Are we on the same track? An exploration of educators', autistic students' and adults' conceptual understandings of autism.

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ABSTRACT

Billions of dollars are spent globally on autism related research, service provision, education, media campaigns and merchandise. In turn this has created an autism industry whereby autism has become commodified. This qualitative research explored whether the commodification of autism and/or other factors were of influence on educators' and autistic students' and adults' conceptualisation of autism. The research also aimed to understand whether varied cultural influences on educators', autistic students', and autistic adults' conceptions of autism result in educators and their autistic students being on completely 'different tracks' in their understanding of autism and autistic individuals in educational settings.

The research compared whether conceptions of autism varied between research participants and how they reflected the interaction of the five processes of du Gay et al's (2012) Circuit of Culture, including representation, production, consumption, identity, and regulation.

This qualitative research involved semi-structured interviews using a photo elicitation method with six educators and four autistic students (Bates et al., 2017) to investigate their conceptions of autism and the key elements that were of influence on their conceptualisations. Focus group interviews with four autistic adults provided insights into their past educational experiences and influences on their conceptions of autism. Individual research participants' responses to the photo elicitation method and interview questions were analysed using reflexive thematic analysis (Braun & Clarke, 2006) and poetic inquiry (Lietz et al., 2006) to determine alignment to media discourses, influence of the autism industry and the five Circuit of Culture processes that contribute to the construction of popular culture. This research was co-constructed with autistic people at various junctures throughout the research.

This research considered whether educators, autistic students and adults are on the same track in their conceptions of autism, recognising that shared conceptual maps are fundamental to successful and positive relationships in educational contexts and beyond (Hall, 2013). My research explored how educators, autistic students and adults consume, represent and re-produce conceptions of autism and subsequently contribute to sustaining an autism culture that emerges from varied realities and myths. The outcomes highlighted that educators and autistic students are on 'different tracks' in explaining their conceptions of autism although both groups' understandings were explicitly influenced by lived experiences and implicitly by the commodification of autism. In addition, the thesis outcomes recommend students are more active participants in supporting their educator's understanding of their lived experience in a school context which is clearly influenced by the commodification of autism.

The research sought to provide evidence to assist educators, autistic students and adults to recognise and understand what has been of influence in their conceptualisations of autism, with the hope this may assist other educators and autistic people to take a more critical and questioning stance when consuming and/or producing information about autism.

Keywords: autism, neurodiversity, conceptions, photo elicitation, education, autism industry.

DECLARATION

I certify that this thesis does not incorporate without acknowledgment any material previously submitted for a degree or diploma in any university; and that to the best of my knowledge and belief it does not contain any material previously published or written by another person except where due reference is made in the text.

Signed: V. Alexander

Date: 22/05/2023

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LIST OF ACRONYMS

ACARA - Australian Curriculum, Assessment and Reporting Authority

AIC - Autism Industrial Complex

ASD - Autism Spectrum Disorder is a clinical diagnostic label used when diagnosing autism

Autism CRC - Autism Co-operative Research Centre for Living with Autism

DDA - Disability Discrimination Act (1992)

DSE - Disability Standards in Education (2005)

DSM - Diagnostic and Statistical Manual

IEP - Individual Education Plan

NAPLAN **-** National Assessment Program – Literacy and Numeracy

NCCD - Nationally Consistent Collection of Data

NDIA - National Disability Insurance Agency

NDIS - National Disability Insurance

PDA- Pathological Demand Avoidance or Persistent Drive for Autonomy

WAAD- World Autism Awareness Day

CHAPTER ONE: INTRODUCTION

> “I am autism. I have no interest in right or wrong. I derive great pleasure out of your loneliness. I will fight to take away your hope” (Autism Speaks, 2009, 1:17).

1.1 Introduction

The word *autism* generates wide-ranging and emotive responses, such as the sentinel quotation above. This quotation is from a video advertisement *‘I am Autism’* developed by Autism Speaks (Appendix One*)*, a global parent advocacy group that originated in the USA. Although the 2009 video was removed after a few months due to public responses of distaste for the way autism was presented as a horror movie ‘grim reaper’ entity designed to destroy lives, it remained a common narrative for many years. The video shifts from the horror movie entity to an equally emotive reaction from families to autism stating, “we are a community of warriors…and if you are not scared, you should be when you came for my child” (Autism Speaks, 2009, 3:00).’[1] This implies that autism is something to be battled and fought against by families. Autism Speaks has since apologised for posting this video and has asked for others not to share the video as it no longer represents their current ‘campaign and mission objectives.’ It was only in 2016 that Autism Speaks removed the word ‘cure’ from its mission statement, but they remain publicly committed to a deficit focused mission of ‘personalised health care, treatments and supports.’[2] A deficit view of autism reflects a biomedical model of disability (Leysen et al. 2021) that views any difficulties as a problem within the autistic person, as opposed to a social model of disability, that views the person as being disabled by societal factors and the physical environment (Woods, 2017a).

Autism Speaks reports they received over $3.2 billion in federal funding between 2007 and 2019 and supported 4.1 million autistic people and their families (Autism Speaks. 2022). This suggests Autism Speaks has been of significant influence on peoples’ perspectives of autism, at least within the USA. The history and relationship of Autism Speaks to the autistic community is still fractious, with concerns that Autism Speaks continues to have a deficit focus, even when using language indicating they are moving away from this. This is one of many autism-focused organisations which, through their access to autistic children and people, families, and social

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[1] The full text from this video can be located in Appendix One

[2] https://www.autismspeaks.org/autism-speaks-questions-answers-facts

media, contribute to the commodification of autism and the creation of a popular culture depiction of autism.

The term ‘popular culture’ is defined as ‘the set of practices, beliefs, and objects that embody the most broadly shared meanings of a social system. It includes media objects, entertainment and leisure, fashion and trends, and linguistic conventions, among other things” (Kidd, n.d. retrieved 2021, n.p). Kidd (2021) goes on to further explain that popular culture emerges from subcultures gaining prominence and the capacity for marketisation. This thesis makes use of the term *autism popular culture* to acknowledge a specific subculture of popular culture whereby multiple representations of autism are produced and consumed. The term also encapsulates the explicit or tacit influence of people’s beliefs, practices, use of language, and ongoing social reproduction of autism popular culture. This culture is different from *autistic culture*, a culture generated by the autistic people who form the *Autistic community,* either diagnosed or self-identifying to acknowledge their identity, belonging, and autonomy (Arnold, 2013). Autistic culture and the Autistic community differ again to the broader *autism community* that has been defined as the community of families, professionals, and researchers who support autistic people. Autism Speaks fits within the autism community and through its actions contributes to autism popular culture. Autistic people may align themselves to autistic culture, with many taking on activist roles to reclaim autonomy over their lives. However, the members aligned to autistic culture also contribute to autism popular culture, albeit in ways that may be in juxtaposition to those from the autism community. A more in-depth review of the differing cultures and communities aligned with autism is presented in Chapter Two. The concept is introduced here to highlight the differences in cultures and cultural perspectives.

As Wadham et al., (2007, p. 4) suggest, “Culture is one of the most complex and differently interpreted words of the English language.” They note varied interpretations of culture, but highlight that humans are cultural beings influenced by multiple factors, including norms, rituals, language, signs and symbols, values, and beliefs, and that it is the interaction between humans and their environments that shape interpretations of their reality and cultural alignment. The sustained, but often implicit interactions between humans and their environments is at the heart of how people make sense of their world, but often without individuals realising what has influenced theirs. This formed a key part of the thesis as I was interested in understanding what influenced educators’, autistic students’ and adults’ conceptions of autism. Schudson, (1978, p.6) stated, “Philosophy, the history of science, psychoanalysis and the social sciences have taken great pains to demonstrate that human beings are cultural animals who know and see and hear the world through socially constructed filters.” Schudson’s reflection on the role of socially constructed filters on individual’s perceptions and interpretation of the world is a relevant foundation for this thesis. Central to the thesis is understanding educators' and autistic students' and adults' conceptions of autism and how these are formed, vary, and influence educational practices and experiences in the South Australian educational context. The notions of human beings as cultural beings aligns with an interpretivist epistemology, where people come to know or understand through their engagement with and interpretation of their world. Diversity in engagement and interpretation between human beings is influenced by our cultural environments, preferences, and choices: in other words, our socially constructed filters (Schudson, 1978).

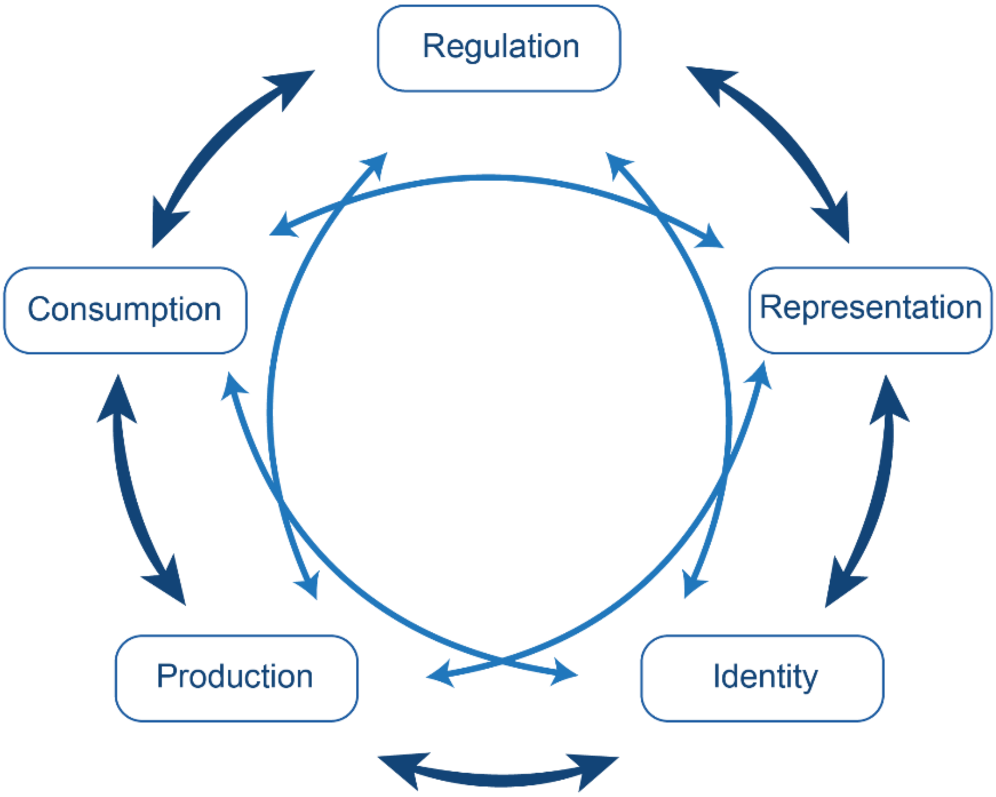
Historically, our socially constructed filters were influenced by a smaller and more localised environment, but with the advent of technology and the internet we have become a globally networked society powered by personal and digital networks. Castells (2013) highlights the influence of the internet on our access to information, social structures and behaviour, and the subsequent creation of a culture of autonomy. By culture of autonomy, Castells is acknowledging the freedom to access information when and where an individual chooses. However, he also notes, "As in all moments of major technological change, people, companies, and institutions feel the depth of the change, but they are often overwhelmed by it, out of sheer ignorance of its effects" (Castells, 2013, p.8). This suggests that while a culture of autonomy has emerged, challenges for individuals arise in determining the quality of information they are consuming, filtering, and subsequently reproducing. They may also feel overwhelmed by the sheer volume of information, mixed with misinformation and disinformation available to consume. It is through their patterns of access to information, generated by artificial intelligence-driven exposure to sites, individuals may no longer be aware of the effects of their information seeking practices on their knowledge, perceptions, conceptualisations, and behaviours.

Understanding how educators and autistic students and adults develop their conceptions of, and beliefs and values about autism is not straightforward, as it may not always be obvious to them. However, I propose the internet has fostered an autism industry which, evidenced-based or not, is easily accessible to all. Castells (2013) refers to the technology driven access to information as a material culture, one in which ideas, interests, and values are socially produced and consumed. The recursive interactions between production and consumption of knowledge and the ways in which knowledge is represented and regulated have significant influence on identity formation, values, beliefs, and actions. These implicit, and often tacit, influences on knowledge development are central to du Gay and colleagues (1997) Circuit of Culture model, in which they contend the five interrelated processes: production, regulation, consumption, representation and identity, are central to understanding potential influences on how people interpret and make sense of their world. They viewed the model as a tool of cultural analysis that could be applied to a cultural phenomenon. Autism popular culture, autistic culture, culture of autonomy, and material culture have all been referenced in this introduction and all reflect a cultural phenomenon in which the interrelationships between elements of the Circuit of Culture may vary. This research sought to understand in more depth the influence of the cultural phenomenon of autism popular culture on educators, autistic students, and adults.

1.2 The Circuit of Culture

The Circuit of Culture model, presented in Figure 1.1 below, was employed in this research as a tool for analysis of the research participants' perspectives on their conceptions of autism and its influence on their lived experiences. It also served to analyse the many media discourses on autism from the varied elements of the model. Leve (2012) recommended the use of the Circuit of Culture as tool for contemporary analysis of the construction and maintenance of a commodity: in this case, the commodification of autism. She applied the model to the commodification of international education, and drew on Hall (1997) and du Gay et al., (1997) research exploring each element of the model and how they interact and assist in explaining the multiple dimensions of commodification.

Figure 1. 1 Circuit of Culture (du Gay et al., 1997).



However, of particular interest to this research is Hall's proposition that 'representation' can be viewed from three different perspectives: 1) Reflection, in which language is used to describe an experience or something that already exists in the world; 2) Intentional, whereby language is used in unique ways to capture the person or 'producers' meaning; and 3) Constructionist, whereby meaning is generated in and through language, reflecting a process of interpretivism (Leve, 2012). These three perspectives of representation have been explored in the findings of the thesis.

Another feature of Hall's work (1997) that particularly resonated with my specific interest in working with educators and autistic students was the importance of people having common understandings. As noted previously, our different histories, communities, and interests activate social filters which may vary our interpretation of specific representations. Given educators and autistic students find themselves in school-based contexts, common understandings of representation and identity should assist in creating a positive learning environment. Leve (2012, p.6) cites Hall on the value of common understandings, noting 'Hall calls this common understanding 'conceptual maps,' and makes the point that in sharing a roughly similar 'conceptual map,' 'we are able to build up a shared culture of meanings and thus construct a social world which we inhabit together' (Hall, 1997b, p. 18). Educators and students spend much time together in school-based contexts and therefore similar conceptual maps should serve to keep them on the 'same track.' This research explores whether educators and autistic students are 'on the same track' in conceptualising of autism.

The five interrelated processes of the Circuit of Culture model (Figure 1.1) are presented in Table 1.1 linked to examples from the autism field, noting at times significant contrasts in perspective that influence an individual's understanding and subsequent actions. The examples provided in Table 1.1 represent a snapshot in time and encapsulate my initial observations of connections to the five areas of the Circuit of Culture. This was generated through engagement with research, observations from television, movies, and social media, and working as a professional in the field of autism for many years. Many of these examples are expanded on in more detail in the following section aligned to previous research. However, this initial table provides an overview of multiple factors of potential influence in the construction of an autism popular culture, noting the subtle and not so subtle influences such factors may have on perpetuating beliefs and knowledge about autism. These, and additional factors of relevance to the thesis, will be explored in more detail in Chapter Two. Chapter Three will explore in more depth how the Circuit of Culture was used in the research design and data analyses.

