summary of the results will be made available on the Facebook page:

<https://fb.me/AutismTransition2Uni> or you can contact the researchers to ask for a summary of the results.

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project Number: 8242). For more information regarding ethical approval of the project the Executive Officer of the Committee can be contacted by telephone on 8201 3116, by fax on 8201 2035 or by email

human.researchethics@flinders.edu.au

If you have any queries or concerns regarding this project, please direct them to Dr Fiona Rillotta by email: or phone: 08 8201 2108 or e-mail fiona.rillotta@flinders.edu.au.

Thank you for your attention and assistance.

Yours sincerely,



--

Dr Fiona Rillotta, PhD
Lecturer & Honours Coordinator
Bachelor of Disability and Developmental Education
Disability & Community Inclusion
College of Nursing and Health Sciences
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<http://www.flinders.edu.au/people/fiona.rillotta>



Flinders
UNIVERSITY
inspiring achievement

CRICOS Provider Number: 00114A

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Information Sheet and Permission Request to Advertise Research

Title: Transition to and first year of university for students on the autism spectrum.

Researcher

Mrs Alison Nuske (PhD Candidate)
College of Nursing and Health Sciences
Flinders University
alison.nuske@flinders.edu.au

Supervisor(s)

Dr Fiona Rillotta
College of Nursing and Health Sciences
Flinders University
Tel: +61 8 8201 2108

Dr Michelle Bellon
College of Nursing and Health Sciences
Flinders University

A/Prof Amanda Richdale
Olga Tennison Autism Research Centre, School of Psychology and Public Health
La Trobe University

Purpose of the study

The purpose of this research is to help us to better understand the barriers and facilitators to transition to university for individuals on the autism spectrum in Australia. It is hoped that the findings of this study will lead to improvements in provision of transition support and services for individuals on the autism spectrum when commencing university studies.

What will participants be asked to do?

Participants who meet the eligibility criteria will be asked to complete an online survey about their experience of supporting individuals on the autism spectrum to transition to university. Participation is **entirely voluntary**. The survey should take approximately 30 minutes to complete.

You can view a copy of the survey at:

Staff survey preview - https://qualtrics.flinders.edu.au/CP/File.php?F=F_0jo5XPQ7AYtYHOd

Will participants be identifiable by being involved in this study?

We do not require participant names in order for someone to complete the online survey and individuals will be able to remain anonymous. Any identifying information will be removed, and comments will not be linked directly to any participant. All information and results obtained in this study will be stored securely, with access restricted to relevant researchers.

Are there any risks or discomforts?

The researcher anticipates few risks from participation in this study, however, given the nature of the project, some participants could experience emotional discomfort. Participants who undertake the survey will be advised to contact Beyondblue on Ph: 1300 224 636 or the 24-hour Lifeline Counselling Service Ph: 13 11 14, or speak with their medical practitioner, if they are experiencing any emotional discomfort or distress in undertaking the online survey.

If you have any concerns regarding anticipated or actual risks or discomforts, please do not hesitate to contact the principal researcher, Alison Nuske (alison.nuske@flinders.edu.au)

Can participants withdraw from this study?

Participation in this study is entirely voluntary. Participants will be asked to indicate consent to participate at the beginning of the online survey, through an online information and consent form. Participant responses for each page of the online survey will be anonymously saved when they click "Next". However, if participants close their browser prior to clicking "Next" responses for that page will not be saved. Participants will have 1 month from commencement of the survey to return and complete the remaining questions. If participants do not complete all of the survey questions, their saved responses for the questions they did complete, will be submitted 1 month after they commenced the survey. Once participants click "Next" on the final question, all responses will be submitted, and participants will not be able to return to the survey. Once information has been submitted it will be stored anonymously, and the data cannot be withdrawn.

What are we asking you to do?

We would be grateful if you could use the recruitment notice that will be provided to you upon receipt of the attached Permission request form, to promote the study to staff across your university.

The recruitment notice outlines eligibility criteria and additional information (including the survey link) for participants who are engaged in an academic or professional position within your university.

If you would be willing to promote this study within your university, please complete the Permission Form below and return it to alison.nuske@flinders.edu.au.

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project Number: 8242). For more information regarding ethical approval of the project only, the Executive Officer of the Committee can be contacted by telephone on (08) 8201 3116, by fax on (08) 8201 2035, or by email to human.researchethics@flinders.edu.au

I, _____ have read and understood the information above and any questions I have asked have been answered to my satisfaction. I agree to assist with the recruitment for this study, by utilising the recruitment notice which will be provided to me on receipt of this permission form.

Disability Services Manager Name or nominee:

(Block letters)

Contact email:

Signature:

Date:

(To be completed by the principal researcher)

Researcher's Name:

(Block letters)

Researcher's Signature:

Date:

Appendix K: Participant recruitment flyers – Round two



**INSPIRING
ACHIEVEMENT**

Participants needed: Transition to and first year of university for students on the autism spectrum.

- ARE YOU THE FAMILY MEMBER (E.G. PARENT, SIBLING, GRANDPARENT) OF SOMEONE ON THE AUTISM SPECTRUM WHO HAS COMMENCED AN UNDERGRADUATE DEGREE AT AN AUSTRALIAN UNIVERSITY WITHIN THE PAST 4 YEARS?
- DID YOU PROVIDE DIRECT SUPPORT TO THAT PERSON DURING THEIR TRANSITION TO AND FIRST YEAR AT UNIVERSITY?

If so, we would love to know more about your experiences supporting your family member to transition to their first year at university.

**Thank you for your
interest!**

About this study

This study is being conducted to meet the requirements for the degree of Doctor of Philosophy by Alison Nuske (alison.nuske@flinders.edu.au) under the supervision of Dr Fiona Rillotta (Flinders University), Dr Michelle Bellon (Flinders University) and Associate Professor Amanda Richdale (La Trobe University).

The aim of this study is to explore the experiences of students on the autism spectrum in their transition to and first year of university in Australia. The primary research question is: *What are the barriers and facilitators to successful transition to university for students on the autism spectrum?*



If you would like to find out more please go to:

<https://tinyurl.com/Transition-ASD-Family>

or use the QR Code below which will take you to the survey link.



This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project number: 8242).

For more information regarding ethical approval of the project only, the Executive Officer of the Committee can be contacted by telephone on (08) 8201 3116, by fax on (08) 8201 2035, or by email to human.researchethics@flinders.edu.au

CRICOS No. 00114A

flinders.edu.au

Participants needed: Transition to and first year of university for students on the autism spectrum.

- **ARE YOU AUTISTIC/ON THE AUTISM SPECTRUM?**
- **HAVE YOU STARTED YOUR UNDERGRADUATE DEGREE AT AN AUSTRALIAN UNIVERSITY WITHIN THE PAST 4 YEARS?**
- **HAVE YOU COMPLETED AT LEAST 6 MONTHS OF YOUR STUDIES IN THIS DEGREE?**

If so, we would love to know more about your experiences of the transition to and first year at university.

Thank you for your interest!

About this study

This study is being conducted to meet the requirements for the degree of Doctor of Philosophy by Alison Nuske

(alison.nuske@flinders.edu.au) under the supervision of Dr Fiona Rillotta (Flinders University), Dr Michelle Bellon (Flinders University) and Associate Professor Amanda Richdale (La Trobe University).

The aim of this study is to explore the experiences of students on the autism spectrum in their transition to and first year of university in Australia. The primary research question is: *What are the barriers and facilitators to successful transition to university for students on the autism spectrum?*

Remuneration

Participants will not receive any remuneration from their participation; however, those who are eligible and complete the survey may also choose to enter a draw to win one of three gift vouchers worth \$100 each.



If you would like to find out more please go to:

<https://tinyurl.com/Transition-ASD-Student>

or use the QR Code below which will take you to the survey link.



This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project number: 8242).

For more information regarding ethical approval of the project only, the Executive Officer of the Committee can be contacted by telephone on

(08) 8201 3116, by fax on (08) 8201 2035, or by email to human.researchethics@flinders.edu.au

Participants needed: Transition to and first year of university for students on the autism spectrum.

- **ARE YOU A CURRENT ACADEMIC OR PROFESSIONAL STAFF MEMBER WITHIN AN AUSTRALIAN UNIVERSITY?**
- **HAVE YOU HAD INTERACTIONS WITH FIRST YEAR STUDENTS ON THE AUTISM SPECTRUM AT YOUR UNIVERSITY?**

If so, we would love to know more about your experiences of these interactions.

Thank you for your interest!

About this study

This study is being conducted to meet the requirements for the degree of Doctor of Philosophy by Alison Nuske

(alison.nuske@flinders.edu.au) under the supervision of Dr Fiona Rillotta (Flinders University), Dr Michelle Bellon (Flinders University) and Associate Professor Amanda Richdale (La Trobe University).

The aim of this study is to explore the experiences of students on the autism spectrum in their transition to and first year of university in Australia. The primary research question is: *What are the barriers and facilitators to successful transition to university for students on the autism spectrum?*



If you would like to find out more please go to:

<https://tinyurl.com/Transition-ASD-Staff>

or use the QR Code below which will take you to the survey link.



This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project number: 8242).

For more information regarding ethical approval of the project only, the Executive Officer of the Committee can be contacted by telephone on (08) 8201 3116, by fax on (08) 8201 2035, or by email to human.researchethics@flinders.edu.au

Appendix L: Recruitment via organisations - documentation

Alison Nuske

From: Alison Nuske
Sent: Thursday, 30 May 2019 3:18 PM
To: autism@marymead.org.au
Cc: Fiona Rillotta
Subject: Students on the autism spectrum and their family members – seeking experiences of transition to university
Attachments: Information sheet and permission form_organisations.pdf; 8242 ETHICS approval notice (5 March 2019).pdf

This email is to introduce Alison Nuske who is a PhD candidate in the College of Nursing and Health Sciences at Flinders University. Alison is undertaking research leading to the production of a thesis or other publications on the subject of transition to and first year of university for students on the autism spectrum.