Table 1. 1 Elements of the Circuit of Culture in relation to autism

Elements of the Circuit of Culture	Examples
Representation How is autism represented to and by others?	Variations between medical model and social model of disability, media representations of either extreme deficits or extraordinary abilities, multiple generalisations, the fight against autism, an external enemy or intrinsic capacities. There are also representations about the responses of others, for example, autism is hard on families, breaks up marriages, is hard on siblings, difficult for teachers, burden on economies
Production How is 'autism' produced?	Evidence-informed research versus myth and power relationships, autistic children and adults as raw materials, commodification of autism through the production of materials and resources, T-shirts, Purple parades, websites for services. Services then have particular claims from cure through to support. Autistic self-advocates produce a narrative. Parent groups 'Super Mum' or 'Autism Warrior Mum' or 'Autism Angels'.
Identity What identities are evident and how are the formed and maintained?	Autistic identities, how they are formed and how they are perceived by autistic individuals and others, for example, family identity – 'I love someone with autism,' 'people first' language vs. autistic pride – 'I am autistic.' Autistic people have self-identity and so do some families about being an 'autism parent' and professionals being autism specialists or autism experts.
Consumption How is 'autism' consumed?	Access to information, services, social networks, NDIS funding, information vs. misinformation vs disinformation. Autism is consumed through media, what people see on TV, in movies, and read through social media and articles. Consumed through personal interactions for example families, educators, health professionals.
Regulation How is autism diagnosed? Who can access funding and services?	The use of the DSM-V in the US is linked directly to insurance and accessing of funds. Changes from DSM-IV to DSM-V were perceived by some to make it 'easier' to get a diagnosis and generate more money for the Government. A diagnosis is subjective as it is based on observation, not a tangible measurable criterion for example, Down syndrome is caused by a chromosomal disorder, while other disabling conditions may be detected through MRI etc. but autism is not. It is believed that people can 'shop around' until they receive a diagnosis. The NDIS was first touted as based on 'need' but now is linked to autism severity levels related to DSM-V diagnostic criteria. Similarly, in schools Nationally Consistent Collection of Data (NCCD) was originally presented as a way of measuring support and not funding, but is now linked to funding that schools receive. There is an interest in the higher the support needs the more funding you receive. Families and schools are encouraged to highlight severity and the negative impacts on the autistic person and those around them. Controversy around receiving an autism diagnosis vs identifying as autistic through self-diagnosis and how the label then equates to access to support or not.

1.3 Sensitising ideas

Since the first clinical descriptions of autism (Kanner,1943; Asperger, 1944), the predominant representation of autism is rooted in a medical model of understanding autism as a life-long developmental disability inherent to the individual, with deficits to be treated. From the mid-1940s, there has been a proliferation of research and services dedicated to understanding in more depth the nature and implications of autism for individuals, families, and education and health services. This exponential growth in research has created an *autism industry*, whereby large and small organisations and professionals, work independently or in collaboration to provide health, therapy, education, and community services to autistic individuals and their families, as well as conduct research, and produce related material goods. The autism industry is “currently big business” (Broderick & Roscigno 2021, p. 79) and it is important to note the industry is lucrative and creates a source of income and profit for many. It has also been described as the ‘’vast and exploitative autism industry” (Milton, 2012, p.3). The ‘commodification of autism’ was described by Mallett & Runswick-Cole (2012) and Woods (2017). The term ‘Autism Industrial Complex’ (AIC) was coined by Anne McGuire in 2013 to describe the commodification of autism through the creation of an industry and the power relations that exist both within and outside the autism industry. It is this point that differentiates the difference between the terms ‘autism industry’ and ‘Autism Industrial Complex.’ Broderick and Roscigno (2021) extended the meaning of Autism Industrial Complex to propose that:

> …autistic people—their very bodies—function as the raw materials from which this industrial complex is built, even as autistic people—their very identities and selves—also become unwitting, and often unwilling, products of the AIC. (p. 77)

I have explored the definitions and evolution of autism into an industry in Chapter Two, but wish to acknowledge here that I am also entwined in this industry. I share my ontological position in conducting this research in a future section of this Chapter. However, I want to highlight at this point that research has not yet uncovered a definitive cause of autism. While genetic links are widely accepted, there is no conclusive genetic cause, nor is there a physical way of diagnosing autism through medical tests such as blood tests or MRI (Whitehouse et al., 2018). It is accepted that autism is present across cultures, although appropriateness of culturally sensitive processes and assessment tools remains an issue (Lilley et al., 2019; Smith et al., 2019). Diagnosticians cannot provide a clear prognosis across the lifespan (American Psychiatric Association, 2022), leading to a high level of subjectivity associated with autism. I propose that the level of subjectivity associated with autism and within the autism industry has enabled more room for opinions and false promises (and questionable services) to be shared in an age in which social and mass media have made space for misinformation and disinformation to proliferate. It is perhaps unsurprising, that the autism industry has continued to grow. It is hoped this research illuminates the influence of the autism industry on educators' and autistic students' and adults' perspectives, and the importance of bringing a critical lens to the industry.

There appears to be two diametrically opposed representations of autism in autism popular culture. One is focused on a range of perceived deficits and extensive impairments experienced by autistic people, whilst the other focuses on popularly understood special abilities and extraordinary talents (Janse Van Rensburg, 2022). For example, reports of autistic people living 'in their own world,' and/or having significant difficulty verbally communicating and extreme anxiety coping in day to living are commonly portrayed in the media (Prochnow, 2014). Alternatively, autistic people are often portrayed as having genius level IQ, as a talented 'nerd' or 'geek' (Falk & Schofield, 2018), or spectacularly gifted in music, mathematics or visual arts (Elder & Thomas, 2005). Some media representations suggest autism is a 'super power' (Chow & Hayakawa, 2022) and likewise parents of autistic children possess super powers and described as 'warrior heroes' or as 'super Mums' (Lo Bosco, 2021) or identify as an 'Autism Mum' or as Ampagna (2020) describes an 'Autism Daddy'. As a result, the two extreme representations of autism primarily perpetuate 'difference from' or 'othering of,' indicating something beyond commonly held perspectives of 'normal.' Hall (1997) describes the 'spectacle of other' as a cultural fascination of marginalised groups by the majority, and that this may underpin stereotypical representation of groups, such as autistic people. This concept will be expanded upon in Chapter Two and throughout the thesis.

The concept of opposing representations is also noted in research about a term that has emerged from the autism industry: 'weaponized autism.' Welch et al., (2002) undertook a discursive analysis of the term 'weaponized autism' in Gab, an alternative right social media platform, and concluded the term simultaneously glorified and derogatorily represented autistic stereotypes. In reflecting on Soetero's (2016) post below (see Figure 1.2) it is apparent the interpretation of this definition may depend on one's lived experiences, one's understanding of the concept presented, and ultimately one's social filter. For example, which words and phrases draw the most attention, what level of agreement/disagreement with the concept is evident; all leading to potential variations in interpretations with different individuals being on quite different tracks in their responses.

Figure 1. 2 Urban Dictionary Definition of Weaponized Autism (2016) Urban Dictionary: weaponized autism

At the time of conducting this research, the Urban Dictionary website had a link immediately underneath the definition presenting an opportunity to purchase a ‘weaponized autism’ mug. These links to profiting from autism caught my attention and interest in contemplating the Circuit of Culture and how it reflected the commodification of autism through production of autistic related items with the express purpose of encouraging others to consume them. Of interest was how this commodification may also infiltrate and influence conceptions of autism by autistic and non-autistic people. Questions arose in my mind such as: Who would consider purchasing such a mug? What experiences might lead to people connecting with the concept? Who would not understand this perspective or even be presented with this information? How might different connections and understanding of autism perpetuated by social media generate scenarios where people who work closely together, for example, autistic students and their educators, are on quite different tracks in their experiences and thinking?

While exposure to some social media sites may be influenced by specific searches, preferences, and social networks, the influence of mainstream television and movies is broader and consequently of influence on a broader population. Popular culture represents ‘gifted’ autistic characters in movies or on television programs such as *Rain Man* (Levinson, 1988), *The Good Doctor* (Shore, 2017), or *The Big Bang Theory* (Lorre and Prady, 2006) and the protagonists from these programs are typically depicted as white, middle class, males. Rarely are autistic women or Indigenous autistic people included in popular culture productions, with the odd exception, such as Quinn 'Quinni' Gallagher-Jones, a female teenage autistic character in *Heartbreak High* (Heaton et al., 2022), who is played by an autistic actress, Chloe Hayden. Significant research about the way autism is represented in film and television, particularly over the last twenty years, has indicated that media has increased public awareness of autism, but this has not helped to reduce stigmatisation for autistic people (Broderick, 2010; Holton, 2013; Holton et al., 2017).

Critical autism studies, as discussed by Woods et al., (2018) aims to illuminate the power dynamics that interact in discourses around autism, challenge the deficit-based definitions of autism, and consider the ways in which biology and culture intersect to produce 'disability' (Waltz, 2014; Davidson & Orsini, 2013). Whilst the research of Woods et al., (2018) calls for a more critial response to the discourses on autism, this message does not seem to have been taken on board by the general public. This research reflects on the ways educators reflect on their beliefs, perspectives, and work with autistic students, exploring if there is an element of critical discourse.

A TED talk by Jac den Houting (2019), *Why everything you know about autism is wrong* (Appendix two), has had over one million views and over 3500 public comments. In this talk, den Houting raises the issue of the divide between autistic and non-autistic people's perspectives and views about autism. The public comments and responses to the TedTalk, often derogatory and highly emotive spoke volumes to further reinforce the divide, but once again, it serves as further evidence of people being on quite 'different tracks' in their thinking about autism and consequent practices and behaviours.

The research related to representations of autism as a signifier of difference intersects with and impacts the body of clinical research about autism as a medical condition with potentially identifiable causes, genetic studies, research into therapies, and approaches to educating autistic students. There are ongoing and emotive tensions between researchers who define autism as a disorder, and autistic advocates who understand autism from the perspective of the social model of disability or neurodiversity paradigm. In the social model of disability, the autistic person is seen to be disabled by society and environment rather than any inherent deficit within the individual themselves. The neurodiversity paradigm suggests that autism is one of many natural variations of the human brain (Taylor & Grandin, 2021), in which people may or may not have higher support needs than others. From this view, autism is not a deficit (Baumer, 2021). The prolific nature of information, resources, and services generated by the autism industry may serve as a further barrier to autistic people, given the multiple generalisations presented to the wider population.

Both the social model and the neurodiversity paradigms propose that there is no need to change or ‘fix’ autistic people, and advocate for acceptance and support instead of a cure or ‘normalising’ of the autistic person to be more like the rest of the neurotypical population (Sinclair, 1993; Singer, 1999). ‘Medical model’ researchers are more likely to advocate and promote therapies that aim to reduce autistic symptomology, and to try to make autistic people indistinguishable from their non-autistic peers, or even to advocate for a cure (Stenson, 2019). Both arguments are emotive and serve the needs of different cohorts. The emphasis on the medical model of autism facilitates the distribution of funding using a simple strategy: the greater the deficits, the higher the allocation of funding from a given funding agency. This in turn reinforces the focus of autism as an economic burden on government systems such as health and education (Rogge & Janssen, 2019), as well as a burden on families (Liao & Li, 2020). This is explored further in Chapter Two.

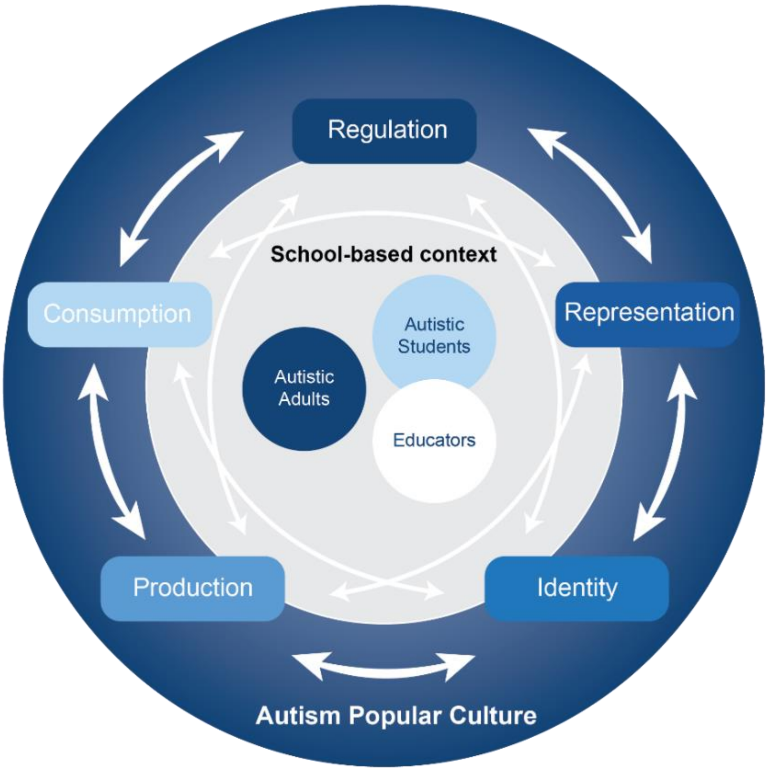
A more recent addition to these models is autism as a ‘predicament model’ (Anderson-Chavarria, 2021). The predicament model understands disability to be both “biologically based and socially constructed, where atypical functionality can, and often is, made restrictive within a society that was not made with atypical function in mind” (Anderson-Chavarria, 2021, p. 1332). This model emerges from the failure of previous models to effectively represent the lived experiences of autistic individuals and their families. It also aims to challenge the ‘spectrum’ metaphor of autism, with a recommendation to focus on autistic individuality in preference to fitting individuals along a spectrum and/or making comparisons with standards of ‘normal.’ Anderson-Chavarria (2021, p. 1337) argues, “that by understanding autism as a predicament, we acquire a flexible, individualizable framework that truly encompasses and represents the wide variety of autism experiences without having to, inadvertently or not, rank autistic human beings on an arbitrary scale of functionality.” The predicament proposition is of particular interest to this thesis, given it prioritises acknowledgement of the many varied and complex influences on autistic individuals’ lived experience and their identity development. It also reflects the Circuit of Culture model’s proposition that complex interrelationships between a range of elements exist and are all of influence on individuals whether at a micro or macro level. Anderson-Chavarria, (2021, p. 1235) also notes that “too frequently…society constructs their [autistic individuals’] identity for them in othering fashions.” The concept of societal constructions connects with how the phenomenon of the commodification of autism (or the autism industry) influences people’s perspectives, generating a predicament whereby there is wide variations in beliefs and actions, while at the same time multiple generalisations about autism and its influence on individuals. This research aims to understand the influences on the research participants' constructions of autism and how their understandings may be reflected through the Circuit of Culture model.

1.4 Significance of the research

There are a number of factors that make this study unique. From a philosophical or meta level, there are already many studies about representations of autism in film and television (Dean & Nordahl-Hansen, 2022) print media (Pesonen et al., 2021), fiction (Loftis, 2015) as well as many studies about perceptions of autism (Cooper et al., 2021) and conceptions of autism (Mac Carthaigh, 2020). However, this research specifically brings together educators' and autistic students' and adults' conceptions and experiences of autism in educational contexts. As introduced in the previous section on sensitising ideas, autism popular culture presents itself in multiple ways, and these may or may not be accessed by educators and autistic students and adults in the same ways. The interest in working with both educators and autistic students in particular, was due to the symbiotic relationships between teachers and students and the influence they have on each other's lived experiences, knowledge, and identity development (as teachers, students, or individuals). I was interested in how this may ameliorate or conflate influences of autism popular culture on conceptual development. However, educators' and autistic students' relationships generally occur in school-based contexts in which the structures and regulations of educational policies and organisations are of significant influence too. The research aims to determine how these policies and regulations connect and/or contrast with the influences of autism popular culture and the teacher/student symbiotic relationship. Given regulations and representations are both part of the Circuit of Culture, it was interesting to determine how these two, and the other elements of the Circuit of Culture, interact and serve to influence educators' and autistic students' conceptions and identities.

There appears to be no research using the Circuit of Culture to frame and analyse research of influences on educators', autistic students' and adults' conceptions and experiences of autism, situated within school-based contexts. Figure 1.3 is designed to highlight how the research design incorporates multiple elements that interact with each other and are of potential influence on educators' and autistic students' and adults' conceptions and experiences of autism. The students and educators are overlapping circles to reflect the potential bi-directional symbiotic relationship. The autistic adults are situated within the school-based context too, as they were invited to reflect on their school-based experiences in this research. The five key processes of the Circuit of Culture feature within the macro level of autism popular culture.

Figure 1. 3 Interrelated elements of the research design



From a methodological point of view or meso perspective, photo elicitation, which is the use of photographs to prompt responses from participants (Boucher, 2018), was used to discuss aspects of autism with autistic secondary school aged students, autistic adults, and educators is also unique. I have not found other studies that have approached semi-structured interviews with autistic students and educators in the same way. While the methods used are unique, and I hope prove of value to other researchers, the significance of the study is embodied in the aim to understand whether varied cultural influences on educators', autistic students', and autistic adults' conceptions and perspectives of autism result in educators and their autistic students being on completely 'different tracks' in their understanding of autism and autistic individuals in educational settings.

The research also seeks to provide evidence to assist educators and autistic students and adults to recognise and understand what has been of influence in their conceptions of autism, with the hope this may assist other educators and autistic people to take a more critical and questioning stance when consuming and/or producing information about autism.

1.5 Research Questions

Differing perspectives and representations of autism in the media and interaction with the autism industry, including models of disability, serve to create an autism popular culture, but one that appears to reflect various diverse ‘truths’ for different individuals. In response to these varying perspectives, representations, consumptions and sense of identity, the following research questions have been designed to critically explore the ways in which understandings of, and responses to, autism have developed for the research participants, and whether these perceptions align or vary with a focus on the implications for the lived experiences of the research participants.

1. How do educators and autistic students and adults conceptualise autism and what influences the development of these ideas?
2. How do the research participants’ conceptions of autism vary and/or align in response to the Circuit of Culture processes?
3. How do media discourses from autism popular culture and the participants’ conception of autism vary and and/or align?
4. How do the experiences of educators and autistic students in a school context reflect features of the commodification of autism?

In the following sections of this Chapter, I explain the choice of language used in this thesis to describe autism, my position as a researcher and outline the overall structure of the thesis.

1.6 Language

There are two things to explicitly mention in relation to language and content in this thesis. One is a sensitivity warning: there are some references in the research literature and in my own qualitative research to suicide, abuse, and neglect of autistic people. I have included direct quotations from grey literature, social media, and public comment, some of which I find very disturbing but that I feel are important to include to highlight the types of information people are exposed to and to demonstrate the breadth and reality of current perceptions of people in the wider community.

The second relates to the language used to describe autism. Broadly, there are three core groups or stakeholders that seem most concerned with language, and these are: autistic people; parents/families of autistic people; and professionals who support autistic people. Within each group there is a lack of consensus, and at times hostility, about the language used when talking about autism and autistic people, and that flows both within and across all groups.

The term ‘Autism Spectrum Disorder’ (ASD) will only be used in direct reference to the clinical definition of autism (American Psychiatric Association, 2022) or if I am directly quoting a source. I acknowledge the body of literature and personally conveyed preferences of many autistic people, who advocate a move away from the use of ‘person-first language’ toward the use of ‘identity-first language’ (Monk et al., 2022). While not every autistic person may prefer to use identity-first language (Callahan, 2018), for example, ‘I am autistic,’ rather than ‘I have autism,’ it is clear that there is a definite trend to accept that identify-first language is viewed by most autistic people as more respectful. I make specific reference to the pioneering work of Jim Sinclair (1993, p. 1), who first challenged the idea of a person ‘having autism;’

> Autism isn't something a person *has*, or a "shell" that a person is trapped inside. There's no normal child hidden behind the autism. Autism is a way of being. It is *pervasive*; it colors every experience, every sensation, perception, thought, emotion, and encounter, every aspect of existence. It is not possible to separate the autism from the person--and if it were possible, the person you'd have left would not be the same person you started with.

The infographic below (Figure 3) from www.identityfirstautistic.org, illustrates the sentiments that can be conveyed in language. The emphasis is that autism is not something outside of the autistic person; rather, it should be understood as an integral part of the person.

Figure 1. 4 Neurology is not an accessory from www.identityfirstautistic.org

In research conducted in the UK by Kenny et al., (2016), it was found that professionals tended to use person-first language, whereas autistic people were more likely to use identity-first language. In Australia, a recent position statement by the federally funded Raising Children Network (2021) clearly stated that identity-first language is preferred by the autistic community. This was further supported by a 2022 online ‘autistic not weird autism survey’ of 11,212 people, whereby 76.16% of autistic respondents reported they use identity-first language exclusively (Bonnello, 2022).

The shift to identify-first language has been a significant change and something that I initially struggled with. When I started my degree in Disability Studies in 1992, it was expected that students and staff use person-first terminology. Undergraduate students were advised that using the term ‘autistic’ in any assignments would result in a failing grade, as this terminology was seen as highly disrespectful at the time. In the 1990s this preference and stance was perceived as progressive and reflected the political position of the time. However, over the past few years, it has become clear that this is not the preferred language of many autistic people themselves. The terminology has shifted to identity-first language, which I understood, and I have acknowledged the need to be very conscious in changing my written and verbal communication to reflect neuro-affirming language (Gottliebsen, 2022) rather than deficit-based language.

Due to the autistic community’s preferences (Kenny et al., 2016), I have chosen to use identity-first language in this thesis. However, it is clear that this is still a contested topic, and I do not intend for my use of identity-first language in this thesis to gloss over the many varied viewpoints of other people. This difference of opinion is demonstrated by a discussion sparked by a poster I presented during the last stage of my candidature at Flinders University *DocFest*. I had used identity-first language in the poster, and a member of the audience contacted me privately to convey their disappointment in my choice of language:

> My brother has autism and finds the label quite uncomfortable because of the limited understanding his peers and teachers tend to have. I'm not sure if you're aware of person-first language, but it's a simple way to avoid intended or unintended marginalisation, and instead describe what a person 'has', rather than asserting what a person 'is'. I obviously can't, and am not trying speak for everyone, but in my experience, it’s been a positive means to reduce the stigma around autism and let my brother/friends with autism know that in no way do I think it defines them (R. Jones, personal communication, September 9, 2020).

I asked, and was granted, permission to use this personal communication in my thesis, as it clearly demonstrates the emotive nature of language and the differences in perspectives about identity-first language. The contrast in perspectives also connected the purpose of my research, the importance of understanding how people develop their conceptions of autism. If perspectives of individuals continue to vary so much, what might this mean for autistic people and their lived experiences? The email also brought home to me that the word ‘autism’ can convey shame and stigma to many autistic and non-autistic people alike. While this email highlighted the belief of this writer that autism doesn’t define a person, the contrary is shared by many autistic people. In a study, “Autism is me: an investigation of how autistic individuals make sense of autism and stigma” (Botha et al., 2022), the researchers found that autistic adults perceived that society viewed autism negatively, which meant that by association, they were personally viewed negatively. Again, connected to the purpose of my research, is the desire to understand whether there are variations in conceptions of autism between educators and autistic students, and how this might influence these participants sense of identity as autistic people.

1.7 Personal position and ontology

I think it is important to share my personal position and some of the key experiences that have shaped my own understanding and conceptions of autism that in turn form my ontology, and epistemology in this research.

In 1991 I read a book, *Skallagrigg* (Horwood, 1987), that changed my life. It was my final year of secondary school and perhaps it was timing or some other moment of serendipity that this book would play in shaping the direction of not only my career, but my life. What held me captive was the historical insight into the institutionalisation of people with disabilities and the power that non-disabled people often have in controlling the lives of people with disabilities. It was this power imbalance that struck me to my 18-year-old core and provided the impetus to pursue my undergraduate degree in Disability Studies.

I completed an undergraduate degree in Disability Studies in 1994. In my final year, I studied an elective topic on autism, and it sparked my interest. I was fortunate to complete a placement at Autism SA (then known as the Autism Association of South Australia). I vividly recall attending a social group for autistic adults, and although I do not have a diagnosis of autism, in that moment I felt a comfortable and happy sense that I belonged and that I wanted to work alongside autistic people. I have worked in the field of autism ever since in many different roles, from direct service provision through to consultancy and delivery of autism-related professional learning.

Although I do not identify as an autistic person, and I am not a parent or sibling of an autistic person (in essence, an ‘outsider’ to lived experience), I am writing from the perspective of a professional with almost 30 years’ experience working closely with autistic people and their families (an ‘insider’ to the autism field). I have autistic friends and colleagues, and as such, this thesis feels very personal. The impact that autistic people have had on my life, the friendships formed, and experiences shared, have been profound. Upon reflecting on my career there are four significant events that I want to share that I believe have influenced my career.

In the year 2000, I moved from Australia to Scotland for a working holiday. By that stage I had been working intensively in the autism field for only six years, and in my mind, I thought working overseas would be incredibly different and I would find experts who could mentor me. I started working at an adult day placement for autistic adults in Edinburgh, and soon realised that the autism field in Scotland looked the same as the autism field in Australia. There was no difference in the way that services were structured, and autistic people presented in the same way as autistic people in Australia. I spent months reflecting on this and came to the realisation that the expert that I was searching for had been in front of me all along: it was the many autistic people that I had met and continue to meet. This realisation contributed to my relativist ontology as my reality was shaped by context and experience.

In 2002 I supported an autistic adolescent whose family were engaging with the Son-Rise Program® (Autism Treatment Center of America®, 2022). I observed the family fundraise thousands of dollars to fly to America to participate in intensive programs. I listened to the parents’ beliefs that the program would cure their son of autism. I worked with other families at the time who were using the Defeat Autism Now! ™ (DAN) Protocol (Autism Research Institute, 2022) of detoxification, diet, and vitamin supplements to try and cure their children. While the specific DAN protocol was discontinued by the Autism Research Institute in 2011 (Rudy, 2022), it is important to note that a range of other medical approaches are still offered by that organisation. I worked with other families who tried auditory integration therapy, and chelation of mercury therapy. None of these approaches ‘cured’ their children. I started to really question the ethics of therapies and promises of cures. This area has continued to be of interest as I have talked with so many people who tried different things, from painting on live horses, to cold laser therapy, hyperbaric oxygen chambers, and swimming with dolphins. I interpret that to mean that some people will try anything, whether that is under the guise of help, support, or cure, and the market and appetite from consumers in the autism community is clearly evident. I understand that families of autistic people may try a range of very unusual options in an effort to attain the family life they envisaged. The experience of seeing very vulnerable families influenced by ever increasing promises drove my motivation to questions the quality of information and services available to parents.

In 2006, I worked with a young autistic man, Ronald (pseudonym), whom I had known for ten years. As an eight-year-old, Ronald was delightful, care-free, and funny. He loved the Titanic, Egyptology, and guinea pigs. However, as an eighteen-year-old man, he had developed severe depression, and he began to self-harm. I was employed as a mentor because of my previous experience and positive relationship with Ronald. Despite a team of professionals and his unwavering family support, he took his own life. This is something I feel like I have never quite made peace with. This taught me that there is a disconnect in treatment for autism and mental health. Disability services said they couldn’t help Ronald as he had a mental health issue, and mental health services said that they couldn’t help as he had autism. It felt as if Ronald became a faceless case, and his needs were never really addressed. Although I tried to help, I couldn’t save him.

In 2017, I participated in a research program as part of the Australian Autism Co-operative Research Centre’s (Autism CRC) Sylvia Rodger Research Program. The aim of the research program was to upskill autistic adults and autism researchers to ‘work together as research co-producers. This ensures that what is being researched, and the way it is being researched is relevant to, and appropriate for, the autistic community’ (Autism CRC, 2022). I participated in the program as an autism researcher and attended a weekend residential program alongside 14 autistic adults and six other autism researchers. Part of the aim of the Research Academy was to provide an opportunity for autism researchers to share their ideas with autistic people, who in turn would provide feedback and suggestions about the research. I found the process very valuable, even though certain elements were challenging. I was faced with a dilemma about co-production: how does that fit with a doctorate when it is already started? I questioned my process, which led to a two-year delay completing my data collection. I was able to conduct the teacher interviews, as I believed that was straightforward, but I continued to question the process of working with autistic students and focus groups in respectful ways.

I acknowledge that all these experiences influenced my own understanding of autism, and in turn my ontological position as a researcher. The varied experiences also highlighted the role played by a growing autism industry and emerging culture influenced by the interaction between regulations, production, representations, consumption, regulation and identity, the key processes of the Circuit of Culture (du Gay et al., 1997). The research design is informed by constructivist epistemology, whereby ‘individuals create or construct their own new understandings or knowledge through the interaction of what they already believe and the ideas, events, and activities with which they come into contact’ (Ültanır, 2012). This paradigm recognises the role of the researcher as part of the research, acknowledging the prior experiences and motivations I bring to the research process and the influence this will have on my interpretation of the data, albeit ensuring a reflexive disposition. My ontological position is one of relativism, which considers reality to be dynamic and context specific (Howell, 2012). I have expanded on these ideas further in the methodology chapter but wished to provide clarity of the experience and stance I bring to this research.

1.8 Background information and context

This section provides some key background information of the Australian context that is important to understand where the research is situated. Outlined below are key references to legislation and policy that governs service provision to autistic people and their families, as well as schools and the field of education at a systemic level. These contextual points will be referenced throughout the findings and discussion chapters, so it is important to signpost now as part of this introduction chapter.

1.8.1 Legislation and policy

Currently Australia does not have any autism-specific legislation, unlike the UK, which has the *Autism Act* (2009) and the US, that recently passed the *Autism Collaboration, Accountability, Research, Education and Support (Autism CARES) Act* in 2019. Similarly, Australia does not have national autism professional competencies, as opposed to the US, UK, and Canada (Alberta Education Department, 2006), which have clear professional guidelines for allied health and education. There are national diagnostic guidelines, but as the name suggests, these are just guidelines and not mandated practices for diagnosis of autism.

There is specific legislation relating to funding of support services in Australia. In 2013, the *NDIS ACT 2013 (Cth)* was passed, and the National Disability Insurance Agency (NDIA) was created to manage the NDIS. The highest proportion of scheme funding has been allocated to autistic people, with approximately 30% of active participants identifying autism as their primary disability and another 5% reporting autism as a secondary disability (Disability Plan Services, 2022).

The creation of the NDIS saw the regulation of national disability funding, and as a result the collapse of state-based funding for disability services. The effect of this has been catastrophic for many small community organisations and private providers who have not been able to compete in the market. The competitive market has also seen a negative impact on a sense of community, as organisations compete for ‘customers.’

In September 2022, the NDIA reported the annual average funding package per autistic male participants was $37,500, and $36,200 for autistic females (National Disability Insurance Agency, 2022). It has been proposed that there has been an increase in autism diagnoses (in some cases questionable) in order to access support. This contextual information is important to note as autistic people and their families navigate this complex system. The NDIS system, its successes, failures, and expenditure, is reported regularly in the media and is a common discussion point in the disability services and education fields.

1.8.2 Australian schooling and education

In a recent 2018 survey by the Australian Bureau of Statistics it was reported that 40.8% of autistic students attended either a special class in a mainstream school or a special school. In Australia, the *National Disability Standards for Education* (DSE) (2005) outlines the rights of students and the obligations of schools, as part of the Commonwealth *Disability Discrimination Act 1992 (Cth)*. Whilst autistic students are not specifically referred to in the DSE, they are included broadly as ‘students with disability.’ The DSE defines ‘disability’ as:

> (a) total or partial loss of the person’s bodily or mental functions; or
>
> (b) total or partial loss of a part of the body; or
>
> (c) the presence in the body of organisms causing disease or illness; or
>
> (d) the presence in the body of organisms capable of causing disease or illness; or
>
> (e) the malfunction, malformation, or disfigurement of a part of the person’s body; or
>
> (f) a disorder or malfunction that results in the person learning differently from a person without the disorder or malfunction; or
>
> (g) a disorder, illness, or disease that affects a person’s thought processes, perception of reality, emotions, or judgment or that results in disturbed behaviour.

This pathologised definition of disability is focused on ‘malfunction’ and ‘disorder,’ and by highlighting difference, reinforces the concept of the ‘other’(Hall,1997).

To look specifically at the South Australian education system, there are three sectors: The Government Department for Education (also known as ‘public’ schooling), the Catholic Education sector (‘private’ schooling), and the Independent (also ‘private’ schooling) sector. Each sector implements the Australian Curriculum in their schools (ACARA, 2022).

The Department for Education has policies and information (Department for Education South Australia, 2022) in place specifically about autism, which is defined as a developmental disability. This is situated in the ‘managing health, education and care’ policy that reinforces the medical model of disability. There are no Department for Education autism-specific schools. However, there are special classes and units currently in operation across Department for Education schools that can be accessed by autistic students, but are not promoted as specialist autism settings or autism specific.

The South Australian Catholic Education system does not have a publicly available policy specifically about autism on their website (Catholic Education South Australia, 2022) however, they have recently developed an inclusive education policy. They refer to ‘autism’ within ‘special education’ and support and also have two special schools that enroll a high percentage of autistic students.

The Independent Schools sector does not have a publicly available policy specifically about autism on their website (Association of Independent Schools SA, 2022). This is not surprising as they are only a representative organisation of 112 different independent schools. Of these schools one is an autism-specific school and is the only autism-specific school in South Australia. Whereas other states in Australia, such as New South Wales and Victoria, have autism specific classes, short term intervention classroom programs and multiple autism specific schools.

The reasons behind parent selection of schools for their child with autism are complex and beyond the scope of this thesis, but it is evident in South Australia there are a wide range of enrolment options for parent to consider across the three sectors when selecting a school for their autistic child. However, the focus of this thesis is on autistic adolescents enrolled in mainstream schools and educators who are also working in mainstream schools. The autistic adults who contributed to the focus group interviews attended mainstream schools for the majority of their education, with some experiences of special school settings and specialist intervention program for periods of their education.