The purpose of this research is to help us to better understand the barriers and facilitators to transition to university for individuals on the autism spectrum in Australia.

Alison is seeking participation from students on the autism spectrum, as well family members of students on the autism spectrum, who have recently transitioned to university. The research will require participants to undertake an online survey which should take no more than 30 - 45 minutes to complete. The attached Information Sheet and Permission Request Form provides further details regarding this study.

Subject to the return of the attached Information Sheet and Permission Request Form, Alison will forward you two recruitment notices via email. It would be gratefully appreciated if you could promote the study through the use of these two flyers to individuals and their family members who are registered for your services. Alison will also forward you a Facebook post template with links to the study's Facebook page. It would be appreciated if you can also promote this link via your own organisation's Facebook page should you have one.

A preview of the surveys can be viewed at:

Student survey preview https://qualtrics.flinders.edu.au/CP/File.php?F=F_3lNQmMjldgXs30F

Family survey preview - https://qualtrics.flinders.edu.au/CP/File.php?F=F_cPd1wQE8wS9vTcF

A summary of the results will be made available on the Facebook page: <https://fb.me/AutismTransition2Uni> or you can contact the researchers to ask for a summary of the results.

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project Number: 8242). For more information regarding ethical approval of the project the Executive Officer of the Committee can be contacted by telephone on 8201 3116, by fax on 8201 2035 or by email human.researchethics@flinders.edu.au

If you have any queries or concerns regarding this project, please direct them to Dr Fiona Rillotta by email: or phone: 08 8201 2108 or e-mail fiona.rillotta@flinders.edu.au.

Thank you for your attention and assistance.

Yours sincerely,



Dr Fiona Rillotta, PhD
Lecturer & Honours Coordinator
Bachelor of Disability and Developmental Education
Disability & Community Inclusion
College of Nursing and Health Sciences
Flinders University
Sturt Road, Bedford Park
South Australia, 5042
Phone: (08) 82012108 (International: +61 8 82012108)
Email: fiona.rillotta@flinders.edu.au

<http://www.flinders.edu.au>

<http://www.flinders.edu.au/people/fiona.rillotta>



CRICOS Provider Number: 00114A

This email and any attachments may be confidential. If you are not the intended recipient, please inform the sender by reply email and delete all copies of this message.

Information Sheet and Permission Request to Advertise Research

Title: Transition to and first year of university for students on the autism spectrum.

Researcher

Mrs Alison Nuske (PhD Candidate)
College of Nursing and Health Sciences
Flinders University
alison.nuske@flinders.edu.au

Supervisor(s)

Dr Fiona Rillotta
College of Nursing and Health Sciences
Flinders University
Tel: +61 8 8201 2108

Dr Michelle Bellon
College of Nursing and Health Sciences
Flinders University

A/Prof Amanda Richdale
Olga Tennison Autism Research Centre, School of Psychology and Public Health
La Trobe University

Purpose of the study

The purpose of this research is to help us to better understand the barriers and facilitators to transition to university for individuals on the autism spectrum in Australia. It is hoped that the findings of this study will lead to improvements in provision of transition support and services for individuals on the autism spectrum when commencing university studies.

What will participants be asked to do?

Participants who meet the eligibility criteria will be asked to complete an online survey about their experiences of transition to university. Participation is entirely voluntary. The URL for the online surveys will be included on the recruitment notices. The surveys should take approximately 30 – 45 minutes to complete.

You can view a copy of the surveys at:

Student survey preview - https://qualtrics.flinders.edu.au/CP/File.php?F=F_3lNQmMjldgXs30F

Family survey preview - https://qualtrics.flinders.edu.au/CP/File.php?F=F_cPd1wQE8wS9vTcF

Will participants be identifiable by being involved in this study?

We do not require participant names in order for someone to complete the online survey and individuals will be able to remain anonymous. Any identifying information will be removed, and comments will not be linked directly to any participant. All information and results obtained in this study will be stored in a securely, with access restricted to relevant researchers.

Individuals on the spectrum who complete the survey will be offered the opportunity to register their interest in a future focus group (face-to-face or online). These participants will need to provide their contact details, however information they provide within the survey will not be linked directly to the individual.

Are there any risks or discomforts?

The researcher anticipates few risks from participation in this study, however, given the nature of the project, some participants could experience emotional discomfort. Individuals who undertake the survey will be advised to contact Beyondblue on Ph: 1300 224 636 or the 24-hour Lifeline Counselling Service Ph: 13 11 14, or speak with their medical practitioner, if they are experiencing any emotional discomfort or distress in undertaking the online survey. Current university students will also be encouraged to seek counselling support if available through their own university, if they are experiencing any emotional discomfort or distress in undertaking the online survey.

If you have any concerns regarding anticipated or actual risks or discomforts, please do not hesitate to contact the principal researcher, Alison Nuske (alison.nuske@flinders.edu.au).

Can participants withdraw from this study?

Participation in this study is entirely voluntary. Participants will be asked to indicate consent to participate at the beginning of the online survey, through an online information and consent form.

Participant responses for each page of the online survey will be anonymously saved when they click "Next". However, if participants close their browser prior to clicking "Next" responses for that page will not be saved. Participants will have 1 month from commencement of the survey to return and complete the remaining questions. If participants do not complete all of the survey questions, their saved responses for the questions they did complete, will be submitted 1 month after they commenced the survey. Once participants click "Next" on the final question, all responses will be submitted, and participants will not be able to return to the survey. Once information has been submitted it will be stored anonymously, and the data cannot be withdrawn.

What are we asking you to do?

We would like to ask that you distribute a recruitment notice (including online survey link) to individuals on the autism spectrum and to family members of individuals on the autism spectrum registered with your service.

The first recruitment notice outlines eligibility criteria and additional information (including the survey link) for participants who are on the autism spectrum; the second outlines eligibility criteria and additional information (including the survey link) for participants who are family members of individuals on the autism spectrum who have transitioned to university in the past two years. **These notices will be provided to you once your written permission to promote the study has been received.**

We would also be extremely grateful if you could promote our study via your organisation's Facebook page if you have one.

If you would be willing to assist us in promoting this study, please complete the Permission Form below and return it to alison.nuske@flinders.edu.au.

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project number: 8242). For more information regarding ethical approval of the project only, the Executive Officer of the Committee can be contacted by telephone on (08) 8201 3116, by fax on (08) 8201 2035, or by email to human.researchethics@flinders.edu.au

Permission Form

I, _____ have read and understood the information above and any questions I have asked have been answered to my satisfaction. I agree to assist with the recruitment for this study, by sending out recruitment notices to individuals on the autism spectrum and family members who are registered with our service and / or making the recruitment notices available via our organisation's Facebook page.

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project number: 8242).

For more information regarding ethical approval of the project only, the Executive Officer of the Committee can be contacted by telephone on (08) 8201 3116, by fax on (08) 8201 2035, or by email to human.researchethics@flinders.edu.au

Manager Name:

(Block letters)

Manager contact email:

Manager Signature:

Date:

(To be completed by the principal researcher)

Researcher's Name:

(Block letters)

Researcher's Signature:

Date:

Appendix M: Facebook post text (August 2019)

Facebook post text (23/8/19)

Students on the autism spectrum who have transitioned to university, and their family members are invited to participate in a study exploring their experiences of the transition to and first year of university in Australia. This research involves completing an online survey that should take no longer than 30 – 45 minutes to complete.

This research is being led by Alison Nuske, a PhD Candidate at Flinders University and it is hoped that the findings of this study will lead to improvements in provision of transition support and services for students on the autism spectrum when commencing university studies.

For more details please see the recruitment notice below.

Further information about this study can also be found on the Facebook page:

<https://fb.me/AutismTransition2Uni>

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project number: 8242). For more information regarding ethical approval of the project only, the Executive Officer of the Committee can be contacted by telephone on (08) 8201 3116, by fax on (08) 8201 2035, or by email to human.researchethics@flinders.edu.au

Appendix N: Recruitment email to professional networks

ADDITIONAL RECRUITMENT VIA PROFESSIONAL NETWORKS:

Dear [name of personal contact],

I am emailing you to request your assistance in recruiting participants for a research project I am supervising.

If possible, could you please forward the relevant recruitment notice that I have attached to this email, to any potential people you know who may be interested in participating (i.e. individuals on the autism spectrum who have completed at least 6 months of undergraduate studies in Australia, their family members, or any professional or academic university staff member).

The recruitment notice outlines the inclusion criteria for the study and provides potential participants with a link to access additional information about participating in the study.

In addition, if you know of any individuals on the autism spectrum who commenced undergraduate university studies in Australia in 2018 or 2019, please forward the above information sheet and consent form to them for further details about participating in a case study exploring their experiences of transition to university. Please feel free to use the attached email template, along with the information sheet and consent form.

Your assistance with this is entirely voluntary. If you do not wish to assist by forwarding the details of the study on, that is fine.

Please note that due to a conflict of interest, your involvement would only be to assist with recruiting participants, and I am not inviting you personally to participate.
Kindest regards,

Appendix O: Interview questions

INTERVIEW QUESTIONS – STUDENT

Please note: The questions below are intended as a guide only. If we are unable to cover all areas in today or you wish to stop the interview at any time you will be offered the opportunity to return at a later date and discuss the remaining areas should you wish to do so.

Demographic information (will be asked in first interview)

How old are you?

Which gender do you most identify with? Male/Female/Other

In what year did you receive your diagnosis of autism/Asperger syndrome/autism spectrum disorder? How old were you then?

In what year did you finish high school?

What was your first year here at university?

What degree area are you currently studying?

Is this the degree you enrolled into when you first started at university?

Theme 1 - First year of university

- Can you please describe for me your experience of starting your first year here at university?

You might want to talk about:

- *Planning and preparation*
- *Your pathway to university (high school, TAFE, diploma, other)*
- *What or who was helpful or not helpful*
- *How you felt*

- Can you tell me about the things you were most looking forward to before you started at university?

- What about any things you remember being worried about before starting at university?

- When you enrolled in your first semester of university was it full time/part time?

- Are you currently enrolled full time/part time?