1.9 Structure of the thesis

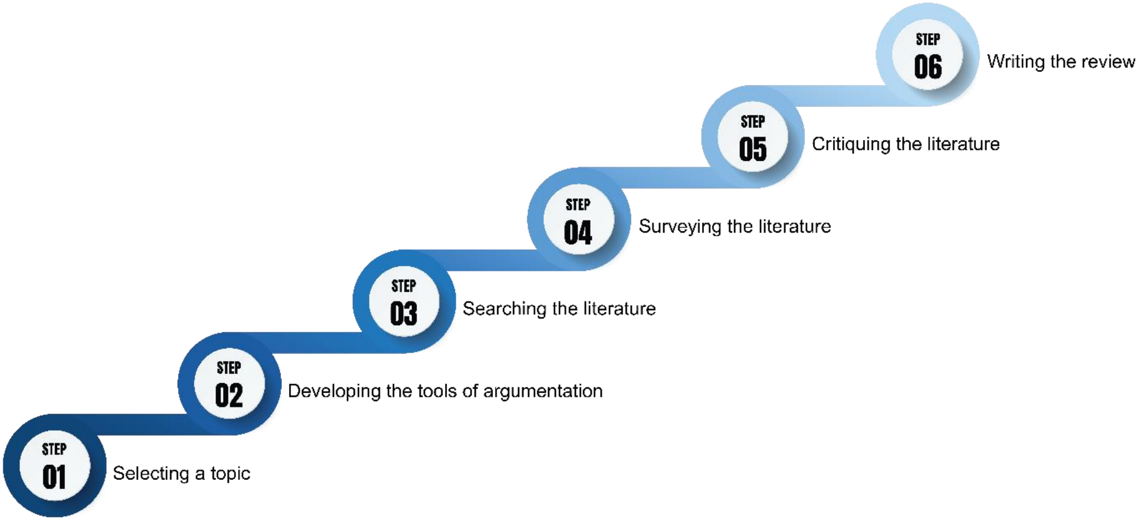
The thesis is presented in six chapters. Chapter One has introduced the background information to set the scene and context for how and why the research was undertaken. Chapter Two provides a traditional review of the literature (Machi & McEvoy, 2016) and identifies the research gap in the literature. Chapter Three describes the methods and methodology employed in the research, including the pilot interviews. The research findings are presented in two chapters. Chapter Four is focused on the outcomes of the responses to interview questions and the photo elicitation process to explore their conceptions of autism. Chapter Five draws on the data generated from the semi-structured interviews to analyse in more depth the participants responses from a thematic approach and how these may align with the five processes of the Circuit of Culture (du Gay et al., 2012). Chapter Six synthesises the key observations from the research including responses to the research questions and concludes with a reflection on the research process and recommendations and ideas for future research.

CHAPTER TWO LITERATURE REVIEW

2.1 Introduction

In this chapter I outline the narrative approach which formed the foundation of my literature review. The narrative approach was informed by Machi's and McEvoy's (2016) six-steps as illustrated in Figure 2.1 and described in more detail in the following section. The literature review grounded my research and informed some of the direction it took methodologically with research design decisions being explained in more detail in Chapter Three.

Figure 2. 1 Machi and McEvoy's (2016) six-step approach to a literature review.



The literature review is presented in six sub-sections commencing with a focus on historical context of autism through to current contemporary understandings of autism. Section two reviews representations of autism and the symbols and signs used by the autism industry and autism popular culture. Section three reviews research focused on autism and the media and included a search on the Factiva database of print media in South Australian newspapers to highlight headlines and articles available to the public. Section four explores the commodification and growth of the Autism Industrial Complex through the autism industry that sets the scene for section five which explores the regulation of autism in policy and practices regulation. Finally, section six discusses perceptions of autistic students by educators and school aged students. The chapter concludes with a discussion of the commodification of autism and perceptions of autism in popular culture highlighting gaps in the literature that informed the aims of my research.

2.1.1 Outline of the approach taken to the literature review

The review of the literature commenced with the selection of a topic, development of the tools of argumentation to search the literature, and then surveying and critiquing the literature to finally write a report (Machi & McEvoy, 2016) or in this case a chapter within a thesis. This is different to a systematic literature review that has explicit rules about the types of literature included or not included and more rigorous approach to answering a highly specific research question (Dixon-Woods, 2010). Due to the nature of the research focus, I was interested in a broad search of the literature that included grey literature and with that in mind believed that the narrative literature review was more appropriate for my research.

Machi's and McEvoy's narrative approach (2016) describe the initial stage as selecting a topic. I used key search terms to enter into a range of databases that included: Proquest, Google Scholar, and Google Scholar Advanced. The purpose was to review peer reviewed journal articles and access other books and readings using the databases. The initial search terms included: autism, ASD, Asperger syndrome, autistic, education, critical disability studies, critical autism studies, media, representations, economics, commodification, history, cultural studies, pop culture. From these search terms, I then read a selection of articles and looked for key quotes and references in the article, to learn who the key authors and contributors to the field were. As part of the review of the history of autism I researched diagnostic terms and theories into causes of autism. I also linked to specific allied health research, such as psychology, speech pathology, occupational therapy, and related autism research into perceptions of autism, related characteristics, student voice, and lived experience. In addition to reading the articles I kept notes that detailed my interpretation of the articles and also discussed the findings with colleagues. I did not specifically review literature regarding evidence informed therapies and support strategies. As a by-product of the literature this was often referenced but does not form a part of this literature review. As a Doctorate of Education candidate, I actively engaged in the profession as a full-time employee in the autism field whereby I discussed latest research in my day to day work that was helpful in my academic understanding of the literature.

I reviewed grey literature, including websites from autism peak organisations, service providers, and many autistic-led organisations and/or self-advocacy networks. I regularly engaged with social media include blogs written by autistic adults, families of autistic people and autism professionals to ensure I was aware of the varying narratives relating to autism. I found engaging with social media ensured that I was aware of autism memes, as well as the autism-related merchandise available to purchase online and where it was advertised. I also completed a search through the Factiva database, that aggregated content from both licensed and free sources and linked directly to the South Australian print media articles. The aim was to immerse myself in what was produced locally. I was aware that I have consumed many of the articles as a professional in the field. In order to gather data about the discourses about autism that are generated in the Australian media. The textual analysis involved examining the discourses evident (Wodak & Meyer, 2009) in newspaper articles published on the subject of autism between the years 2006-2020 in *The Advertiser* (local South Australian daily newspaper) as well as *The Australian (*a national daily newspaper). As part of the narrative approach, I used snowballing (Danglot et al, 2019) to review reference lists and bibliographies generated by key articles, and suggested articles generated by the databases as having similar content.

The volume of autism related literature was overwhelming and reminded me of the term ‘infodemic’ that was used during the Covid-19 pandemic. “An infodemic is an overabundance of information – some accurate and some not – occurring during an epidemic. In a similar manner to an epidemic, it spreads between humans through digital and physical information systems. It makes it hard for people to find trustworthy sources and reliable guidance when they need it” (World Health Organization, 2020, p.1). This definition of an infodemic could be applied to describe an ‘autism infodemic’ that relates to the autism field. In this way the autism infodemic is in response to the metaphorical epidemic relating to the information regarding autism. I use the term with caution, as the term autism epidemic is used regularly in the media as an emotive term (Eyal et al., 2010) with similar terms such as ‘autism tsunami’ (Blaxill et al., 2022). However, in this case I feel that the term autism infodemic is fitting and has been discussed further throughout the thesis.

2.2 Historical context and development of contemporary understandings of autism

In order to explore conceptions of autism it was necessary to include the historical conceptualisations of autism in the literature review and how these ideas have developed over time. In Chapter One, a brief definition of autism was provided to reflect the current diagnostic criteria and medical model of autism as well as the counter argument proposed by the neurodiversity paradigm. As an experienced professional I have learnt much of the historical context and contemporary issues in the field of autism. However, as part of the literature review it was important to include this section as this sets the scene for how understandings of autism have evolved over time and how these changes may influence varied conceptions of autism.

The origin of the word “autism” is thought to be from the Greek word *autos,* meaning ‘self.’ It is believed to have been first used in 1911 by German psychiatrist Eugen Bleuer in the context of ‘Autismus Infantum’ (Bleuer, 1911), to describe his patients with schizophrenia who reflected a ‘morbid self-absorption’. It was not used again until 1944 by Leo Kanner, an American psychologist, to describe 11 children that he found had similar behavioural traits which he labelled ‘autistic disturbances of affective contact’ (Kanner, 1943)**.** Similarly, in Austria in 1944, Hans Asperger, a Viennese psychiatrist, identified ‘autistic psychopathy’ (Asperger, 1944) as a commonality of behaviours in four young boys. Many researchers have suggested that there is evidence of cases much earlier, but these were simply not seen collectively as belonging to a clinically defined group (Silberman, 2015). In addition, in the early years of autism diagnostics, information transfer both locally and globally was significantly slower than it is now. This may be one of the reasons why so few children were diagnosed in decades prior to the 1950s and such a small amount of research was carried out at the time.

Leo Kanner’s work would become known as ‘childhood schizophrenia’ for many years before becoming reclassified as ‘infantile autism’ both labels focused on childhood. Kanner’s work dominated the field of autism for many years, as Asperger’s work was hidden during the Nazi regime to protect his patients from genocide (Silbermann, 2015). Asperger’s work would not be translated into English until the 1980s (Wing, 1981), after which it rapidly gathered interest. ‘Asperger syndrome’ was finally recognised in the American Psychiatric Association’s Diagnostic and Statistical Manual (DSM-IV) for the first time in 1994 (Attwood, 2000). However, there are many historical accounts and retrospective diagnoses of autism of a number of historical figures, although the evidence for these claims are limited (Sacks, 2001). Itard’s ‘wild boy of Aveynon’ (1801), Albert Einstein (Attwood, 2000), and Wolfgang Amadeus Mozart (Fitzgerald, 2000) are examples of historical figures who may have met the same criteria described by Kanner and Asperger (Elder, 2005).

The application of the word ‘autism’ as a diagnostic term in the 1940s was heavily influenced by psycho-analytical perspectives. The early discussions were about autistic subjects as ‘frosted children’ or ‘diaper-age schizoids’ (Silberman, 2015), who were considered emotionally disturbed as an outcome of emotional neglect from their unloving mothers. Bruno Bettelheim, a survivor of the Holocaust who moved to America and practiced as a psychiatrist in the 1960s added weight to the argument, blaming cold and unemotional mothers as the cause of their children’s autism (Tsatanis, 2003). Bettelheim coined the term ‘refrigerator mother syndrome’ (Bettelheim, 1967). He compared the children who were raised in Nazis Concentration camps, who displayed poor attachment and social despondency, to autistic subjects. Although discredited, the effects of Bettelheim’s work were far reaching, and is still echoed today by some clinicians, who blame poor attachment from caregivers or trauma as the cause of autism (Grinker, 2007). ‘Mother blaming’ is unfairly linked to many psychological and psychiatric conditions, including autism (Jackson &

Mannix, 2004). Interestingly, Michael Rutter and his colleagues (1999) made links between autistic traits and sensory-deprived Romanian orphans, tracking their developmental trajectories to note the presentation of some autistic traits. The researchers proposed the orphans were not autistic and coined the term 'quasi autism'. In the same year Wakefield (1999) proposed that autism was caused by the measles, mumps, rubella (MMR) vaccination and whilst this theory was debunked (Miller & Reynolds, 2009; Hviid et al., 2019) many believe it still to be true and a resurgence of this theory was linked to the Covid-19 vaccination (Ullah et al., 2021). In all these instances, autism is viewed very much through the lens of trauma and the medical model, as a deficit or group of deficits.

The field of autism has changed significantly over the past 60 years, as have prevalence rates, with autism once considered a rare disability and cited as affecting approximately 2-4 in every 10 000 people (Lotter, 1966; Treffert,1970; Rutter, 2005). Current prevalence rates cited in research are much more common and affecting 1 in every 100 people (Zeidan et al., 2022) and estimated there at least 78 million autistic people world-wide (Lord et al., 2022). Autism was first included in the American Psychiatric Association's Diagnostic and Statistical Manuals (DSM III) in 1980 and referred to as 'infantile autism'. Howlin (2021) reported that the DSM III criteria was revised in 1987 as Autistic Disorder, however the criteria were still focused on childhood indicators of autism. The diagnostic criteria for autism expanded in the 1990s and was included in the American Psychiatric Association's Diagnostic and Statistical Manuals (DSM) (2000; 2004) and categorized as a number of related pervasive developmental disorders known as Asperger Syndrome, Autistic Disorder, and Pervasive Developmental Disorder - Not Otherwise Specified (PDD-NOS).

During the 1980's and 90s the terms high functioning autism (Mesibov et al., 2001) and low functioning autism (Mayes et al., 2011) were used and whilst not formal labels, were used primarily to distinguish the intellectual ability and communication skills of the autistic person. In simple terms high functioning differentiated that the person did not have an intellectual disability whilst low functioning meant that the person did have an intellectual disability and more severe presentation of communication, often non-verbal or limited speech affecting daily living skills (Layton et al., 2015). Some sources referenced Asperger syndrome as meaning 'high functioning' but debated whether there were distinct differences between 'high functioning autism' and Asperger syndrome (Schopler et al., 1998). Whilst other terms like 'classic autism', or 'Kanner's autism' were more likely to be categorized as low functioning autism (Rosen et al., 2021). The term broader autism phenotype also gathered interest in the 1990's to describe non-autistic people who had autistic traits but did not meet the full criteria for an autism diagnosis (Losh et al., 2008) and usually family members of autistic people.

In 2013, a single diagnostic category, Autism Spectrum Disorder (American Psychiatric Association 2013), was introduced and replaced the three diagnostic categories of Asperger's Disorder, Autistic Disorder, and PDD-NOS. In 2022 the DSM text revised fifth addition (DSM-5- TR) was released and is considered the primary source to define autism diagnostic criteria. One of the purposes of defining autism as a spectrum is to demonstrate the diversity of the spectrum and to disrupt the linear understanding of autism and use of terms such as high functioning and low functioning. This has been taken up by many in the autism community however a recent paper by Lord et al., (2022) proposed a new label of 'profound autism' to refer to autistic people with high support needs who are typically non-verbal with co-occurring intellectual disability. This has been met with profound concern from the autistic community (Kapp, 2023) and seen as a step backwards in the use of language to describe autistic people.

In contrast to this deficit-based medical model, in the past twenty years a network of autistic adults has formed an autistic self-advocacy network, which has gathered momentum through social media (Baker, 2011). This movement is focused on either a social model of disability or the neurodiversity paradigm to understand the lived experience of autism. Autistic self-advocates embrace their autistic identity and claim that their autism cannot be separated from them as a person. They argue that autism is not a deficit, but rather a *difference*. This has led to a strong push to change the way these self-advocates describe autism, and a shift to identity-first language as self-advocates describe themselves as *autistic people*, not *people with autism*. This is not semantics: it is a political stand (Baker, 2011).

Runswick-Cole (2014) makes a distinction between 'autism advocates' and 'autistic advocates'. Raising awareness of autism and lobbying for services is typically the work of autism advocates from the autism community who perpetuate the idea that autism is a disorder. Runswick-Cole explains that "science is highly valued in the neoliberal West and so identifying autism based on the scientific 'truth' of 'autism-as-disorder' is powerful" (p. 1122). *Autistic advocates* who form part of the autistic community reject the idea of autism as a disorder and define 'autism-as-difference.' It is important to note autistic self-advocates were some of the first to describe non-autistic people as 'neurotypical,' as opposed to autistic people being defined as neurodivergent. These distinctions are intrinsically linked to the neurodiversity movement (McGuire, 2013) as introduced in Chapter One.

A fundamental aspect of the neurodiversity movement is the framing of autism to celebrate the individual differences and unique strengths of not only autistic people but of all people (Baker, 2011). Silberman (2015) has extended this discussion in "Neuro-tribes: The

Legacy of Autism and the Future of Neurodiversity.” Silberman suggests that in the future the idea of diagnosing people with autism will become irrelevant, and that the acceptance of all neurodiversity will see pathologising and stigmatising terms such as Autism Spectrum Disorder fade. Autistic self-activists challenge the pathological definition of autism and prefer to identify as neurodivergent within the neurodiversity movement. Part of this paradigm is the promotion that every person is perfectly fine just the way they are, and do not need to be made into something that they are not (Kapp et al.,2013).