- Can you tell me a bit about what your reasons were (for enrolling full time/part time)?

- When you first enrolled did you enrol to study your topics internally? online? Or a combination of both?

- Are you currently enrolled in your degree mostly online or on campus or a combination of both?

- Can you tell me a bit about what your reasons were (for enrolling internally/online/both)?

- Tell me about where you choose to do most of your study (e.g. on campus, home, a

local library, somewhere else)

- Tell me about any orientation programs at your university that you attended (either general orientation days or specific for student with disabilities/autism)?

You might want to talk about:

- What they involved
- What was helpful or unhelpful
- What could have been done differently

- Were you involved in any mentoring or similar support programs in your first year of university and if so, can you tell me more about these programs?

You might want to talk about:

- What they involved
- What was helpful or unhelpful
- What could have been done differently

- Are there other things that might have been helpful during your first few weeks of university? *Can you tell me a bit more about these?*
- What about later, in your first year of university?

Theme 2 – Support

- Tell me about the role that your family members played in your transition to and first year at university.

You might want to talk about:

- *What they did or didn't do*
- *Planning and preparation*
- *Whether it was helpful or not helpful*
- *How you felt*

- Tell me about the role that friends or peers played in your transition to and first year at university.

You might want to talk about:

- *What they did or didn't do*
- *Planning and preparation*
- *Whether it was helpful or not helpful*
- *How you felt*

- How about people at the university, can you tell me about any university people who helped you during your first year at uni?

You might want to talk about:

- *What they did or didn't do*
- *Planning and preparation*
- *Whether it was helpful or not helpful*
- *How you felt*

➤ Can you tell me about anyone else who may have helped you in your first year at uni?

Theme 3 – autism spectrum disorder and first year at uni

- Can you describe for me your experiences with organisation, planning, or time management during your first year?
 - *Did you have any difficulties in this area?*
 - *How did you manage these issues?*
- In your first year of university, did you experience any sensory issues that impacted on your experiences at university? If so, *can you please describe these for me?*
 - *How did they impact on your experience at university?*
 - *How did you manage these issues?*
- Can you describe for me your experiences social interaction and communication during your first year?
 - *Did you have any difficulties in this area?*
 - *How did you manage these issues?*
- In your first year of university, did you experience any issues with anxiety difficulties that impacted on your experiences at university? *If so, can you please describe these for me?*
 - *How did they impact on your experience at university?*
 - *How did you manage these issues?*
- Do you think being on the autism spectrum made your transition to university different to other students? If so... how?
- From your perspective, please tell me what you think students on the autism spectrum need most when they start university and why?

Theme 4 – Service and supports

- So, you are registered with the disability services at your university. Did you register with disability services in your first year at university?
- Can you tell me about your reasons for registering or not registering in your first year? If you did register with disability services...

➤ Can you tell me a bit about your experience registering for disability services?

You might want to talk about:

- *What you needed to do*
- *When did you register?*
- *How did you feel?*
- *Why did you decide to register?*
- *What was helpful or unhelpful in this process*

➤ Did you access any other support services (e.g. counselling)? If so, can you tell me a bit about your reasons for accessing this support and what you found helpful or unhelpful?

➤ If not, were there reasons why you did not access this service?

➤ Had you heard about the Disability Discrimination Act before you started at university? If so, how did this impact on your experience of transition?

➤ What about the Disability Standards for Education?

➤ Are you accessing support through the NDIS to help you at university?

If so, can you please tell me a bit more about what these supports are for and how you are using them at university?

Theme 5 – disclosure

➤ Can you tell me about your experience of disclosing your autism/Asperger/autism spectrum disorder diagnosis at university?

You might want to talk about:

- *Who you chose to disclose to*
- *Who you chose not to disclose to*
- *Why you made these choices*
- *How you went about disclosing*

Theme 6 – University staff

I'd like to know a bit more about the interactions you have had with people at university.

➤ Can you please tell me a bit about any interactions you have had with professional university staff (e.g. librarians, student support services, security) in your first year?

You might want to talk about:

- *Staff you found particularly helpful or unhelpful*
- *Any positive interactions you had*
- *Any difficult interactions you had*

- Can you please tell me a bit about any interactions you have had with academic university staff (e.g. tutors or lecturers) in your first year?
- People working in universities often have varying knowledge and awareness levels of autism spectrum disorder. What would be two or three things that you think are really important for people who work at a university to know about autism so that they can best support students on the autism spectrum when they are starting at university?

INTERVIEW QUESTIONS – ACADEMIC

Please note: The questions below are intended as a guide only. If we are unable to cover all areas in today or you wish to stop the interview at any time you will be offered the opportunity to return at a later date and discuss the remaining areas should you wish to do so.

Theme 1 – autism spectrum disorder

- How would you describe your knowledge, experience and confidence in supporting students with autism spectrum disorders?
- Have you had a student with autism spectrum disorder provide you with an Access Plan? If so, did you have any issues/difficulties in implementing the accommodations outlined in the plan?
- What is your understanding of the Disability Discrimination Act and the role it plays in supporting students on the autism spectrum?
- What about the Disability Standard for education?

Theme 2 – student support

- Can you please tell me about your experiences in supporting (_____) during their first year at university?
- What information did you find most useful in supporting (_____) during their first year at university?
- What information do you think would have been useful to support (_____)?
- Did you feel there were any barriers or difficulties that impacted on your ability to successfully provide support for (_____) during their first year at university?

Do you have anything else you would like to add about your experience providing support to (_____) during their transition to and first year at university?

INTERVIEW QUESTIONS – DISABILITY ADVISOR

Please note: The questions below are intended as a guide only. If we are unable to cover all areas in today or you wish to stop the interview at any time you will be offered the opportunity to return at a later date and discuss the remaining areas should you wish to do so.

Theme 1 – Support for autistic students in their first year

- I am interested to know a bit about the types of support is available at your university for students on the autism spectrum in their first year. Can you tell me what support is available and how students access this support?
- How is the disability service at your university promoted to students?
- Does your university run any orientation or mentoring programs in first year? *If so, can you tell me about these programs?*
- Does your university have any specific programs aimed at supporting students on the autism spectrum in their transition to university? *If so, please tell me more about this program*
If not, are there any reasons why this type of program is not currently available?

Theme 2 – autism spectrum disorder

- How would you describe your knowledge, experience and confidence in supporting students with autism spectrum disorders?
- In your experience, what are some of the things that disability advisors might need to know about autism spectrum disorder before supporting autistic students in their first year at university?
- In your experience, what are some of the things that other professional university staff have need to know about autism spectrum disorders before supporting autistic students in their first year at university?
- In your experience, are there any areas that you have found academic university staff might need to know about autism spectrum disorders before supporting autistic students in their first year at university?

Theme 3 – Student specific questions

- Can you please describe for me your experiences of supporting (____) during their first year of university?
- What do you feel were the best strategies for getting to know (____), and developing their access plan?
- Can you please tell me a bit about the process that you and (____) used to set up the access plan (e.g. how often did you meet, was this face-to-face, over email or phone, where did you meet?...)
- What was your experience of implementing this process? (e.g. what worked well, or not so well)
- Did you feel there were any barriers or difficulties that impacted on your ability to successfully provide support for (____) during their first year at university?
- Were there any additional supports, strategies or accommodations that were offered to (____) that they indicated they did not wish to utilise?
- Were there any supports, strategies or accommodations that (____) requested that you were not able to provide? Please describe what these were and why you feel they may not have been available or suitable?

Do you have anything else you would like to add about your experience providing support to (____) during their transition to and first year at university?

INTERVIEW QUESTIONS – FAMILY/OTHER

Please note: The questions below are intended as a guide only. If we are unable to cover all areas in today or you wish to stop the interview at any time you will be offered the opportunity to return at a later date and discuss the remaining areas should you wish to do so.

Theme 1 – Supporting your family member in their transition to university

➤ I understand you supported () in their transition to/first year at university?

Can you please tell me a bit more about what this involved?

You may wish to talk about:

- *What types of support you provided in this transition.*
- *When this support was needed.*
- *What the outcome of this process was.*
- *Your experience in providing this support*

➤ What would you say were the benefits for () of providing this support?

➤ Any challenges?

Theme 2 – Communication

➤ Did you have any interactions with university staff members in relation to

()'s transition to university?

You might want to talk about

- What was that person's role
- What the interaction involved
- The outcome of the interaction
- Any challenges that occurred in this interaction

Theme 3 – Legislation and services

➤ Before () started university, had you heard of the Disability Discrimination Act? Were you aware of how this would impact on ()'s transition to university.

How useful do you think this was in supporting ()'s transition to university?

➤ What about the Disability Standard for Education?

Do you have anything else you would like to add about your experience providing support to () during their transition to and first year at university?

Appendix P: Email to Disability Services – Case study recruitment

Alison Nuske

From: Alison Nuske
Sent: Monday, 4 May 2020 11:39 AM
To:
Cc: Fiona Rillotta
Subject: Seeking autistic students for case studies regarding the transition to and first year at university
Attachments: Letter of Introduction_Case Studies_2020.pdf; Information Sheet_DisabilityServices_CaseStudies_2020.pdf; Email_Students_CaseStudies.docx

Dear Sir/Madam,

PhD Research Project: Transition to and first year of university for students on the autism spectrum

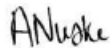
We are seeking participants to take part in some case studies leading to the production of a PhD thesis or other publications on the subject of transition to and first year of university for students on the autism spectrum. The purpose of this research is to help us to better understand the barriers and facilitators to transition to university for individuals on the autism spectrum in Australia.

For further information please see attached Letter of Introduction and Information Sheet.

If you agree to assist with recruitment for this study, please forward the attached email template to any students on the autism spectrum who are registered with your service.

Thank you for your attention and assistance.