Autism has been a word primarily used in western culture, and some literature has suggested that autism is a western construct. In Grinker’s book ’Unstrange Minds’ (2007) he took an anthropological approach to autism, to highlight that in some African and Asian countries autism was not formally diagnosed until the 1990’s however that did not mean that autism did not exist before that in those countries, rather it was not recognised as a ‘disability’ (Grinker & Cho, 2013). Similarly, in Australian Aboriginal and Torres Strait Islander culture there traditionally was not a word for disability let alone for autism (Lilley et al., 2019). It was only in 2017 Maori culture in New Zealand developed the word ‘takiwātanga’ to represent autism as meaning, ‘my/his/her own time and space’ (Opai, 2017). One questions whether these cultures were more inclusive of diversity within their populations prior to the Western model of pathologising differences and disabilities gaining greater influence.

Confusion in understanding and conceptions of autism is not surprising given how diagnostic criteria, labels and terms have regularly changed particularly in recent decades. Figure 2.2 highlights the many terms and autism related labels from the 1940s to present times that were noted during the literature review, and illustrates the variance in terminology. Whilst some of the terms are considered outdated and some over eighty years old, they can still be found in books or websites online. The range of terms still featuring in web searches is problematic for those searching for a definitive description of autism given associated terms and concepts are used in so many different ways. The use of terms continues to shift and change and therefore it is timely for this research to investigate educators’, autistic students’ and adults’ conceptions of autism to determine if they align or vary from one another and how they reflect current research on contemporary understandings of autism. Contemporary understandings of autism will be further explored in the following section.

Figure 2. 2 Autism related terms and labels

2.2.1 Contemporary understandings of autism

Of significance the contemporary field has moved from viewing autism simply as behaviours to prioritising lived experience and looking at intersectionality (Sassu & Volkmar, 2023) as a way to further explain the intersect between autism with co-occurring conditions (Yarar et al., 2022) as well as consideration of gender (Mallipeddi & Van Daalen, 2021), gender identity and sexuality (Hillier et al., 2020), Race (Morgan et al., 2022) and other cultural and socio-economic factors (Singh & Bunyak, 2019). The increase in participatory research and co-production of knowledge with autistic people has been a significant factor in the development of contemporary understanding of autism. These understandings sit alongside the DSM-5-TR (American Psychiatric Association, 2022) diagnostic criteria as well as deeper understandings of cognitive theories and how these may relate to impacts on daily living experienced by autistic people. This is included in the literature review in order to highlight the ways that autism is discussed and referred to, and then further explore whether these understandings were reflected in the research participants' conceptions of autism.

The Australian Bureau of Statistics (ABS) released findings from their last national Survey of Disability, Ageing and Carers (SDAC) conducted in 2018 and published in November 2019 that estimated that there were 205, 200 autistic people in Australia. This was an increase of 25.1% since the last survey in 2015. The 2018 survey results identified that males were 3.5 times more likely than females to receive an autism diagnosis. The survey also considered the degree to which autistic people require assistance with daily living activities and functional skills. The findings showed that 68.9% of autistic people required support or supervision in at least one of three areas: communication, self-care and mobility. In relation to school, the survey identified 92.3% of students (101, 900) attending school experienced some form of educational restriction and a small number were unable to attend school because of their disability (Australian Bureau of Statistics, 2019). The survey found that 77.7% of autistic people aged 5 to 20 years who were attending school, or another educational institution, experienced a range of difficulties that impacted on their education, for example; difficulties in fitting in socially (59.8%), learning difficulties (55.3%), and difficulties with communication (51.5%). These findings are expanded further in Figure 2.3. One of the most important findings was that 45.9% of young people in this age group said that they needed more support in their education than they are currently receiving.

The literature has varying explanations for the causes of the functional impacts experienced by autistic people in daily living. Whilst there are no physical markers of autism the presence of co-occurring conditions is common for autistic people (Al-Beltagi, 2021) and may explain some of the functional impacts. Previously, the term co-morbidities were often used in describing co-occurring conditions however, this medical-driven term has been changed by many to co-occurring conditions, another example of the shifting nature of language associated with autism. Similarly, Donna Williams proposed the ‘fruit salad model’ (1996) to describe autism and the presence of co-occurring physical, psychological, psychiatric conditions and genetic predispositions that in turn interact with the environment.

Figure 2.3 Difficulties experienced by autistic students aged 5-20 years attending school or educational institution, by type of difficulty (a), 2018. Australian Bureau of Statistics (2019).

In 2021, Bougeard et al., undertook a systematic literature review regarding the prevalence of autism and co-occurring conditions in children and adolescents in the United States and five European countries. They found the most frequently observed co-occurring conditions were Attention Deficit/ Hyperactivity Disorder (Miller et al., 2022), anxiety, depressive disorders (Hudson et al., 2019), epilepsy (Buckley & Holmes, 2016), intellectual disability, sight impairment/ loss, hearing impairment/loss, sleep disorders and gastro-intestinal syndromes. The presence of other neurological conditions such as tics (Marland et al., 2017) and epilepsy are common. Al-Beltagi (2021) reported the prevalence of autism and genetic disorders such as Fragile X syndrome, Down syndrome, Duchenne muscular dystrophy, neurofibromatosis type I, and tuberous sclerosis complex. Al-Beltagi (2021) included the co-occurrence of a number of neurological disorders, including macrocephaly, hydrocephalus, cerebral palsy, migraine/headaches, and congenital differences in the nervous system as commonly occurring with autistic people. There are no medications available to directly treat autism (Houghton et al., 2018) however it is reported that many autistic people are medicated (Houghton et al., 2017) and often related to the co-occurring conditions as opposed to autism (Coleman et al., 2019) as such. The literature reports autistic people have increased mortality (Catalá-López et al., 2022) and Hwang et al. (2019), found mortality rates were 2.06 times than the general population. An Australian study identified the leading cause of death of autistic people is injury and poisoning or related complications from co-occurring conditions such as epilepsy (Hwang et al., 2019). Whereas Stewart et al., (2022) British study proposes that suicide is the leading cause of death in autistic people, that supported findings from Hirvikoski et al., (2020) who found that suicide is over-represented by autistic people and the leading cause of death in autistic people under the age of fifty years. The prevalence of co-occurring conditions and other intersectionality reflects the heterogenous nature of autism and the diversity of autistic people. In a recent meta-analysis of autism and quality of life (Mason, et al., 2020) found approximately half of autistic people have 'poor' life outcomes. I was interested to know whether references to co-occurring conditions would form part of the participants' conceptions of autism, and whether their ideas would vary or align.

The difference in prevalence of anxiety is highly variable with some researchers proposing it is difficult to distinguish between behaviours associated with anxiety and autism (Nathanson & Rispoli, 2022). Whilst others propose that anxiety is a response in trying to navigate the sensory and social world and expectations from neurotypical people. In recent years it has been proposed that autistic people mask their autism by trying to appear more neurotypical or as Holliday Wiley (1999) explains "pretending to be normal". Other terms such as camouflaging (Lai et al., 2019) or adaptive morphing (Lawson, 2020) are also used in the literature to describe masking of behaviours which is reported to be more prevalent in autistic women (Lai et al., 2017). Masking is thought to come at a high cost in terms of fatigue, burn out, stress (Lai et al., 2017) and depression (Hull et al., 2021) and at the same time has challenged the deficit view that autistic people lacked self-awareness (Lilley et al., 2021) and instead proposes a hyper-awareness of other people. The literature, in particular grey literature refers to pathological demand avoidance (PDA), described by Longo (2021) as a profile of autism where people avoid daily demands, often utilising 'social' strategies to do this. The underlying cause for this avoidance is said to be a high level of anxiety, usually from expectations of demands being placed on them, which can lead to a feeling of not being in control of a situation. This is similar to the work of Donna Williams who coined the term 'exposure anxiety' (2002) in which the person "feels acutely self-conscious; it leads to a persistent and overwhelming fear of interaction" (Waterhouse, 2015, p.2). Whilst PDA is not a formally recognised diagnosis it is attracting a lot of interest and identification, it is concerning that the label reinforces a medical pathologizing of behaviour. However, an alternative and more recent use of the acronym redefines PDA as a 'persistent drive for autonomy' (Enright, 2022). This autistic led reframing of PDA to reflect a 'persistent drive for autonomy' is of interest to this research as it further demonstrates how language and terms associated with autism are consistently being reinterpreted but not always clearly understood by all.

Differences in processing sensory input was only formally included in the DSM 5 Autism Spectrum diagnostic criteria in 2013. However, these differences in tactile, hearing, smell, gustatory, visual, proprioception, and vestibular input have been reported by countless autistic people (Grandin, 1986; Yontz et al., 2015) and researchers for many years prior and since the formal recognition in the research literature as well as grey literature (Bogdashina & Casanova, 2016; Aykan et al., 2021)There is emerging evidence in the area of interoception as an eighth sense that relates to internal body signals (Goodall, 2020; 2021). These differences in sensory processing interact and impact on self-regulation (Goodall & Brownlow, 2022; Mahler et al., 2022). This difference was relevant to this research to see whether the research participants would cite sensory processing differences as part of their conceptualising of autism, particularly as lived experiences shared by autistic people in the literature heavily feature sensory differences.

Research into information processing styles and neurological functioning that affect autistic people has gained in significance in the research literature. In particular, three cognitive-related theories of information processing; theory of mind, executive functioning and central coherence have been central in research on autism over the past 30 years (Van de Cruys et al., 2014). These theories are briefly mentioned here as they explain the development of more contemporary understandings of autism. Theory of mind proposes that, at approximately 3-4 years of age, children move beyond their egocentric view of the world to consider situations from another's perspective. While theory of mind is indeed more complex than this simplistic summary Baron-Cohen's (1997) research indicated that autistic people had gaps in their theory of mind capacities at times failing to realise their thoughts and feelings were not the same as another's. He also suggested that autistic people often fail to recognise that their actions and behaviours can have an effect on the thoughts and feelings of others. Baron-Cohen's (1997) findings have been challenged in more recent research with Milton (2012) proposing the 'double empathy problem', defined as "a disjuncture in reciprocity between two differently disposed social actors which becomes more marked the wider the disjuncture in dispositional perceptions of the lifeworld– perceived as a breach in the 'natural attitude' of what constitutes 'social reality' for 'non-autistic spectrum' people and yet an everyday and often traumatic experience for autistic people" (p. 884). With these new developments of understanding it appears that theory of mind is being contested in the autism literature (Brownlow et al., 2022) and was of interest to consider whether the research participants would explicitly mention as part of their conceptions of autism.

Executive functioning encompasses a number of cognitive skills that relates to planning, working memory organisation, flexibility, inhibition, initiation and monitoring of action and support many adaptive functioning skills (Kiep & Spek, 2017). The literature presents some variance in defining executive functioning but has highlighted executive functioning as an area of difficulty for many autistic people (Barlow, 2018; Brown, 2021). Lynch et al., (2017) as cited in Alsaedei et al., (2020) estimates that up to 78% of autistic people have difficulty with executive functioning. In personal accounts from autistic people this is an area that is commonly discussed a problematic (Wallace et al., 2016).

Central coherence "the natural human tendency to draw together several pieces of information to construct higher-level meaning in context" (Frith & Happe, 1994, p. 121) aligns to cognitive-based theories of information processing. These concepts generated research interest in trying to explain the information processing of autistic people. Frith and Happe (1994) suggested autistic people had weak central coherence and were often 'stuck' on details and therefore missed the bigger picture. Murray et al., (2005) referred to this as 'monotropism' and suggested that this was a strength for autistic people and in some cases a source of joy. Rather than being viewed as a deficit, such information processing skills enables autistic people to focus on minute details for long periods of time, while others may get bored or miss the intricate details.

Vermeulen (2015) acknowledged the three major cognitive theories in his research and took the findings a step further to describes autism as ‘context blindness’ meaning a “lack of spontaneous use of context when giving meaning, especially to vague or ambiguous stimuli” (p. 23). There are similarities in all these cognitive theories, that researchers use in an attempt to understand autistic people and their view of the world. However, such research is firmly grounded in the psychology domain rather than the social model of disability propositions. Milton’s (2012) ‘double empathy’ theory aligns more closely with the social model of disability suggesting that information processing should not be viewed from within an individual alone, but from the context in which the individual is functioning, including the influence of how others are processing and delivering information. Such counter positions contribute to varying conceptions of autism and the functioning of autistic people, especially noting the role and power of neurotypical people and the influence of ableist’s view on the lived experiences of autistic people. Ableism is defined by Campbell (2001, p. Campbell (2001, 44) as a “network of beliefs, processes and practices that produces a particular kind of self and body (the corporeal standard) that is projected as the perfect, species-typical and therefore essential and fully human. Disability is cast as a diminished state of being human”. This research will seek to determine whether participants’ conceptions of autism reflect contemporary understandings of autism.

2.3 Representations of autism

As highlighted by Hall (2013), “Representation is the production of the meaning of the concepts in our minds through language. It is the link between concepts and language which enables us to refer to either the ‘real’ world of objects, people or events, or indeed to imaginary worlds of fictional objects, people and events.” *(*Hall, 2013, p.3). The notion of real and fictional is of interest in this research given the sources for people’s conceptions of autism can be driven by both real and fictional accounts. The vast majority of the wider community generally do not engage with academic research and therefore often rely on the media, grey literature and ‘word of mouth’ as information sources for knowledge of autism.

On searching grey literature, the terms ‘autism and analogy,’ Hooper (2019) described three common analogies; 1) an autistic person being like a Mac OS computer operating system in a PC (Windows) world, 2) the 'Coke Bottle’ analogy whereby undertaking daily tasks create increasing stress, like shaking a bottle of coke until it explodes, or 3) being a cat in a room full of dogs. It is not clear from Hooper’s article whether autistic people were consulted when developing these analogies however, it is clear that analogies abound in an effort to help neurotypical people understand the lived experiences of autistic people. Unfortunately, many analogies appear to be generalisation of autistic people’s lived experiences and served to reinforce conceptions that may be far from reality for many.

Autism has been referred to as an ‘invisible disability’ (Brugha, 2019; Hutchinson, 2019) suggesting that you can’t recognise an autistic person just by looking at them. Volkers (2018) suggests that autistic girls specifically are ‘invisible’ to refer to lower diagnostic rates, that ae thought to be under represented as behaviours are not as overt compared to autistic boys. Interestingly, other conditions are also referred to as ‘invisible’ in the literature such as mental health conditions, chronic pain or diabetes as opposed to a person using a wheelchair or missing a limb. If people look ‘normal’ to others, they are expected to behave in ways that fit within the ‘normal behaviour’ domain. When a behavioural response varies from one that is expected by another person then misunderstandings and confusion can occur. This representation of autism as ‘invisible’ is of interest in this research to see if it reflected in the participants conceptions of autism.

Research on representations of autism, including in the mass media, were commonly located in critical disability studies and critical autism studies journals. According to Anderson-Chavarria (2022) the master narrative of autism is still the medical model, with its nomenclature of ‘disorder’. By utilising the search terms of autism and representations, a number of research articles were retrieved and proved influential in the development of my own thinking about how these representations relate to educational contexts and autistic students. The following sections review the varied representations of autism including changes in foci, dominant representations as introduced in the Chapter One and counter arguments to these representations. Finally, a number of symbols and images are reviewed given the significant use by the autism industry.

Representations of autism are highly variable and whilst scientific literature focuses on autism through the medical model of disability, critical autism studies deconstruct autism through a post structuralist lens. Waltz (2003) presents multiple representations of autism as metaphor, referring to animal nature, the puzzling metaphor, military metaphors, and alien/cyborg. Waltz (2008) proposed that autism =death and proposed that the “identification of autism with self-loss, otherness and dehumanisation pervades the dominant, medicalised discourse of autism” (p.23). She goes on to say “metaphors of ferality, monstrosity, inhumanness, zombification or even death are commonplace in narratives of autism” (p. 15). Waltz challenged the reader to consider the ways in which autistic people have been dehumanised and described as ‘monsters’ (Tustin, 1992), and that as result murder of autistic people (Seidel, 2006) committed by their family members has repeatedly been reported in the media as ‘mercy killing’ as opposed to ‘murder’.

Waltz talks about counter representations to the dominant medical model of autism representations of autism (2012, p. 7):

> The metaphors employed by people with autism position themselves as normal but different. Metaphors of people with autism as strangers, or even as aliens, have frequently been highlighted and places the “problem” and its solution outside the person with autism, in accordance with the social model of disability: the “problem,” they proclaim, is not autism or people with autism, but the rigid social structures and expectations of mainstream culture. They position autism as a culture, not a problem, in much the same way deaf culture has been constructed. They reculturise autism, exposing the epistemological impacts of dominant representations.

This powerful explanation of the counter representations of autism was of significant relevance to this research given the use of the Circuit of Culture as a framework to examine the participants’ responses to conceptualising autism.