Yours sincerely,



Alison Nuske
Associate Lecturer (Scholarly Fellow), Disability & Community Inclusion (Tue, Wed, Fri)
PhD Candidate - PhD project Facebook page: <https://fb.me/AutismTransition2Uni>

College of Nursing and Health Sciences
Flinders University
Sturt Road, Bedford Park, South Australia 5042
GPO Box 2100 Adelaide SA 5001

E: Alison.Nuske@flinders.edu.au | flinders.edu.au

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Appendix Q: Case studies – Letter of introduction



College of Nursing and Health Sciences
Sturt Road, Bedford Park
South Australia, 5042
GPO Box 2100
Adelaide SA 5001
Tel: 08 8201 2108
fiona.fliotta@flinders.edu.au
CRICOS Provider No. 00114A

Letter of Introduction

Title: Transition to and first year of university for students on the autism spectrum.

This letter is to introduce Alison Nuske who is a PhD candidate in the College of Nursing and Health Sciences at Flinders University.

Alison is undertaking research leading to the production of a thesis or other publications on the subject of transition to and first year of university for students on the autism spectrum.

The purpose of this research is to help us to better understand the barriers and facilitators to transition to university for individuals on the autism spectrum in Australia.

Alison is seeking participation from individuals on the autism spectrum enrolled in an undergraduate degree at a South Australian university, in order to conduct a case study to explore their experiences of transition to and first year at university. The case study will involve an interview with a student of approximately 1 to 1.5 hours. Where permission is granted by the student, Alison would then also like to conduct an interview with a Disability Advisor and/or academic staff member/s from your university who have been nominated by the student to ask them about their experiences in supporting students on the autism spectrum in their transition to and first year of university, as well as seek an understanding of the university's transition related supports, processes and policies. These interviews would be approximately 1 to 1.5 hours in length.

Be assured that any information provided will be treated in the strictest confidence and none of the participants will be individually identifiable in the resulting thesis, report or other publications. Participants are, of course, entirely free to discontinue their participation at any time or to decline to answer particular questions.

The attached Information Sheet provides further details regarding this study. **If you agree to assist with recruitment for this study, please forward the attached *email template* to any students on the autism spectrum who are registered with your service.**

A summary of the results will be made available at the completion of the study on the Facebook page: <https://fb.me/AutismTransition2Uni> or you can contact the researchers to ask for a summary of the results.

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project Number: 8242). For more information regarding ethical approval of the project the Executive Officer of the Committee can be contacted by telephone on 8201 3116, by fax on 8201 2035 or by email human.researchethics@flinders.edu.au

If you have any queries or concerns regarding this project, please direct them to Dr Fiona Rillotta by email: or phone: 08 8201 2108 or e-mail fiona.rillotta@flinders.edu.au.

Thank you for your attention and assistance.

Yours sincerely,



—
Dr Fiona Rillotta, PhD
Lecturer & Honours Coordinator
Bachelor of Disability and Developmental Education
Disability & Community Inclusion
College of Nursing and Health Sciences
Flinders University
Sturt Road, Bedford Park
South Australia, 5042
Phone: (08) 82012108 (International: +61 8 82012108)
Email: fiona.rillotta@flinders.edu.au

<http://www.flinders.edu.au>

<http://www.flinders.edu.au/people/fiona.rillotta>



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Appendix R: Case studies – Information sheet



College of Nursing and Health Sciences

Sturt Road, Bedford Park
South Australia, 5042

GPO Box 2100
Adelaide SA 5001

Tel: 08 8201 2108
fiona.rillotta@flinders.edu.au

CRIOS Provider No. 00114A

Information Sheet For Disability Services (Case studies)

Title: Transition to and first year of university for students on the autism spectrum.

Researcher

Mrs Alison Nuske (PhD Candidate)
College of Nursing and Health Sciences
Flinders University
alison.nuske@flinders.edu.au

Supervisor(s)

Dr Fiona Rillotta (Primary)
College of Nursing and Health Sciences
Flinders University
Tel: +61 8 8201 2108

Dr Michelle Bellon
College of Nursing and Health Sciences
Flinders University

A/Prof Amanda Richdale
Olga Tennison Autism Research Centre, School of
Psychology and Public Health
La Trobe University

Purpose of the study

The purpose of this research is to help us to better understand the barriers and facilitators to transition to university for individuals on the autism spectrum in Australia. It is hoped that the findings of this study will lead to improvements in provision of transition support and services for individuals on the autism spectrum when commencing university studies.

What will participants be asked to do?

Participants who meet the eligibility criteria will be asked to participate in a one-on-one semi-structured interview with a researcher who will ask some questions regarding their experiences of transition to and first year at university. **Participation is entirely voluntary.** The interview will take approximately 1 to 1.5 hours. The interview will be audio recorded using a digital voice recorder to help with reviewing the results. Once recorded, the interview will be transcribed (typed-up) and stored as a computer file, and will only be destroyed if the transcript is checked by the participant.

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We will also be asking student participants for their permission to interview their disability advisor, a family member/other support person, and/or an academic staff member of their choice to explore the transition experience in more detail. Participation from the student's disability advisor, family member, support person or an academic staff member is **entirely voluntary**. It is anticipated that involvement for these participants would be no more than 1 to 1.5 hours. An Information Sheet will be made available to these participants with information on how they can indicate their interest in participating in this study.

Remuneration

Students who participate in this study will receive a \$50 gift voucher.

Will participants be identifiable by being involved in this study?

Any identifying information will be removed, and participant comments will not be linked directly to them. All information and results obtained in this study will be stored in a secure way, with access restricted to relevant researchers.

Are there any risks or discomforts?

The researcher anticipates few risks from participation in this study, however, given the nature of the project, some participants could experience emotional discomfort. Students who participate in this study will be advised to contact their university counselling service, Beyondblue on Ph: 1300 224 636 or the 24-hour Lifeline Counselling Service Ph: 13 11 14, or speak with their medical practitioner, if they are experiencing any emotional discomfort or distress participating in the case study. If you have any concerns regarding anticipated or actual risks or discomforts, please do not hesitate to contact the principal researcher, Alison Nuske (alison.nuske@flinders.edu.au)

Can participants withdraw from this study?

Students who express interest in participating in the case study will be provided with an information sheet and consent form. Participation is **voluntary**. Participants may answer 'no comment' or refuse to answer any questions and are free to withdraw from the study at any time without effect or consequences.

What are we asking you to do?

We would be grateful if you could promote this study to any students registered with your services who have a diagnosis of autism spectrum disorder, autism or Asperger syndrome. **If you agree to assist with recruitment for this study, please forward the attached email template to any students on the autism spectrum who are registered with your service.**

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project Number: 8242). For more information regarding ethical approval of the project only, the Executive Officer of the Committee can be contacted by telephone on (08) 8201 3116, by fax on (08) 8201 2035, or by email to human.researchethics@flinders.edu.au

Appendix S: Case study recruitment – Email to students

Subject Line: Seeking autistic students to share their experiences of transition to uni

Dear student,

PhD Research Project: Transition to and first year of university for students on the autism spectrum

This email is to inform you of a research project exploring the transition to university for students on the autism spectrum.

Hi,

My name is Alison and I am a PhD candidate in the College of Nursing and Health Sciences at Flinders University. I am undertaking research leading to the production of a thesis or other publications on the subject of *transition to and first year of university for students on the autism spectrum*.

As part of this research, I am seeking participants to take part in some case studies. The **purpose** of this research is to help us to better understand the barriers and facilitators to transition to university for students on the autism spectrum in Australia.

If you

- have a diagnosis of autism, autism spectrum disorder or Asperger syndrome and
- commenced your undergraduate university studies in 2018, or 2019

I would like to interview you about your experiences of transition to and your first year of university.

If you meet the above criteria, and you are interested in taking part in this study please contact Alison Nuske alison.nuske@flinders.edu.au or ph. 08 8201 5449 to receive further information.

Yours sincerely,



Alison Nuske
PhD Candidate - PhD project Facebook page: <https://fb.me/AutismTransition2Uni>
College of Nursing and Health Sciences
Flinders University
Sturt Road, Bedford Park, South Australia 5042
GPO Box 2100 Adelaide SA 5001

E: Alison.Nuske@flinders.edu.au | flinders.edu.au

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Appendix T: Participant recruitment flyer – Case studies



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Transition to and first year of university for students on the autism spectrum.

Disability Advisors

Are you currently supporting students on the autism spectrum who started their undergraduate degree in 2018 or 2019?

We are keen to speak with them about their experiences in their transition to and first year at university.

The purpose of this research is to help us to better understand the barriers and facilitators to transition to university for students on the autism spectrum in Australia.



If you know of any students who may be interested and willing to participate in a short interview, please contact Alison Nuske for more information:

alison.nuske@flinders.edu.au

Thank you for your assistance!

This study is being conducted to meet the requirements for the degree of Doctor of Philosophy by Alison Nuske under the supervision of Dr Fiona Rillotta (Flinders University), Associate Professor Michelle Bellon (Flinders University) and Professor Amanda Richdale (La Trobe University).

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project number: 8242).

For more information regarding ethical approval of the project only, the Executive Officer of the Committee can be contacted by telephone on (08) 8201 3116, by fax on (08) 8201 2035, or by email to human.researchethics@flinders.edu.au

CRICOS No. 00114A

flinders.edu.au

Appendix U: Case studies - Recruitment email

Alison Nuske

From: Alison Nuske
Sent: Wednesday, 9 December 2020 11:49 AM
To:

Cc: Fiona Rillotta
Subject: Seeking autistic students for case studies regarding the transition to and first year at university
Attachments: Letter of Introduction_Dec2020.pdf; Information Sheet DisabilityServices_Dec2020.pdf; Email_Template_Dec2020.docx

Hi – apologies for cross posting.

PhD Research Project: Transition to and first year of university for students on the autism spectrum

Please note the inclusion criteria for this study has been expanded. We are now seeking autistic students who commenced their undergraduate studies in 2016, 2017, 2018, 2019 or 2020.

We are seeking participants to take part in some interviews as part of a series of case studies leading to the production of a PhD thesis or other publications on the subject of transition to and first year of university for students on the autism spectrum. **The purpose** of this research is to help us to better understand the barriers and facilitators to transition to university for individuals on the autism spectrum in Australia.

For further information please see attached *Letter of Introduction* and *Information Sheet*.

If you agree to assist with recruitment for this study, please forward the attached *email template* to any students on the autism spectrum who are registered with your service.

Thank you for your attention and assistance.

Yours sincerely,



Alison Nuske

Associate Lecturer (Scholarly Fellow), Disability & Community Inclusion (Tue, Wed, Fri)
PhD Candidate - PhD project Facebook page: <https://fb.me/AutismTransition2Uni>

College of Nursing and Health Sciences
Flinders University
Sturt Road, Bedford Park, South Australia 5042

Appendix V: Case studies - Information sheet (Students)



College of Nursing and Health Sciences
Sturt Road, Bedford Park
South Australia, 5042

GPO Box 2100
Adelaide SA 5001
Tel: 08 8201 5449
alison.nuske@flinders.edu.au
CRICOS Provider No. 00114A

Information Sheet For students (Case studies)

Title: Transition to and first year of university for students on the autism spectrum.

Researcher

Mrs Alison Nuske (PhD Candidate)
College of Nursing and Health Sciences
Flinders University
alison.nuske@flinders.edu.au

Supervisor(s)

Dr Fiona Rillotta (Primary)
College of Nursing and Health Sciences
Flinders University
Tel: +61 8 8201 2108

Dr Michelle Bellon
College of Nursing and Health Sciences
Flinders University

A/Prof Amanda Richdale
Olga Tennison Autism Research Centre, School of
Psychology and Public Health
La Trobe University

Description of the study

This study is part of the project titled "Transition to and first year of university for students on the autism spectrum." This project will investigate the experiences of students on the autism spectrum in their transition to and first year of undergraduate studies at university. This project is supported by Flinders University, College of Nursing and Health Sciences.

Purpose of the study

The purpose of this research is to help us to better understand the barriers and facilitators to transition to university for individuals on the autism spectrum in Australia. It is hoped that the findings of this study will lead to improvements in provision of transition support and services for individuals on the autism spectrum when commencing university studies.

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What will I be asked to do?

You are invited to take part in a case study to explore your experiences of transition to and first year at university. You will be invited to participate in a one-on-one interview with a researcher, who will ask you some questions regarding your experiences when you first started at university. Participation is **entirely voluntary**. The interview will take about 1 to 1.5 hours.

The interview will be audio recorded using a digital voice recorder to help with reviewing the results. Once recorded, the interview will be transcribed (typed-up) and stored as a computer file, and will only be destroyed if the transcript is checked by you (the participant).

You will also be asked whether you give permission for the researcher to interview your disability advisor regarding their experiences supporting you during your transition to university and the supports and services available for students on the autism spectrum when transitioning to your university. In addition, we would also like to ask your permission to interview a family member, other support person and/or an academic staff member of your choosing regarding their experiences during your transition to university and the support they may have provided to you during this time. This will be discussed in more detail at your interview, and permission to interview your disability advisor, family member, support person and/or academic staff member will be **completely voluntary**. It is anticipated that involvement for these people will be no more than 1 to 1.5 hours each.

We would also be interested in reviewing your Disability Access Plan, in order to better understand the strategies in place to support you at your university. We will ask you for your permission to review your Access Plan and this is **entirely voluntary**.

Recognition of contribution

If you would like to participate, in recognition of your contribution and participation time, you will be provided with a \$50 gift voucher.

What benefit will I gain from being involved in this study?

It is anticipated that the sharing of your experiences will help us to develop a better understanding of the transition to and first year of university for students on the autism spectrum. It is hoped that this information will lead to recommendations for transition services and supports specific to students on the autism spectrum.

Will I be identifiable by being involved in this study?

Any identifying information will be removed, and your comments will not be linked directly to you. All information and results obtained in this study will be stored in a secure way, with access restricted to relevant researchers.

Are there any risks or discomforts?

The researcher anticipates few risks from participation in this study, however, given the nature of the project, some participants could experience emotional discomfort. If any emotional discomfort is experienced please contact your university counselling service, Beyondblue on Ph: 1300 224 636 or the 24-hour Lifeline Counselling Service Ph: 13 11 14, or speak with your medical practitioner. If you have any concerns regarding anticipated or actual risks or discomforts, please raise them with the researcher.

Can participants withdraw from this study?

Participation is **voluntary**. You may answer "no comment" or refuse to answer any questions, and you are free to withdraw from the study at any time without effect of consequences. If you choose to withdraw from the study, and you wish for data collected from you to date to be removed from the data analysis, you can contact the primary researcher in writing to make this request alison.nuske@flinders.edu.au.

How do I agree to participate?

If you agree to participate please contact Alison Nuske via email at alison.nuske@flinders.edu.au or by phone on 8201 5449 to indicate which days and time would suit you best for your interview.

Alison will then contact you to arrange a time for your interview and will provide you with copies of the interview questions prior to your interview.

How do I receive feedback?

On project completion, a summary of the results will be made available on the Facebook page: <https://fb.me/AutismTransition2Uni> or you can contact the researchers to ask for a summary of the results.

Thank you for taking the time to read this information sheet, and we hope that you will accept our invitation to be involved.

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project Number: 8242). For more information regarding ethical approval of the project only, the Executive Officer of the Committee can be contacted by telephone on (08) 8201 3116, by fax on (08) 8201 2035, or by email to human.researchethics@flinders.edu.au

Appendix W: Interview consent forms



CONSENT FORM FOR PARTICIPATION IN RESEARCH

**Student
(Interview)**

Transition to and first year of university for students on the autism spectrum.

I
being over the age of 18 years hereby consent to participate as requested in the
..... for the research project with the title listed above.

1. I have read the information provided.
2. Details of procedures and any risks have been explained to my satisfaction.
3. I agree to audio recording of my information and participation.
4. I am aware that I should retain a copy of the Information Sheet and Consent Form for future reference.
5. I understand that:
 - I may not directly benefit from taking part in this research.
 - Participation is entirely voluntary and I am free to withdraw from the project at any time; and can decline to answer particular questions.
 - The information gained in this study will be published as explained, and my participation will be anonymous and confidential.
 - Whether I participate or not, or withdraw after participating, will have no effect on any current or future service being provided to me.
 - Whether I participate or not, or withdraw after participating, will have no effect on my progress in my course of study, or results gained.
 - I may ask that the audio recording be stopped at any time, and that I may withdraw at any time from the session or the research without disadvantage.
 - Even though information provided will be treated with the strictest confidence, disclosure of illegal activities will not be safe from legal search and seizure and may need to be reported to authorities.
6. I understand that only the researchers on this project will have access to my research data and raw results; unless I explicitly provide consent for it to be shared with other parties. If the need to seek my consent to share my research data with other parties does arise, I will be contacted by the researchers via email.

7. I have had the opportunity to discuss taking part in this research with a family member or friend.

Participant's name.....

Participant's signature.....Date.....

I certify that I have explained the study to the volunteer and consider that she/he understands what is involved and freely consents to participation.

Researcher's name.....

Researcher's signature.....Date.....

NB: Two signed copies should be obtained (one for researcher; one for participant). The copy retained by the researcher may then be used for participant review and approval of interview transcripts (point 8) where relevant.

Review / Approval of Interview Transcriptions

8. I, the participant whose signature appears below, have read a transcript of my interview participation and agree to its use by the researcher as explained.

Participant's signature Date.....

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project Number: 8242). For more information regarding ethical approval of the project only, the Executive Officer of the Committee can be contacted by telephone on (08) 8201 3116, by fax on (08) 8201 2035, or by email to human.researchethics@flinders.edu.au



CONSENT FORM FOR PARTICIPATION IN RESEARCH

Family member
(Interview)

Transition to and first year of university for students on the autism spectrum.

I

being over the age of 18 years hereby consent to participate as requested in the for the research project with the title listed above.

1. I have read the information provided.
2. Details of procedures and any risks have been explained to my satisfaction.
3. I agree to audio recording of my information and participation.
4. I am aware that I should retain a copy of the Information Sheet and Consent Form for future reference.
5. I understand that:
 - I may not directly benefit from taking part in this research.
 - Participation is entirely voluntary and I am free to withdraw from the project at any time; and can decline to answer particular questions.
 - The information gained in this study will be published as explained, and my participation will be anonymous and confidential.
 - I may ask that the audio recording be stopped at any time, and that I may withdraw at any time from the session or the research without disadvantage.
 - Even though information provided will be treated with the strictest confidence, disclosure of illegal activities will not be safe from legal search and seizure and may need to be reported to authorities.
6. I understand that only the researchers on this project will have access to my research data and raw results; unless I explicitly provide consent for it to be shared with other parties. If the need to seek my consent to share my research data with other parties does arise, I will be contacted by the researchers via email.

Participant's name.....

Participant's signature.....Date.....

V2

I certify that I have explained the study to the volunteer and consider that she/he understands what is involved and freely consents to participation.

Researcher's name.....

Researcher's signature.....Date.....

NB: Two signed copies should be obtained (one for researcher; one for participant). The copy retained by the researcher may then be used for participant review and approval of interview transcripts (point 8) where relevant.

Review / Approval of Interview Transcription

8. I, the participant whose signature appears below, have read a transcript of my interview participation and agree to its use by the researcher as explained.

Interview 1: Participant's signature Date.....

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project Number: 8242). For more information regarding ethical approval of the project only, the Executive Officer of the Committee can be contacted by telephone on (08) 8201 3116, by fax on (08) 8201 2035, or by email to human.researchethics@flinders.edu.au

Appendix X: Permission form



PERMISSION FORM (Case Study)

Transition to and first year of university for students on the autism spectrum.

I
being over the age of 18 years hereby

- do / do not (please circle) give permission for the researcher to discuss my transition to and first year at university with my **disability advisor/s**

(Name/s)
.....
.....

- do / do not (please circle) give permission for the researcher to conduct an interview with my **family member/s** to discuss my transition to and first year at university

(Name/s)
.....
.....