Throughout the literature review there were a number of visual representations of autistic characteristics and or diagnostic criteria that were repeatedly referenced. For example, the use of a Venn diagram to show autism as a triad of impairments (Wing & Gould, 1979) relating to DSM III criteria and a similar Venn diagram to illustrate autism as a dyad of impairments to reflect the DSM 5 criteria (2013).

Figure 2.4 Triad of impairments (Wing & Gould, 1979)
https://mentaleducationhealth.files.wordpress.com/2019/04/fig2__saplingsschoolmullingar_autismspectrumdisorder.jpg

Figure 2.5 dyad of impairments DSM 5 criteria (2013).
Autism / Autistic Spectrum Disorders | National Council for Special Education - CPD and In-School Support (sess.ie)

Another common visual representation of autism was represented as an ‘umbrella’ to reflect an over-arching term that incorporated a number of pervasive developmental conditions. The same concept has been applied to neurodiversity as demonstrated in Figure 2.6. These images are of interest see whether they have been of influence to the research participants conceptions of autism.

Figure 2.6 Illustration of neurodiversity as an ‘umbrella’ term
Understanding Neurodiversity - Therapy Focus

A popular image to describe autism was a series of little stick figures depicting behaviours that was presented from a deficit point of view. I draw attention to the figure below to reinforce that the frequency of such images contributes to autism popular culture. I remember this image below was shared in information packs to families following an autism diagnosis and often places in school staff rooms and other places to share information about autism in the 1990’s and early 2000s. Even though it is considered outdated by many, I still came across the image regularly as part of my engagement with the literature. When organisations and social media share such images that becomes part of the narrative of autism and reinforces particular understandings and language used to describe autism.

Figure 2.7 image of autism represented as characteristics primarily used in 1990s and early 2000's

https://www.autism360.com/wp-content/uploads/2015/02/signs-of-autism-in-children.jpg

.

Early conceptions of autism as a spectrum became linear and more like a continuum in its visual representation and as previously mentioned reinforced high functioning and low functioning as represented below in Figure 2.8.

Figure 2.8 Autism represented as a continuum
https://raisingmylittlesuperheroes.com/2019/04/

Of note it is thought that Lorna Wing’s idea of the spectrum (1981) was actually never meant to be linear but rather demonstrate the complexity and diversity of autism Current visual representations of the spectrum appear more circular and deviate away from the idea of a continuum. Autistic cartoonist Rebecca Burgess developed a comic (2016) that illustrates autism as variable and challenged the high functioning/low functioning ideas as highlighted below. Similar images now feature in grey literature and websites to illustrate the autism spectrum.

Figure 2.9 Autism spectrum comic by Rebecca Burgess (2016)

2.3.1 Symbols to represent autism

A number of symbols have been used to represent autism, and in doing so are produced and consumed, in ways that can impact on the identity of autistic people and understandings of families and the broader community. There are four in particular that have been highlighted below, jigsaw piece, butterfly, autism awareness ribbon and the infinity symbol.

In 1963 the National Autistic Society in the UK designed a symbol of a child’s face within a jigsaw piece puzzle to represent autism in their logo, shown below in Figure 2.10. This symbol represented autism as a ‘puzzling condition’ (Johnson, 2021) and as the child appeared sad or ‘weeping’ (Muzikar, 2019) it could be interpreted that it was designed to evoke empathy to assist fundraising and reinforced the narrative of autism as a tragedy.

Figure 2.10 National Autistic Society (1963) logo
The Autism Puzzle Piece A Symbol That's Going to stay or go? | The Art of Autism (the-art-of-autism.com)

This symbol was adopted by many autism organisations across the world. I recall the use of this symbol in South Australia as part of the Autistic Children’s Association, later named as the Autism Association and now known as Autism SA. The jigsaw piece puzzle as referenced in Chapter One, has been used for many years as depicting autism as a puzzle to be solved or as a deficit showing a piece ‘missing’ from the autistic person. Whilst Grinker and Mandell (2015) suggest the intent of the puzzle piece was to value autistic people but instead had the opposite effect. In a study by Gernsbacher et al., (2017) about the effect of the puzzle piece it was found that it evoked negative connotations and should be avoided. Despite the puzzle piece being challenged by many in the autistic community as an ableist symbol (Crossman, 2020), the puzzle piece is still easily found in merchandise produced by the autism industry and used by some organisations.

The use of the butterfly to represent autism appears more positive as a symbol of transformation and possibilities (Zauderer, 2022) although some organisations and merchandise have filled the wings of the butterfly with jigsaw pieces in the image to make the link to autism such as the Figure 2.11. Similarly, an autism awareness ribbon that was first launched in 1999 by the American Autism Society is an image also filled with jigsaw puzzle pieces as shown below in Figure 2.12. This This ribbon has become a symbol that is widely recognisable and still features on may websites and merchandise, despite concerns raised about the use of jigsaw pieces to represent autism.

Figure 2.11 Butterfly symbol to represent autism
https://boredshirtless.com/view/4166/autism-awareness-butterfly-t-shirt

Figure 2:12 Autism Awareness ribbon
https://www.autism-society.org/archive/about-the-autism-society/history/auism-awareness-ribbon/

In 2005, the rainbow coloured infinity symbol was developed by autistic people and used on Autistic Pride Day and shows the diversity and interconnectedness of the autistic community (Johnson, 2021). This symbol as illustrated in Figure 2.13 features in most autistic led organisations and autistic self-activism organisations. The examination of symbols in the literature highlighted the vary perspectives and beliefs help by the autism community, autistic community and the broader community.

Figure 2:13 Infinity symbol to represent autism
https://www.linkedin.com/pulse/awareness-pride-evolution-autism-symbols-from-1963-amber

Research into the use of logos has not attracted research but given the intent expressed in some of the symbols it is timely for such organisations to reflect on how their logos are interpreted, consumed and reproduced by others. Of interest in this thesis is whether the participants make any specific reference to autism symbols. While they may not make explicit reference to symbols as being of influence to their conceptions of autism it is possible these symbols work as implicit influences reinforcing the idea of autism as a puzzle to be solved through to a diverse array of characteristics to be embraced.

2.4 Autism and the media

Autism is produced, represented, and consumed through the media in a number of ways such as newspaper articles, television programs and film. Baroutsis (2019) highlights that media portrayals are often presumed to be factual however, emphasised that portrayals can be ‘spun’ in particular ways to highlight particular agendas and could lead to misinformation and misconceptions (Baroutsis et al., 2021).

Early research into autism and the media such as Manning’s (1998) work concerning the portrayal of autism in movies and the effect on public perception found that the broader community focused on characters such as Dustin Hoffman’s character *Rain Man* (Johnson & Levinson, 1988). With movies forming the general community’s main frame of reference, Manning suggests it is difficult for most people to imagine other representations or manifestations of autism. Hall (1997) describes the “spectacle of the ‘other’” (p.225) and draws our attention to the representational practices of stereotyping that is used in popular culture and mass media. This is supported by (Eastwood et al., 2022, p.9) who said “Autistic people represented in film have often been displayed as an exotic other, or a plot device, further embedding ableist assumptions and stereotypes”.

Baker’s (2008) work on autism and representation describes the ‘autism formula’ that is used in many films and TV shows depicting fictional characters with autism as cute, innocent, endearing, and attractively quirky', establishing vulnerability by depicting reliance on parents or caregivers; and typically endowing the character with savant or superhuman powers. This autism formula appears to still carry weight and is easily identifiable in many films and TV shows such as The Good Doctor or implied such as Dr Spock (Star Trek science fiction television and movie series) or Sheldon Cooper (The Big Bang TV sitcom series). Matthews (2019) articles explains why the character Sheldon Cooper cannot be a coloured person.

> 'After Rain Man, the autistic look shifted to an aesthetic exemplified by Sheldon, a physical expression of clean lines and sanitized surfaces. The autistic became paler in form and more systemizing in function. The portrayed autistic physiognomy evolved to reinforce hierarchies of colour, symmetry, and regimented order. Today, the autism aesthetic integrates the autistic character with a world of digital technologies and positions him, in all his ethnic whiteness, as the prototype for being human in a digital world.' (p. 63).

This same prototype is seen in the portrayal of the Good Doctor who is a young White genius doctor. In addition, popular culture has autistic characters who are often represented as highly intelligent and technocentric (Matthews, 2019), or having genius abilities in computer hacking or music or art (Murray, 2008). In addition, other qualities such as socially awkward, male, white, and middle-class (Jack, 2014; Shettle, 2014; Blanchett, 2010) and heterosexual (Aspler et al., 2022) appear to be perpetuated.

While researchers typically stand by the belief that autism equally affects all races, religions, and socio-economic classes (Turner, 2013) this is not apparent in the dominant representation in mass media (Murray, 2008). Matthews (2019) concludes;

> '…the visual rhetoric of autism hides in plain sight. Sheldon Cooper looks how audiences expect him to look. But even more apropos, he looks how producers and consumers of popular culture, need him to look. If, in the modern climate of reactionary Western politics, economic neoliberalism, neo-racist ideologies, Islamophobia, racial fear-mongering, and cultural efforts to preserve beleaguered whiteness where white considers itself the new black, then autism, in all its contingent and constructed rhetorical glory, is the new white' (p. 71).

Similarly, the research highlights the increased prevalence of gender diversity, non-binary reported by autist people, yet this is not represented in the media. This aligns with the research literature that White people are more likely to receive an autism diagnosis that Black people (Maenner et al., 2020). Some researchers have suggested that this relates to an underlying racial bias that the diagnosticians are more likely to attribute poor parenting, attachment disorder or fetal alcohol spectrum disorder than autism. The concern with the aforementioned 'autism formula' is that it perpetuates a stereotypical representation of autistic people.

Jones and Harwood's (2009) research about autism representations in Australian print media between 1996-2005 suggested a limited amount of factual information was evident when describing autistic people. They proposed the dual stereotype of autistic people represented as "dangerous and uncontrollable or unloved and poorly treated" (Jones & Harwood, 2009, p.5). Dosch (2019) researched popular tropes found in American newspapers and found familial abuse and violence against autistic people was dangerously presented as reasonable. Tang and Bie (2016) in their study of stigma related content relating to autism and representations in Chinese newspapers found autistic people were represented as patients or savants. Huws and Jones (2011) highlighted the repeated media references to perpetrators of violent crimes as having 'undiagnosed autism'. Solomon (2015) discusses the myth of the "autistic shooter," referencing many examples of American mass shootings where the shooter was reported to have (unconfirmed or undiagnosed) autism. Further fear mongering is fostered by social media groups such as "Families against autistic shooters," who buy into the argument as a result of misinformation from media and other sources. A study of Australian print media by Baroutsis et al., (2021) built on findings from an earlier study by Jones and Harwood (2009) and completed a systematic identification, review, and content analysis process to document the content and tone of 2,544 newspaper articles newspaper articles in relation to depictions of autism in Australian print media that spanned 2016–2018. The highest number of articles over the 36-month period were health and medical issues (n =454, 33%) and profiles of people on the autism spectrum (*n* = 338, 25%). This aligns with den Houting and Pellicano (2019) analysis of autism research funding in Australia between 2008-2017 that predominantly focussed on genetic and biological research. News stories in these two categories constituted 58% of all stories (*n* = 792). Only 3% (*n* = 13) of the health and medical stories included the perspectives of medical experts and instead was based on opinion. Across all categories, only 1% (*n* = 16) of all news stories (*n* = 1,351) included first-hand perspectives from individuals on the autism spectrum and 3% (*n* = 43) where that of family members. One of the most significant findings is the lack of authentic lived experience. This was further supported by Nordahl-Hansen (2017) who concluded that for portrayals of autistic characters to "have true value in developing public understanding of the condition, a larger and more varied number of autistic characters need to be included in the cultural canon" (p. 3). I am interested in whether the research participants draw on any media representation as being of influence in their conceptions of autism or whether through their lived experiences they can take a more critical view of media representations.

Research into social media such as Facebook has looked at the ways it connects autistic people and their families (Abel et al., 2019) rather than representations of autism in social media specifically. The autism industry generates a plethora of representations of autism. These representations range from informal memes about autism (an amusing or interesting idea or symbolic representation which spreads widely within popular culture) to slick information videos about autism by government, non-governmental organisations and advocacy groups. Commercial advertisement for a wide range of products overlay the topic as experienced by a social media user in Australia. Products promoted range from self-help for young people with a recent autism diagnosis through to educational interventions or teacher resources by Pearson and other multinational publishers. An example that resonated strongly with me goes back to 2015, when a letter went viral on social media from a 10-year-old autistic student (Knopf, 2015). It was reported to have been written to the student's mother while sitting under the teacher's desk (Figure 2.14). The primary question asked by the student is "does autism make me bad". Responses from the Mother are written in smaller font. In the accompanying news article, the child's mother poses a question for all to consider "What 'messages are our autistic children hearing – from ourselves, from other parents, at school, from media and in the general community?" (p. 2). This question aligns closely with my research in seeking to understand the influences on the research participants' conceptions of autism either from lived experiences and/or other information sources.

Figure 2. 14 Social media post (cited in Knopf, 2015)

2.5 The “Commodification of Autism” - raising awareness/ understanding, or raising revenue?

In 2002, the United Nations declared April 2nd ‘World Autism Awareness Day’ (WAAD) signifying the attention autism has garnered worldwide. The WAAD was designed as a public health promotion strategy designed to increase communities’ understanding of autism. Autism support organisations and service providers around the world mark the occasion with various campaigns and events. Ahmed et al., (2018) researched whether the WAAD had an impact on the information sharing platform Twitter and how such information sharing may influence public sentiment. They reported that over 1.7 million tweets were posted before late March and early May with April 2nd being the more prolific date for postings. The majority of the tweets were generated in the USA and UK with very little evidence of tweets coming from developing countries. They also identified that the majority of tweets expressed a positive sentiment, but it could not be determined if these tweets had any influence on individuals rather it only confirmed that such public health promotion approaches certainly assist to spread a message about autism. However, questions arising about the purposes and outcomes of the WAAD are: what is the quality of information being shared, how is autism being represented, who is consulted in the organisation of events and information being posted on social media platforms, how does it influence public perceptions and/or is the day designed a major revenue raising exercise?

As part of the literature review a broad search of websites and grey literature from a range of autism services internationally was reviewed to identify the language used in seeking to represent autism in ways to not only raise awareness but attract donations of money for autism services. A selection of artefacts located on website have been included in this section of the chapter to capture how autism is represented for potentially dual purposes. These dual purposes of awareness raising while seeking additional funding may serve to perpetuated mixed messages about autism. This thesis commenced with a focus on an emotive driven message of autism stealing one’s hope for a child’s future and the ransom note below reinforces this message. Whether the organisation intended to explicitly link a ransom to the need to funding to support autistic children is not known but the connection is evident. The ransom note in Figure 2.15 was signed by ‘Autism’ and clearly sought to generate fear into families of autistic children. This deficit-based message is problematic for a number of reasons including the message that autistic children would be unable live an independent life, that an autistic child would result in the need for families to rely on others for support and pay for this support, but more so that such ‘marketing’ techniques were employed with vulnerable families. This campaign predated the Autism Speaks campaign referenced in Chapter One, but a similar marketing strategy was still being used with vulnerable families at the heart of the emerging autism industry.

Figure 2. 15 Ransom Note campaign (New York University Child Study Center, 2007).

Marketing strategies appeared to become more sophisticated with the use of the word campaign by a number of organisations to describe, or disguise, their fundraising methods. While a campaign can be defined as a course of action to achieve a goal it is often associated with military or political campaigns, often referring to a specified approach of fighting for victory. One part of an Autism Speaks campaign was the use of a blue puzzle piece to represent autism as a puzzle to be solved, with blue representing depression and sadness experienced by autistic people and their families and to also represent the high prevalence of autistic males, assumingly opposed to pink for females. Autism Speaks worldwide “Light it up blue” campaign encouraged organisations to shine a light both figuratively and metaphorically by using blue lights on building facades to attract funding and draw attention to autism and raise awareness. Famous sites, such as the Sydney Opera House and the Pyramids of Giza have participated over the past 15 years. These shifts in metaphorical meaning associated with campaigns highlights again, the multiple mixed messages that are presented to the wider community in building autism awareness. Linked to the campaigns is raising of funds and through such campaigns the questions need to be raised, are such campaigns helping to raise awareness of autism or is it the industry simply raising revenue?

2.6 Perceptions and conceptions of autism

This final section of the literature review examines previous research on perceptions and concepts of autism in educational contexts. This was viewed as important given the research focus on exploring educators' and autistic students' conceptions of autism. However, a search of the literature highlighted limited research on conceptions of autism within an educational context, rather the focus was on constructions of the autistic student and/or experiences of teaching autistic students or being an autistic student in a mainstream setting. Of interest, several research papers used words such as views and perceptions in their titles yet switched to the word conceptualisation in the text without an explanation of the differences between these terms. Certainly perceptions, views and conceptions have similarities, but the word conceptualise was specifically chosen for this research given my interest in understanding what factors were of influence in how educators and autistic students generated their ideas about autism. Conceptions have been defined as an abstract or general idea arising from prior or new knowledge which are often driving by experiences. Conceptions has also been associated with clarity of ideas while perceptions are often associated with feelings or sensing something. While perceptions are very important to the generation of new ideas, they may often amount to nothing. Although some dictionary definitions indicate perceptions are beliefs and values stemming from people's feelings about products, services or a company (Cambridge Dictionary, retrieved, 11th October, 2022) which certainly aligns with my interest in educators and students as consumers of information about autism from various sources. However, I chose to use conceptions as I viewed this as referring to more fully formed ideas, in this thesis, being about the research participants' conceptions of autism.

The previous section on autism and the media highlighted the plethora of representations of autism in film and other media noting the influence these may have on people's conceptions of autism. However, there appeared to be limited research seeking to understand what has been of influence on educators' and students' conceptions of autism and whether these very or align. Research has focused on attitudes towards autistic student, variations between teachers' and parents' understandings of autism and many autistic adults have shared their experiences of schooling. However, once again, these focus on knowledge about autism and/or the construction of the autistic student rather than how people conceptualise autism and what has been of influence on those conceptualisations. Constructions of the autistic student are likely to be closely intertwined with conceptions of autism but seeking to understand the interaction between influences on conceptions of autism is central to this research.

Stone and Rosenburg (1988) researched teachers' and parents' views on autism and noted in the first line of their abstract that, "Changing conceptualisations of autism have led to an increased focus on parents and teachers as treatment agents" (p. 403). The relatively dated research drew my attention as it provided evidence to support my observations of the many changes that have occurred in the autism field, with significantly more occurring since 1988. Of interest in this sentence was the use of the words, 'treatment agents', once again supporting a deficit-focused medical model of autism. The outcomes of Stone's and Rosenburg's research indicated that both teachers and parents held misconceptions about aspects of autism including "cognitive, developmental, and emotional features of autism" (p.403). However, of particular interest was that parents and teachers held discrepant views suggesting they were not always on the same track with the researchers indicating these held implications for how they may work effectively together to support the autistic child. Such findings may not be surprising given the difference and investment in parenting and teaching roles, yet there is recognition in the value of a shared vision for the child's success (Department of Education and Training, 2018). Stone's and Rosenburg's research was of interest to my research aims as one may hypothesise that being on the same track in conceptions about autism would be a sound foundation for successful relationships and teaching and learning outcomes. Hall (2013) also noted the importance of shared 'conceptual maps' being the foundation for creating a social and cultural world that all involved can inhabit with ease.

Park and Chitiyo (2011) researched teachers' attitudes towards autistic students finding that with experience most teachers were positive about autistic students. However, it was the introduction to their paper which was of particular relevance to the tenets guiding my research. They stated:

> Since Leo Kanner first described it in 1943, the disorder has stirred a lot of interest in the research community. As a result, different conceptualisations have emerged over the years. Early psychogenic theories that viewed autism as an emotional disorder have given way to more recent conceptualisations of autism as a developmental disability (Helps, Newsom-Davies and Callias, 1999; Stone and Rosenbaum, 1988). This shift in conceptualisation has been largely because of advances in research. Although there are still many questions to be answered about autism, a lot of progress has been achieved,

> resulting in us getting closer to understanding of the disorder (Helps, 1999). p.70

Park and Chitiyo's research is just over a decade old, but the introduction clearly suggests that people conceive of autism in different ways, and they suggest this is mostly influenced by research. They did not mention the potential influence of media or other sources on conceptions of autism. They acknowledged advances in research but maintained a strong focus on defining autism as a disorder, once again aligning with a deficit-focused medical model. This generated a question about why they positioned autism in this way and yet were seeking to understand teachers' attitudes. The introduction went on to highlight the importance of teachers' attitudes to outcomes for autistic students citing previous research that acknowledged professionals' attitudes and knowledge were fundamental to the types of "interventions they will choose" (2011, p.70) again focusing on autism as a disorder that needs to be treated. They also stated:

> Teachers in particular 'convey messages of acceptance or disapproval through their own actions or symbolic gestures which represent a powerful influence on school-wide acceptance of differences' (Horrocks, White and Roberts, 2008, p. 1464). p. 71

This proposition was of particular interest to my research given the position of power educators hold in schools and the fact that their conceptions of autism and autistic students may be of influence to others colleagues and students and to autistic students' own sense of identity.

Ashburner et al., (2010) compared educators' perceptions of autistic students with their perception of non-autistic students. The study found that the educators rated autistic students as exhibiting behavioural and emotional difficulties at significantly higher levels than their typically developing peers. These educators' perceptions drew on their lived experiences of educating autistic students and clearly this was of influence in how they constructed the autistic student in relation to non-autistic students. Of interest this research used the word perceptions in the title which is fitting given the responses were associated with feelings toward autistic and non-autistic students. My research is more interested the influences on how educators and autistic students conceptualise autism.

Bolourian et al., (2022) examined general education teachers' perceptions of autism and pedagogical practices in early elementary classrooms in the United States. The research aimed to explore mainstream educators' knowledge about autism generated from their experience of teaching autistic students in their mainstream classrooms and how they responded pedagogically to including autistic students. Eighteen teachers were involved in a focus group in which the teachers were invited to share words that came to mind when thinking about a student with autism. They then needed to rank the words in terms of importance to their pedagogical responses. The word autism and term ASD had been explained to the focus group participants at the commencement of the research. Whether this was of influence on their following responses is not clear. In my research, I was interested in educators' and students' initial responses to the word autism without the influence of my own conceptions. I also chose to interview my participants separately as I was keen for individuals to share their personal responses without the potential influence of others. I did not explore how understandings of autism were associated with specific pedagogical practices. Bolourian et al., (2022) research found that the five most salient terms teachers associated with autism were 'social disconnect', 'sensory sensitivities', 'difficulty with social interactions', 'emotion dysregulation', and 'focused or fixed interests'. The researchers suggested these responses displayed that the teachers had an awareness of core characteristics of autism and even though they were deficit focused they viewed this as a positive outcome linking this important knowledge to the quality of the pedagogical approaches the teachers were using to effectively include autistic students in their classroom.

Much of the research reviewed about perceptions and conceptions of autism was focused on teachers or parent response with very limited evidence of including autistic students in such research. It was encouraging to note that more recent research has included autistic students with Horgan et al., (2022) completing a systematic review of the experience of autistic students in mainstream high schools. From an initial 1061 papers they refined the focus on 33 papers which met their search criteria. Three analytical themes emerged from the review; demands of mainstream schools, social participation and impacts on the students. They went on to identify a number of sub-themes that were both positive and negative. In particular, they identified that autistic students experienced g a sense of being 'different' to other students. This sense of difference proved of relevance to their experiences of school and also their sense of identity. Horgan et al., (2022) systematic review proved of relevance to my own research in seeking to understanding factors of influence on lived experiences on autistic students but their research did not focus on how autistic students or others' conceptualised autism.

Reviewing previous research on perceptions of autism highlighted that researchers have explored parents', teachers' and finally autistic students' understandings and experiences of autism but there appeared to be no research that sought to explore the influences on how these groups conceptualised autism and whether such conceptions varied or aligned.

2.7 Summary

The literature review illuminated the historical understandings of autism and how these ideas have developed into contemporary understandings of autism over time. A deeper examination of the representations of autism through the media, autism popular culture and the autism industry highlighted some of the tensions between the medical model and social model of autism, and highlights the complexities that may be of influence on conceptions of autism.

To address current gaps in the literature, my research aims to contribute new knowledge in the importance of understanding whether educators and autistic students and adults are on the same track in their conceptions of autism, recognising that shared conceptual maps are fundamental to successful and positive relationships in educational contexts and beyond (Hall, 2013). My research is also seeking to understand how educators, autistic students and adults consume, represent and re-produce conceptions of autism through the Circuit of Culture processes and subsequently contribute to sustaining an autism culture that emerges from varied realities and myths. The following chapter will explain the research design and methods designed to respond to the research questions.

CHAPTER THREE METHODOLOGY

3.1 Introduction

This chapter describes the qualitative research methodology and methods I employed to investigate the ways in which autism is conceptualised by educators and autistic students and adults, and how these concepts are, influenced by, and reflect the interactive nature of the Circuit of Culture processes.

The literature review highlighted the ‘autism infodemic’ as a plethora of multi-modal information represented by experiences, histories, stories, and research that constructs autism in multiple ways to reflect broader cultural, political, and economic factors. In this way there is no one *autism* but rather multiple *autisms* that are described in particular ways within broader institutions such as education, medicine, psychology, and are described by a range of “autism archetypes” such as “quirky,” “genius,” “disabled,” or “living in their own world.”

The ways in which the autism infodemic is interpreted is further influenced by the filters we use to make sense of the world. These filters have generally been influenced by personal experiences. As a researcher I am looking through my own filters to interpret, analyse and make sense of the same autism infodemic. I previously shared my personal experiences of working as a professional across many autism-focused roles and environments, noting how these experiences have influenced my construction of knowledge of autism. However, I am mindful from my extensive experience of working with autistic children and adults and teachers that their lived experiences generate different filters through which they view the world and the importance of illuminating these autistic interpretations in this thesis. The different groups of research participants may all bring varied realities to this thesis. Exploring how these ‘realities’ have been generated is a key focus of the thesis. These ideals focused on ontological beliefs of varied realities known as a relativist ontology. This approach assumes that we cannot separate ourselves from what we know. The investigator and the object of investigation are linked such that who we are and how we understand the world is a central part of how we understand ourselves, others, and the world. In seeking to understand the influences on the participants’ conceptions of autism, an interpretivist epistemology frames the research methods designed to answer the four research questions:

1. How do educators and autistic students and adults conceptualise autism and what influences the development of these ideas?

2. How do the research participants’ conceptions autism vary and/or align in response to the Circuit of Culture processes?

3. How do media discourses from autism popular culture and the participants’ conception of autism vary and and/or align?

4. How do the experiences of educators and autistic students in a school context reflect features of the commodification of autism?

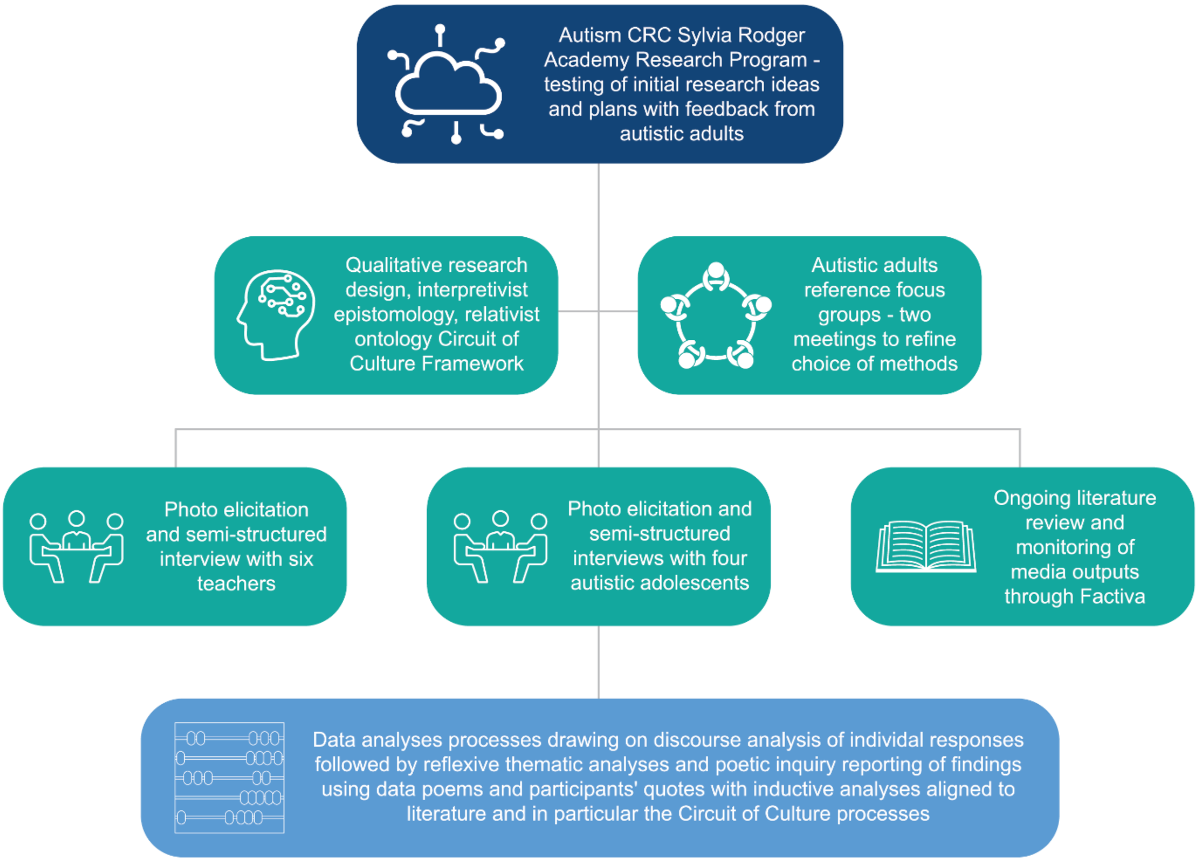
The following sections of this chapter will describe the qualitative research design, including pilot interviews that led to the semi-structured interviews using researcher driven photo elicitation. The ways in which data was collected and analysed will be explained along with justification for combining elements of discourse and thematic analysis and use of data poems for reporting on outcomes. The ethical considerations made throughout the research process will be addressed, as well as how I managed my researcher bias.

3.2 Research Design

A fundamental part of the qualitative research design was ensuring that autistic people were active contributors to the design and data collected, while maintaining my position as a doctoral researcher. The phrase “nothing about us, without us” (Charlton, 1998) was at the forefront of my mind throughout developing, researching, and writing this dissertation. As discussed in Chapter One, I participated in the Autism CRC Sylvia Rodger Academy Research Program, which provided me the opportunity to learn about co-production of research with autistic people and autism researchers to “ensure what is being researched, and the way it is being researched is relevant to, and appropriate for, the autistic community" (Autism CRC, 2022). As part of that process, I presented my initial thoughts about the research design and received feedback that I will refer to throughout this chapter.

In designing my research, I considered many different approaches including portraiture, critical discourse analysis, coding of various values, beliefs, attitudes. I decided to employ reflexive thematic analysis as a method to achieve a holistic overview of themes from the data. However, I certainly employed discourse analysis methods as I worked through each utterance of participants’ responses seeking to ensure extensive coverage of the data noting linguistic details, for example, the use of specific words aligned to concepts of autism. This in-depth review of the data generated an extensive range of codes which were than aligned with major themes. The five Circuit of Culture (du Gay et al., 2012) processes acted as a framework for reporting on the outcomes of the reflexive thematic analysis. Figure 3.1 provides an overview of the research design noting the additional engagement of a local group of autistic adults in refining methodological choices.

Figure 3. 1 Overview of the research design



Following the meeting with participants in the Autism CRC Sylvia Rodger Academy Research Program to discuss initial plans for the research focus group interviews were conducted with autistic adults with a dual purpose of exploring autistic adults' responses to the value of this research and seeking their feedback on the research design used with the autistic students. Specifically, they were asked to comment on the use of the photo elicitation method and choice of the photos. Their responses to the photos generated rich dialogue about conceptions of autism and their own experiences of education along with their observation of current educational experiences for autistic students. Their input proved of much relevance to the research questions and as such, with their permission, were included in the data analyses processes.

An initial method employed to explore the research participants' conceptions of autism involved the use of researcher driven photo elicitation prior to a more in-depth semi-structured interview. Twelve black and white photographs were presented to the participants from which they could choose any number of pictures that they believed captured their understandings of autism (Harper, 2002). By asking the participants to choose the photographs that represented, for them, an aspect of autism, the responses highlighted the discursive formation of stereotypes, and representation of sameness/difference and visible/invisible through an insider/outsider perspective. Chapter Four reports on these findings and examines the participants' conceptions of autism, comparing and contrasting the similarities and differences within the responses and noting any themes.