- do / do not (please circle) give permission for the researcher to conduct an interview with the **following person/s** (e.g. friend, academic staff member, any other person who supported your transition) to discuss my transition to and first year at university

(Name/s)
.....
.....

- do / do not (please circle) give permission for the researcher to obtain a **copy of my Disability Access Plan** from my Disability Advisor for the purpose of analysis within this study.

V2

1. I have read the information provided.
2. I am aware that I should retain a copy of this Permission Form for future reference.
3. I understand that:
 - Granting this permission is entirely voluntary and will have no effect on any current or future service being provided to me, nor will it have any effect on my progress in my course of study, or results gained.

Participant's name.....

Participant's signature.....Date.....

I certify that I have explained the study to the volunteer and consider that she/he understands what is involved and is providing these permissions freely.

Researcher's name.....

Researcher's signature.....Date.....

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project Number: 8242). For more information regarding ethical approval of the project only, the Executive Officer of the Committee can be contacted by telephone on (08) 8201 3116, by fax on (08) 8201 2035, or by email to human.researchethics@flinders.edu.au

Appendix Y: Case studies - Information sheets (Support Network)



College of Nursing and Health Sciences
Sturt Road, Bedford Park
South Australia, 5042

GPO Box 2100
Adelaide SA 5001
Tel: 08 8201 5449
alison.nuske@flinders.edu.au
CRICOS Provider No. 00114A

Information Sheet For academic staff member (Case studies)

Title: Transition to and first year of university for students on the autism spectrum.

Researcher

Mrs Alison Nuske (PhD Candidate)
College of Nursing and Health Sciences
Flinders University
alison.nuske@flinders.edu.au

Supervisor(s)

Dr Fiona Rillotta (Primary)
College of Nursing and Health Sciences
Flinders University
Tel: +61 8 8201 2108

Dr Michelle Bellon
College of Nursing and Health Sciences
Flinders University

A/Prof Amanda Richdale
Olga Tennison Autism Research Centre, School of
Psychology and Public Health
La Trobe University

Description of the study

This study is part of the project titled "Transition to and first year of university for students on the autism spectrum." This project will investigate the experiences of students on the autism spectrum in their transition to and first year of undergraduate studies at university. This project is supported by Flinders University, College of Nursing and Health Sciences.

Purpose of the study

The purpose of this research is to help us to better understand the barriers and facilitators to transition to university for individuals on the autism spectrum in Australia. It is hoped that the findings of this study will lead to improvements in provision of transition support and services for individuals on the autism spectrum when commencing university studies.

inspiring
achievement

What will I be asked to do?

You are invited to take part in a case study to explore the experiences of transition to and first year at university for students on the autism spectrum. You will be invited to participate in a one-on-one interview with a researcher who will ask you some questions regarding your experiences supporting a student on the autism spectrum during their transition to and first year at university. Your participation is **entirely voluntary**. The interview will take about 1 to 1.5 hours.

The interviews will be audio recorded using a digital voice recorder to help with reviewing the results. Once recorded, the interview will be transcribed (typed-up) and stored as a computer file, and will only be destroyed if the transcript is checked by you (the participant).

What benefit will I gain from being involved in this study?

It is anticipated that the sharing of your experiences will help us to develop a better understanding of the transition to and first year of university for students on the autism spectrum. It is hoped that this information will lead to recommendations for transition services and supports specific to students on the autism spectrum.

Will I be identifiable by being involved in this study?

Any identifying information will be removed, and your comments will not be linked directly to you. All information and results obtained in this study will be stored in a secure way, with access restricted to relevant researchers.

Are there any risks or discomforts?

The researcher anticipates few risks from participation in this study, however, given the nature of the project, some participants could experience emotional discomfort. If any emotional discomfort is experienced please contact Beyondblue on Ph: 1300 224 636 or the 24-hour Lifeline Counselling Service Ph: 13 11 14, or speak with your medical practitioner. If you have any concerns regarding anticipated or actual risks or discomforts, please raise them with the researcher.

Can participants withdraw from this study?

Participation is **voluntary**. You may answer "no comment" or refuse to answer any questions, and you are free to withdraw from the study at any time without effect of consequences. If you choose to withdraw from the study, and you wish for data collected from you to date to be removed from the data analysis, you can contact the primary researcher in writing to make this request alison.nuske@flinders.edu.au.

How do I agree to participate?

If you agree to participate please contact Alison Nuske via email at alison.nuske@flinders.edu.au or by phone on 8201 5449 to confirm your availability. Alison will then contact you to arrange a time for your interview and will provide you with copies of the interview questions prior to your interview.

How do I receive feedback?

On project completion, a summary of the results will be made available on the Facebook page: <https://fb.me/AutismTransition2Uni> or you can contact the researchers to ask for a summary of the results.

Thank you for taking the time to read this information sheet, and we hope that you will accept our invitation to be involved.

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project Number: 8242). For more information regarding ethical approval of the project only, the Executive Officer of the Committee can be contacted by telephone on (08) 8201 3116, by fax on (08) 8201 2035, or by email to human.researchethics@flinders.edu.au

Information Sheet For Disability Advisor (Case studies)

Title: Transition to and first year of university for students on the autism spectrum.

Researcher

Mrs Alison Nuske (PhD Candidate)
College of Nursing and Health Sciences
Flinders University
alison.nuske@flinders.edu.au

Supervisor(s)

Dr Fiona Rillotta (Primary)
College of Nursing and Health Sciences
Flinders University
Tel: +61 8 8201 2108

Dr Michelle Bellon
College of Nursing and Health Sciences
Flinders University

A/Prof Amanda Richdale
Olga Tennison Autism Research Centre, School of
Psychology and Public Health
La Trobe University

Description of the study

This study is part of the project titled "Transition to and first year of university for students on the autism spectrum." This project will investigate the experiences of students on the autism spectrum in their transition to and first year of undergraduate studies at university. This project is supported by Flinders University, College of Nursing and Health Sciences.

Purpose of the study

The purpose of this research is to help us to better understand the barriers and facilitators to transition to university for individuals on the autism spectrum in Australia. It is hoped that the findings of this study will lead to improvements in provision of transition support and services for individuals on the autism spectrum when commencing university studies.

What will I be asked to do?

You are invited to take part in a case study to explore the experiences of transition to and first year at university for students on the autism spectrum. You will be invited to participate in a one-on-one interview with a researcher who will ask you some questions regarding your experiences supporting students on the autism spectrum in their transition to university. Your participation is **entirely voluntary**. The interview will take about 1 to 1.5 hours. The interviews will be audio recorded using a digital voice recorder to help with reviewing the results. Once recorded, the interview will be transcribed (typed-up) and stored as a computer file, and will only be destroyed if the transcript is checked by you (the participant).

What benefit will I gain from being involved in this study?

It is anticipated that the sharing of your experiences will help us to develop a better understanding of the transition to and first year of university for students on the autism spectrum. It is hoped that this information will lead to recommendations for transition services and supports specific to students on the autism spectrum.

Will I be identifiable by being involved in this study?

Any identifying information will be removed, and your comments will not be linked directly to you. All information and results obtained in this study will be stored in a secure way, with access restricted to relevant researchers.

Are there any risks or discomforts?

The researcher anticipates few risks from participation in this study, however, given the nature of the project, some participants could experience emotional discomfort. If any emotional discomfort is experienced please contact Beyondblue on Ph: 1300 224 636 or the 24-hour Lifeline Counselling Service Ph: 13 11 14, or speak with your medical practitioner. If you have any concerns regarding anticipated or actual risks or discomforts, please raise them with the researcher.

Can participants withdraw from this study?

Participation is **voluntary**. You may answer "no comment" or refuse to answer any questions, and you are free to withdraw from the interviews at any time without effect of consequences. If you choose to withdraw from the study, and you wish for data collected from you to date to be removed from the data analysis, you can contact the primary researcher in writing to make this request alison.nuske@flinders.edu.au.

How do I agree to participate?

If you agree to participate please contact Alison Nuske via email at alison.nuske@flinders.edu.au or by phone on 8201 5549 to confirm your availability. Alison will then contact you to arrange a

time for your interview and will provide you with copies of the interview questions prior to your interview.

How do I receive feedback?

On project completion, a summary of the results will be made available on the Facebook page: <https://fb.me/AutismTransition2Uni> or you can contact the researchers to ask for a summary of the results.

Thank you for taking the time to read this information sheet, and we hope that you will accept our invitation to be involved.

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project Number: 8242). For more information regarding ethical approval of the project only, the Executive Officer of the Committee can be contacted by telephone on (08) 8201 3116, by fax on (08) 8201 2035, or by email to human.researchethics@flinders.edu.au

Information Sheet For family member/other (Case studies)

Title: Transition to and first year of university for students on the autism spectrum.

Researcher

Mrs Alison Nuske (PhD Candidate)
College of Nursing and Health Sciences
Flinders University
alison.nuske@flinders.edu.au

Supervisor(s)

Dr Fiona Rillotta (Primary)
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Dr Michelle Bellon
College of Nursing and Health Sciences
Flinders University

A/Prof Amanda Richdale
Olga Tennison Autism Research Centre, School of
Psychology and Public Health
La Trobe University

Description of the study

This study is part of the project titled "Transition to and first year of university for students on the autism spectrum." This project will investigate the experiences of students on the autism spectrum in their transition to and first year of undergraduate studies at university. This project is supported by Flinders University, College of Nursing and Health Sciences.

Purpose of the study

The purpose of this research is to help us to better understand the barriers and facilitators to transition to university for individuals on the autism spectrum in Australia. It is hoped that the findings of this study will lead to improvements in provision of transition support and services for individuals on the autism spectrum when commencing university studies.

What will I be asked to do?

You are invited to take part in a case study to explore the experiences of transition to and first year at university for students on the autism spectrum. You will be invited to participate in a one-on-one interview with a researcher who will ask you some questions regarding your experiences supporting your family member on the autism spectrum during their transition to and first year at university. Your participation is **entirely voluntary**. The interview will take about 1 to 1.5 hours. The interviews will be audio recorded using a digital voice recorder to help with reviewing the results. Once recorded, the interview will be transcribed (typed-up) and stored as a computer file, and will only be destroyed if the transcript is checked by you (the participant).

What benefit will I gain from being involved in this study?

It is anticipated that the sharing of your experiences will help us to develop a better understanding of the transition to and first year of university for students on the autism spectrum. It is hoped that this information will lead to recommendations for transition services and supports specific to students on the autism spectrum.

Will I be identifiable by being involved in this study?

Any identifying information will be removed, and your comments will not be linked directly to you. All information and results obtained in this study will be stored in a secure way, with access restricted to relevant researchers.

Are there any risks or discomforts?

The researcher anticipates few risks from participation in this study, however, given the nature of the project, some participants could experience emotional discomfort. If any emotional discomfort is experienced please contact Beyondblue on Ph: 1300 224 636 or the 24-hour Lifeline Counselling Service Ph: 13 11 14, or speak with your medical practitioner. If you have any concerns regarding anticipated or actual risks or discomforts, please raise them with the researcher.

Can participants withdraw from this study?

Participation is **voluntary**. You may answer "no comment" or refuse to answer any questions, and you are free to withdraw from the interviews at any time without effect of consequences. If you choose to withdraw from the study, and you wish for data collected from you to date to be removed from the data analysis, you can contact the primary researcher in writing to make this request alison.nuske@flinders.edu.au.

How do I agree to participate?

If you agree to participate please contact Alison Nuske via email at alison.nuske@flinders.edu.au or by phone on 8201 5549 to confirm your availability. Alison will then contact you to arrange a time for your interview and will provide you with copies of the interview questions prior to your interview.

How do I receive feedback?

On project completion, a summary of the results will be made available on the Facebook page: <https://fb.me/AutismTransition2Uni> or you can contact the researchers to ask for a summary of the results.

Thank you for taking the time to read this information sheet, and we hope that you will accept our invitation to be involved.

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project Number: 8242). For more information regarding ethical approval of the project only, the Executive Officer of the Committee can be contacted by telephone on (08) 8201 3116, by fax on (08) 8201 2035, or by email to human.researchethics@flinders.edu.au

Appendix Z: Case studies - Interview guides

INTERVIEW: STUDENT

Qualitative Interview Guide for Study:

Transition to and first year of university for students on the autism spectrum

Length of interview: 1 to 1.5 hours

Primary goal: to discuss your experiences during the transition to and first year at university.

Introduction (10 minutes)

- Welcome participant and introduce myself;
- Explain the general purpose of interview;
- Explain the presences and purpose of recording equipment;

Pre-interview briefing (approx. 5 min)

Verbal Script

Hi (name), thank you for agreeing to meet with me today. The goal of this interview is to explore your experiences of transition to university. We are interested to learn:

- What sorts of things went well or worked during your transition to university.
- What sorts of things maybe didn't work so well during your transition to university.

Your responses, identifying information and any other names mentioned during this interview will remain confidential.

Informed consent process

Before we begin, I would like to go through the consent form with you (*researcher will talk through every statement on the consent form with the participants*). If you agree with all of the statements on the form, could you please sign your name at the bottom of the sheet? (*signed consent will be required for first interview, verbal consent will also be confirmed at commencement of any additional interview recording*)

Thank you for agreeing to participate. Even though you have signed this consent form, I want to remind you that participation is voluntary and you do not have to answer every question. You can also stop at any time.

**If a participant brings a support person with them to the interview, this additional person will be reminded that we are interested in the experiences and opinions of the student. The researcher will ask this individual to refrain from making comments.*

Verbal Script

This interview will consist of some structured questions, however please feel free to provide as much information as you are comfortable doing. During the interview I may ask you to add some additional information, clarify or elaborate on your answers. You are free to refuse to answer any questions or provide any additional detail if you are not comfortable doing so. You may also ask to take a break at any time during this interview or ask to end the interview at any time.

If we are unable to cover all areas in your interview today or you wish to stop the interview you will be offered the opportunity to return at a later date and respond to the remaining questions should you wish to do so.

I would also like to record this interview for the purposes of transcription and data analysis. This will ensure the responses you give are captured correctly and transcribed accurately. I will be transcribing the data myself, so I will be the only person who has access to your audio recording. It will be stored on a password protected computer. You will have an opportunity to review and approve the transcript of your interview. This will be sent to you via email marked "CONFIDENTIAL". The transcripts, with identifying information removed, will be available for the other researchers in this study (as listed on the information sheet). These will be transferred via email marked "CONFIDENTIAL".

Are you okay for this interview to be audio recorded?

Do you have any questions for me before we begin?

Begin recording

Main interview questions (approx. 45 – 60 min)

Verbal Script

First of all, thank you very much for agreeing to participate in this study. We really appreciate you taking the time to help us to better understand your experience of transition to university.

In order to ensure that your experiences are represented appropriately can you please let me know which you would prefer to be used when discussing your experiences in the results of this study:

- person-first language (i.e. student with autism)
- identity-first language (i.e. autistic student)

Would you like to select your own pseudonym?

I would like to begin by asking you some background questions about yourself and your studies.

- How old are you?
- Which gender do you most identify with? Male/Female/Other
- In what year did you receive your diagnosis of autism/Asperger syndrome/autism spectrum disorder? How old were you then?
- In what year did you finish high school? (Year 12? Other?)
- What was your first year here at university?
- What degree area are you currently studying?
- Is this the degree you enrolled into when you first started at university?

Thanks.

I would now like to begin asking you some questions about (theme).

***Begin with questions from Theme 1 and ensure all theme areas are addressed.**

Debriefing (approx. 5 - 10 min)

Verbal Script

Do you have anything else you would like to add at this time?

Thank you very much for your time. We really appreciate you taking the time to participate in this study.

I will transcribe your interview and email you a copy of the transcript in the next 4 weeks. You will have an opportunity to provide some feedback or clarification if there is anything you feel needs to be clarified or added to the transcript. You can provide this feedback via email, by phone or in person.

If you are happy for me to do so I may also request additional clarification or elaboration on your responses to ensure clarity and accuracy of the information gathered. If you are happy to provide this additional information it can be provided by phone, email or in person, depending on what you would prefer.

We are hoping to gather some additional information to assist us to better understand what is and perhaps isn't working in supporting students on the autism spectrum in their transition to university. Before we finish up today, I would like to give you some more information about the ways in which we would like to do this.

**Give student a copy of the permission and address each point below.*

- Firstly, as part of this case study we are planning to conduct an interview with a disability advisor from your university. This interview will cover broad areas such as the policies in place for supporting students during transition to university, and the role the disability advisor plays in supporting students during their transition and first year. These general questions will not be in relation to your experiences specifically.

If you are happy for us to do so we would also like to ask your disability advisor some questions about the role they may have played in supporting you during your transition to university. If you are happy for us to do this, you can indicate this on the permission form by circling "do". If you do not wish for us to discuss your transition experiences specifically with your disability advisor, you can indicate this on the permission form by circling "do not".

This decision is entirely voluntary. You do not need to make this decision now, you can take the permission form home with you and I will also provide you with a copy of the *disability advisor interview questions* so that you will know what questions we will be planning to ask them.

Secondly, if you feel there is a family member or other support person/s who provided support to you during your transition to university, we would also like to ask them some questions about the role that they played during this transition period. If you are happy for us to interview one of your family members or another person that you feel supported you during this time, you can indicate this on the permission form by circling "do". If you do not want us to interview a family

member or other person regarding these experiences, you can indicate this on the permission form by circling “do not”.

This decision is entirely voluntary. You do not need to make this decision now, you can take the permission form home with you and I will also provide you with a copy of the *family member interview questions* so that you will know what questions we will be planning to ask them.

Similarly, if there is a academic staff member that you feel may be able to provide some insight into the experiences of supporting you during your transition to and first year at university we would be interested in asking them some questions also. If you are happy for us to interview an academic staff member who supported you during this time, you can indicate this on the permission form by circling “do”. If you do not want us to interview an academic staff member regarding these experiences, you can indicate this on the permission form by circling “do not”.

This decision is entirely voluntary. You do not need to make this decision now, you can take the permission form home with you and I will also provide you with a copy of the *academic staff member interview questions* so that you will know what questions we will be planning to ask them.

Please indicate on the permission form which individuals you give us permission to interview in relation to your experiences. There is an information sheet which outlines what this interview process will involve, we would ask that you provide this information sheet to the relevant family members, support person or staff in order for them to decide whether they would like to participate in this case study.

**Provide information sheets and interview questions*

- Finally, we would like the opportunity to review your disability access plan if you had one during your first year at university. This will assist us to understand what supports were in place for you during this time, and what information was communicated in order to support you in your first year at university. If you are happy for us to access a copy of your access plan or similar learning plan document from your university, you can indicate this on the permission form by circling “do”. If you do not wish for us to view a copy of your access plan you can indicate this on the permission form by circling “do not”.

This decision is entirely voluntary. Again, you do not need to make this decision now. You can take this information home with you and read through it and if you have any questions please feel free to contact me.

Once you have had a chance to think about this, please complete and sign the permission form and return it via email to alison.nuske@flinders.edu.au

Do you have any questions?

If you have any further questions or concerns, please feel free to contact me.

Final tasks

- Stop recording

INTERVIEW: Disability Advisor/Academic staff member

Qualitative Interview Guide for Study:

Transition to and first year of university for students on the autism spectrum

Length of interview: 1 to 1.5 hours

Primary goal: to discuss your experiences supporting the transition to and first year at university for autistic students

Introduction (10 minutes)

- Welcome participant and introduce myself;
- Explain the general purpose of interview;
- Explain the presences and purpose of recording equipment;

Pre-interview briefing (approx. 5 min)

Verbal Script

Hi (name), thank you for agreeing to meet with me today. The goal of this interview is to begin to explore your experiences supporting autistic students in their transition to university. We are interested to learn:

- What sorts of things went well or worked during this transition period.
- What sorts of things maybe didn't work so well during this transition period.

Your responses, identifying information and any other names mentioned during this interview will remain confidential.

Informed consent process

Before we begin, I would like to go through the consent form with you (*researcher will talk through every statement on the consent form with the participants*). If you agree with all of the statements on the form, could you please sign your name at the bottom of the sheet? (*signed consent will be required for first interview, verbal consent will also be confirmed at commencement of any additional interview recording*)

Thank you for agreeing to participate. Even though you have signed this consent form, I want to remind you that participation is voluntary and you do not have to answer every question. You can also stop at any time.

Verbal Script

This interview will consist of some structured questions, however please feel free to provide as much information as you are comfortable doing. During the interview I may ask you to add some additional information, clarify or elaborate on your answers. You are free to refuse to answer any questions or provide any additional detail if you are not comfortable doing so. You may also ask to take a break at any time during this interview or ask to end the interview at any time.

If we are unable to cover all areas in your interview today or you wish to stop the interview you will be offered the opportunity to return at a later date and respond to the remaining questions should you wish to do so.

I would also like to record this interview for the purposes of transcription and data analysis. This will ensure the responses you give are captured correctly and transcribed accurately. I will be transcribing the data myself, so I will be the only person who has access to your audio recording. It will be stored on a password protected computer. You

will have an opportunity to review and approve the transcript of your interview. This will be sent to you via email marked "CONFIDENTIAL". The transcripts, with identifying information removed, will be available for the other researchers in this study (as listed on the information sheet). These will be transferred via email marked "CONFIDENTIAL".

Are you okay for this interview to be audio recorded?

Do you have any questions for me before we begin?

Begin recording

Main interview questions (approx. 20 - 30 min)

Verbal Script

First of all, thank you very much for agreeing to participate in this study. We really appreciate you taking the time to help us to better understand the transition experiences for autistic students

I would like to begin asking you some questions about (theme).

***Begin with questions from Theme 1 and ensure all areas are covered**

Debriefing (approx. 5 - 10 min)

Verbal Script

Do you have anything else you would like to add at this time?

Thank you very much for your time. We really appreciate you taking the time to participate in this study.

I will transcribe your interview and email you a copy of the transcript in the next 4 weeks. You will have an opportunity to provide some feedback or clarification if there is anything you feel needs to be clarified or added to the transcript. You can provide this feedback via email, by phone or in person.

If you are happy for me to do so I may also request additional clarification or elaboration on your responses to ensure clarity and accuracy of the information gathered. If you are happy to provide this additional information it can be provided by phone, email or in person, depending on what you would prefer.

Do you have any questions?

If you have any further questions or concerns, please feel free to contact me.

Final tasks

- Stop recording

INTERVIEW: Family Member/Other

Qualitative Interview Guide for Study:

Transition to and first year of university for students on the autism spectrum

Length of interview: 1 to 1.5 hours

Primary goal: to discuss your experiences supporting the transition to and first year at university of your autistic family member.

Introduction (10 minutes)

- Welcome participant and introduce myself;
- Explain the general purpose of interview;
- Explain the presences and purpose of recording equipment;

Pre-interview briefing (approx. 5 min)

Verbal Script

Hi (name), thank you for agreeing to meet with me today. The goal of this interview is to begin to explore your experiences supporting (_____) in their transition to university. We are interested to learn:

- What sorts of things went well or worked during this transition period.
- What sorts of things maybe didn't work so well during this transition period.

Your responses, identifying information and any other names mentioned during this interview will remain confidential.

Informed consent process

Before we begin, I would like to go through the consent form with you (*researcher will talk through every statement on the consent form with the participants*). If you agree with all of the statements on the form, could you please sign your name at the bottom of the sheet? (*signed consent will be required for first interview, verbal consent will also be confirmed at commencement of any additional interview recording*)

Thank you for agreeing to participate. Even though you have signed this consent form, I want to remind you that participation is voluntary and you do not have to answer every question. You can also stop at any time.

Verbal Script

This interview will consist of some structured questions, however please feel free to provide as much information as you are comfortable doing. During the interview I may ask you to add some additional information, clarify or elaborate on your answers. You are free to refuse to answer any questions or provide any additional detail if you are not comfortable doing so. You may also ask to take a break at any time during this interview or ask to end the interview at any time.

If we are unable to cover all areas in your interview today or you wish to stop the interview you will be offered the opportunity to return at a later date and respond to the remaining questions should you wish to do so.

I would also like to record this interview for the purposes of transcription and data analysis. This will ensure the responses you give are captured correctly and transcribed accurately. I will be transcribing the data myself, so I will be the only person who has access to your audio recording. It will be stored on a password protected computer. You

will have an opportunity to review and approve the transcript of your interview. This will be sent to you via email marked "CONFIDENTIAL". The transcripts, with identifying information removed, will be available for the other researchers in this study (as listed on the information sheet). These will be transferred via email marked "CONFIDENTIAL".

Are you okay for this interview to be audio recorded?

Do you have any questions for me before we begin?

Begin recording

Main interview questions (approx. 30-45min)

Verbal Script

First of all, thank you very much for agreeing to participate in this study. We really appreciate you taking the time to help us to better understand the transition experiences for autistic students

I would like to begin asking you some questions about (theme).

***Begin with questions from Theme 1 and ensure all theme areas are covered**

Debriefing (approx. 5 - 10 min)

Verbal Script

Do you have anything else you would like to add at this time?

Thank you very much for your time. We really appreciate you taking the time to participate in this study.

I will transcribe your interview and email you a copy of the transcript in the next 4 weeks. You will have an opportunity to provide some feedback or clarification if there is anything you feel needs to be clarified or added to the transcript. You can provide this feedback via email, by phone or in person.

If you are happy for me to do so I may also request additional clarification or elaboration on your responses to ensure clarity and accuracy of the information gathered. If you are happy to provide this additional information it can be provided by phone, email or in person, depending on what you would prefer.

Do you have any questions?

If you have any further questions or concerns, please feel free to contact me.

Final tasks

Stop recording

Appendix AA: Co-analyst confidentiality agreement form



CONFIDENTIALITY AGREEMENT

Co-analyst

Transition to and first year of university for students on the autism spectrum.

I, _____, agree to be a co-analyst in Alison Nuske's doctoral study exploring the experiences of individuals with autism spectrum disorder in their transition to and first year at university. I agree to maintain full confidentiality in regards to any and all data and documentation I access as co-analyst. Furthermore, I agree:

1. To hold in strictest confidence the identification of any individual that may be inadvertently revealed during the analysis, or in any associated documents;
2. To not make copies of any of the transcribed interview texts, unless specifically requested to do so by Alison Nuske
3. To delete all electronic files containing study-related documents from my computer hard drive and any backup devices.

I am aware that I can be held legally liable for any breach of this confidentiality agreement, and for any harm incurred by individuals if I disclose identifiable information contained in the files to which I will have access.

Co-analysts' name (printed) _____

Co-analysts' signature _____

Date _____

Copy to be retained by the co-analyst

Original to be retained by Alison Nuske

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project number: 8242). For more information regarding ethical approval of the project only, the Executive Officer of the Committee can be contacted by telephone on (08) 8201 3116, by fax on (08) 8201 2035, or by email to human.researchethics@flinders.edu.au

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Appendix AB: Overview of staff characteristics (from survey)

Response	Role	Years in Higher Education
1	Lecturer, Other	6-10
2	Disability Services	1-3
3	Disability Services	1-3
4	Tutor	6-10
5	Topic/Unit Coordinator, Lecturer, Tutor	6-10
6	Topic/Unit Coordinator, Degree Coordinator, Lecturer	11-15
7	Disability Services	6-10
8	Topic/Unit Coordinator, Degree Coordinator, Lecturer	15+
9	Tutor, Disability Services	11-15
10	Lecturer, Tutor	3-5
11	Topic/Unit Coordinator, Lecturer, Tutor	11-15
12	Topic/Unit Coordinator, Lecturer, Tutor, Other	6-10
13	Topic/Unit Coordinator, Tutor	1-3
14	Topic/Unit Coordinator, Lecturer	11-15
15	Topic/Unit Coordinator	6-10
16	Topic/Unit Coordinator, Lecturer	15+
17	Topic/Unit Coordinator, Lecturer	15+
18	Topic/Unit Coordinator, Lecturer, Tutor	15+
19	Tutor, Disability Services	3-5
20	Tutor, Disability Services	0-1
21	Lecturer, Tutor, Other	3-5
22	Disability Services, Other	6-10
23	Other	3-5
24	Topic/Unit Coordinator, Lecturer, Tutor	6-10

Appendix AC: Staff awareness of DDA (from survey)

Response	Never heard of it	Heard of it, but don't know much about it	Heard of it, but I don't think it applies to my role	Familiar with it and the impact it has on my role	No response
1					X
2				X	
3				X	
4				X	
5				X	
6				X	
7				X	
8				X	
9				X	
10				X	
11		X			
12				X	
13				X	
14				X	
15				X	
16				X	
17				X	
18		X			
19				X	
20				X	
21		X			
22				X	
23				X	
24				X	

Appendix AD: Staff confidence in supporting autistic students (from survey)

Response	Not at all confident	Not very confident	Somewhat confident	Very confident	No response
1			X		
2				X	
3					X
4				X	
5				X	
6			X		
7			X		
8				X	
9			X		
10				X	
11		X			
12				X	
13			X		
14			X		
15			X		
16			X		
17			X		
18	X				
19					X
20					X
21					X
22					X
23					X
24					X

Appendix AE: Staff autism training provision & interaction with family (from survey)

Response	Training in autism	Interaction with family
1	No	Yes
2	No	Yes
3	Not answered	Not answered
4	Yes	No
5	Yes	No
6	No	Yes
7	Yes	Yes
8	Yes	Yes
9	No	No
10	No	No
11	No	No
12	No	No
13	Yes	Yes
14	No	No
15	No	No
16	No	No
17	No	No
18	No	No
19	Not answered	Not answered
20	Not answered	Not answered
21	Not answered	Not answered
22	Not answered	Not answered
23	Not answered	Not answered
24	Not answered	Not answered