The data generated from the semi-structured interviews was reviewed as individual responses drawing on critical discourse methods seeking examples of Hall's three levels of representation with a specific aim of identifying influences on individuals' conceptions of autism. Following reviews of the individual interviews the total data set including the autistic adults' contributions were reviewed drawing in Braun and Clark six stages of reflexive thematic analysis (Braun & Clarke, 2006; 2022). The themes generated from this process were then reviewed for alignment with the Circuit of Culture processes. Finally, poetic inquiry (Lietz et al., 2006) was used to capture the many themes generated from the participants' conceptions of autism. Further details and justification for the choice of methods and the analyses processes are included in following sections.

3.2.1 Qualitative Research

Qualitative approach is exploratory in nature and seeks to explain 'how' and 'why' a particular phenomenon or behaviour operates as it does in a particular context. It can be used to generate propositions and theories from the data (McLeod, 2019). In simple terms, qualitative research "answers the how's and whys instead of how many or how much" (Tenny et al., 2022).

As a researcher there was never any question about whether I would be undertaking qualitative or quantitative research. It was important to me to listen to the stories of participants, specifically to understand how they experience the world and subsequent influences on their conception of autism. I needed the flexibility to be responsive to the participants throughout the research while recognising my own influence given the interpretivist epistemology framing the research design.

The nature of qualitative research enabled me as the researcher to be an active participant in the research. I interacted with the research participants in semi-structured interviews and focus group interviews. In turn, I reflected on how the research participants' perspectives resonated with my own perspectives, experiences, and biases. In this way the qualitative research approach had a degree of subjectivity. My own reflexivity and exploration of my tacit knowledge was part of the research process but required a mindful approach to ensure I was representing the participants' voices in preference to my own.

3.2.2 Pilot interviews

Prior to undertaking the semi-structured interviews with the research participants, I piloted the interview questions to understand how potential participants may respond to the questions. I interviewed an autistic adult and a teacher. To explore representations of autism within the semi-structured interviews, I asked the participants to bring an artefact to the interview that represented autism to them, and gave examples such as a picture, photo, drawing, and or poem. In addition, I chose a selection of six images that I thought represented stereotypical views of autism. My intention was to show the participants the images and ask their reaction to the images. This approach is defined as researcher-driven photo elicitation (Bates et al., 2017). The images I selected included a couple of stock images that I noted often appeared in magazines or newspaper articles about autism. The images depicted below include an image of a child behind glass, and a child sitting alone in the corner of an empty room, representing the stereotype of autistic people as "being in their own world". I also chose an image that could evoke the media representation of autistic people as school shooters that features in American media (Fitzgerald, 2015). I selected three other images from popular culture that referenced the film *Rain Man,* the television program *The Big Bang Theory*, which has a character commonly believed to be autistic, and the character of Julia from the children's television program, *Sesame Street*. Figure 3.2 incorporates the six images initially selected and provides an indication of images that generated personal responses, particularly noting how a visual image or cue constructs a particular image, in this case the autistic child/person.

Figure 3. 2 Images trialed in pilot interviews

3.2.3 Outcomes of pilot interviews

Neither participant brought an artefact to the pilot interview. The autistic interviewee explained that it was difficult to think of what to bring to the interview, and that they found the expectation stressful. Both participants shared that my request seemed ambiguous and commented that autism could not be represented by one image or object. The teacher interviewee commented that they felt they were being tested or analysed, and this raised a sense of suspicion and worry that they would bring something or say something that was 'wrong.'

The inclusion of the six images through researcher-driven photo elicitation directed the participants into a broader discussion about stereotypes. I felt that led to a discussion about autistic stereotypes and dominant representations of autism rather than participants sharing personal conceptions of autism. This prompted me to reconsider ways of engaging in the semi-structured interviews, for example, just commencing with asking participants what came to mind when they heard the word autism. However, I was still interested in the use of photo elicitation so considered more appropriate ways to include this process in my research.

3.2.4 Photo elicitation

Bates et al., (2017) describe the following three variations to the photo elicitation method:

(1) Participant-driven (open): participants choose to take any photo they feel is relevant to the phenomenon under exploration;

(2) Participant-driven (semi-structured): the researcher shares a set of questions with the participants and asks them to take photos that align with those;

(3) Researcher-driven: the researcher provides the photos for the interview to stimulate discussion only.

The process of asking participants to bring a photo is known as auto-driven or reflexive photo elicitation (Clark, 1999). Hermeneutic photography method asks participants to take their own photos of aspects of their life and share their perspective (Hagedorn, 1994). Similarly, Photo Voice (Wang & Burris, 1992) is where a camera is provided to a participant to capture their perspectives.

As part of the research design, I considered the evidence base arising from photo elicitation research. I made the decision to use the same images in all interviews, therefore taking a 'researcher-driven' photo elicitation (Bates, 2017) approach. I made this decision for ease and consistency in stimulating discussion at the beginning of the interviews. By doing this, the various responses and interpretations of the photos could be part of the data analysis in the research. This was a significant shift from the approach taken in the pilot interviews.

I searched for sets of images that were not disability- or autism-specific, and found *Photo Language Cards (*Barton & Cooney, 2001). The set of 130 black and white photographs in A5 size capture various scenes of nature, suburbia, and human interactions. The photographs do not have a title or text. My next step was to engage with autistic people about the images, as a way of member checking, which I did both formally and informally. I informally shared the images with three autistic colleagues, who shared their thoughts about the 130 cards. In this interaction I wanted to determine whether there were any images that could be perceived as disrespectful or problematic. The only concern that was raised was the number of cards. My colleagues suggested that it would be unrealistic and overwhelming to present all of the 130 images to participants, and that I should select a group of images rather than all of them.

My university supervisor holds a regular meeting with doctoral students, and suggested I present the images to the group to seek their thoughts about the choice of images. At a meeting of six people, I asked the group to review the 130 cards and to select 2-3 images that they thought represented “an aspect of autism.” I specifically said *an aspect of autism* to reflect the diversity of the spectrum. I also specified that an image may remind them of “a thought, feeling or experience.” Evans (2021) recommends trialling as a useful research practice when exploring creative ways to ensure participation in autistic students.

Initially, each person reviewed the cards silently, and then as a group we discussed why they chose the particular images. Through a process of consensus, the group narrowed the images down from 130 images to a group of 25. By this stage, I was due to complete the Autism CRC Research Academy and therefore I took the pack of 25 cards as part of my presentation to the autistic adults. The adults could choose which research interested them the most from a range of researchers sharing their research proposals. I asked for feedback about my proposed research questions and about my proposed use of the photo language cards and engaged in a two-hour discussion with the group interested in my research. They reviewed the 25 photo images with 12 images finally selected by the group and recommended for use in my research. They recommended sharing these with a local focus group prior to commencing the research as well. I greatly valued the process of working with the Autism CRC Research Academy group and gained many insights from the lengthy and insightful discussion. I also felt that their input into the selection of the photo images removed any potential bias I might bring to the selection of images.

Figure 3. 3 Final selection of images used in semi-structured interviews and focus group.

3.2.5 Semi-structured interviews

I conducted semi-structured interviews with six educators and four autistic secondary school aged students. The format of a semi-structured interview is open-ended questions that are non-scheduled, and partly standardised (Seale, 2012). This means that the order and exact wording of the questions does not need to be identical. Through an interpretivist lens the semi-structured interview process is seen as an active interview, whereby the “respondent is seen as an active producer of meaning, not, as in more traditional models, a well spring of information” (Gray, 2003, p.95).

After I completed each interview with the educators, I transcribed the recordings verbatim. The transcription process was immersive as I am not a fast typist which meant I had to actively listen, type, then re-listen to check my work multiple times. The combined teacher interviews were 24 704 words and it took me approximately an hour to transcribe 750 words that equated to approximately 33 hours to complete the task. On completion of the transcription, I deidentified the data and emailed the typed transcriptions back to the teachers to ask them to check for accuracy and whether there were any parts that they wished to be omitted as part of the research. There were no omissions requested by the educators. I then safely stored the audio recordings as per the ethics guidelines. Interviews with students followed the same process and were completed over a period of 8 weeks.

I commenced the interviews with educators and autistic students by directly asking them to “describe the first feeling, memory, or image that comes to mind when I say the word ‘autism.’” The purpose of asking a direct and open question was to capture the participants first thoughts associated with the word “autism.” I used the phrase “feeling, memory, or image” to try to elicit any deeply held personal beliefs. I was concerned that if I simply asked the participants to “describe autism,” that they could potentially recite the diagnostic criteria or give a theoretical response that they thought I wanted to hear. This initial question then led onto the photo elicitation process, and I asked both the educators and autistic students to choose an image/s that reminded them of an “aspect of autism.”

The focus on educators and secondary school students in particular brings into focus the ways in which autism is conceptualised in an education context. I was interested in understanding whether, or how, school context, autism popular culture and/or other factors were of influence in the research participants’ conceptions of autism.

3.2.6 Focus Group interviews

I ran two focus group interviews with four autistic adults. The first interview with the focus group looked at preparing for the interviews with the secondary school students. It was important to me to discuss the interview questions and format, particularly considering environmental set up of the interview space to ensure my approach was clear and respectful. This was built on the feedback already gathered from pilot interviews and the Autism CRC Research Academy. Therefore, the questions used in the focus group were hypothetical, based on what I intended to say to the autistic students, and to seek feedback from the autistic adults about the appropriateness to assist in building trust and rapport. I used photo elicitation in the same way, to present the selected images and ascertain appropriateness.

At the second focus group interview participants were asked about their experiences at school and their thoughts about whether education and awareness have changed since they were at school. The purpose of this discussion was to seek feedback on the role of the school-context in development of conceptions about autism for educators, autistic students and their peers.

3.3 Ethics process

I followed the guidelines set out by the Flinders University Human Research Ethics Committee, and was allocated approval number of 7517 by the committee prior to undertaking the research. Children and adults with disabilities are classified as ‘vulnerable people'. This meant that the semi structured interviews with autistic secondary students and the focus group interviews with autistic adults both required informed consent. It was imperative that I listed the ways in which I would mitigate any risks that could cause harm or distress during the interview process. The secondary school students required signed consent from their parents to participate, but I also wanted to ensure the students also understood and had consented, so I asked both parents and the students to sign the consent forms (see Appendix 5, 6 & 7 for example consent forms, letter of introduction and information sheet). I also provided a $50 gift card for each participating autistic student and adult. I did not provide a gift card to teachers.

All interviews with the autistic secondary students were negotiated with the parents. I gave the young people the choice if they wanted their parent to stay with them during the interview, and all said that they preferred their parent to stay. I provided the participants the choice of an environment in which they felt safe and secure. Three of the interviews were conducted at the young person's home, and one interview was conducted at Flinders University. I provided the contact numbers of support services in case any of the young people became distressed during or after the interview. I sought signed informed consent from both the young person and their parent.

3.4 Autism CRC Guidelines

The Australian Autism Co-operative Research Centre (Autism CRC) has developed inclusive practice guidelines (2016) for conducting research with autistic people. As discussed earlier, I attended the Autism CRC Research Academy to learn more about the guidelines and respectful ways to engage autistic people during the research process. This provided guidance about considerations of the ways in which written materials are designed, and environmental adjustments and sensory issues that may arise during the interview process with the students and autistic adults. Whilst none of the educators identified as autistic I was still mindful of the inclusive practice guidelines as part of universal design for learning principles.

During the focus group interviews I chose a room that was quiet, ensured the fluorescent lights were not on, and had good ventilation (Autism CRC, 2016). Communication with participants about environmental preferences and comfort levels were raised at various points throughout the interviews. There were no issues in the student interviews as they had choice over the location, three were conducted in their homes and the other was at the university late in the day so it was quiet at the time. The focus group interviews were also held at the university and presented no issues in terms of location or environment.

3.5 Data collection

The data corpus consists of 65,236 transcribed words collected from:

- Semi-structured interviews with six educators;
- Two focus group interviews with four autistic adults; and
- Semi-structured interviews with four autistic students.

3.5.1 Educator interviews: recruitment and set up of interviews

Six educators were recruited through a university post-graduate studies program. All six had recently completed post-graduate studies in the field of autism. A letter from my supervisor outlining the research project was sent to participants, along with a permission form and an information sheet (refer to Appendix Six, Seven and Eight for examples) as per the university guidelines. Confidentiality and anonymity of participants was ensured throughout the research, through the transcription of the interviews using pseudonyms and safe storage of raw data.

3.5.2 Focus group: recruitment and set up of group

Four autistic adults were recruited for the focus group through the Autism Co-operative Research Centre (Autism CRC). My rationale for contacting the Autism CRC was that they could provide access to a database of autistic people who have already identified that they want to be involved in autism research in Australia. This was really important to me, as it aligned to my experience in the Autism CRC’s Sylvia Rodger Research Academy. The group met collectively on two occasions. I also followed up individually with two of the adults as one had to leave early to pick up their child and another was ill on the second meeting so unable to attend all of the session at the time.

The two focus group interviews were held in a meeting room at a local university. The focus group interviews were transcribed verbatim by a professional transcriber, which I then checked against the recordings and sent to the participants to verify the transcripts and to give them opportunity to delete any sections they did not want included. There were minor amendments made where one participant felt they had disclosed too much information about an organisation that they felt would be a risk to their anonymity, and in response that section was deleted from the interview transcript.

3.5.3 Student interviews: recruitment and set up

Four autistic secondary school students aged between 14 and 17 were recruited through a local autism parent support groups in a self-selection process. This was due to the ethical considerations of interviewing adolescents on school campuses/sites. Finding consenting autistic students was far more challenging that recruiting educators or autistic adults. Permission needed to be sought from families prior to engaging with the students. Therefore, it made sense to go directly to autism parent support groups to engage families who would then share my research with their children. Due to my long history in the field, all the families were aware of my work history prior to the research. Consideration of these aspects and adherence to ethical protocols have ensured that the research was conducted professionally and respectfully. The autistic students' interviews were transcribed verbatim by a professional transcriber, I then checked these against the recordings and sent them to the participants and their parents to verify the transcripts. As with other research participants, an opportunity to delete any sections that they did not want included was provided. No amendments were requested.

I asked each participant if they wanted to choose the name of their pseudonym, which two of the autistic students and one of the autistic adults provided, the rest of the participants did not have a preference, so I chose their pseudonyms to ensure their anonymity.

3.6 Limitations

It is equally important to recognise the limitations of the study. The practical limitation relates to the number of interviews possible within a dissertation. As previously mentioned, I did not intend to undertake a population-based study. I acknowledge that the sample size is small. By definition this means that this thesis is not a definitive statement but a collection of opinions. This has been explored further in the discussion chapter of the thesis.

All the participants in the study used verbal speech to communicate. This could be a limitation of the study. I did not purposely exclude non-speaking participants or specify speech as a condition of recruitment. As part of the ethical considerations, parental consent was imperative and therefore the adolescents were recruited through their parents. I could have included autistic individuals who use alternative or augmentative communication, but no non-verbal participants volunteered for this research.

As part of the recruitment, I did not specify whether the participants had co-occurring conditions, including intellectual disability. None of the participants who volunteered for the research presented with an intellectual disability. However, I did not ask about specific learning disabilities or mental health conditions, and it is possible some participants experienced challenges in learning and/or mental health. Throughout the interviews with the focus group participants the adults discussed other diagnoses and misdiagnoses prior to receiving an autism diagnosis but this was not a feature of nor included in this research.

Interviews with the autistic students' peers or family members were not part of the study. They were present at the four secondary school students interviews but their comments were not included in the interview. There wasn't a connection between recruiting the autistic students and educators, or the autistic adults meaning that each participant group were standalone groups.

3.7 Data Analysis

Qualitative data was analysed using reflexive thematic analysis as described by Braun and Clarke (2006; 2013; 2021; 2022). I selected this approach as it aligned well with an interpretive epistemology and my ontological stance which acknowledges that different people interpret the world in different ways. The initial review of participants' responses to the visual images and word 'autism' along with the semi-structured interviews, involved detailed analysis of their discourses drawing on my own lived experiences and review of literature and popular media (Braun & Clarke, 2006). As described by Neuendorf (2019), thematic analysis produces a depth of understanding of the meaning of the data set, whereby the researcher and their personal experience is acknowledged. Braun and Clarke (2022) highlight researcher subjectivity as key element of reflexive research as it "treats knowledge as situated, and as inevitably and inescapably shaped by the processes and practices of knowledge production, including the practices of the researcher" (p. 12). It was apparent from my reading that the reflexive thematic analysis process can provoke a level of uncertainty and I noted my own discomfort with this approach as I reflected on my assumptions, choices and actions that I made throughout the research and more broadly throughout my career in the autism field. The deeper I went into reflecting about the Autism Industrial Complex the more I saw myself as part of *it* and experienced many emotional moments and some profound realisations that impacted throughout the analysis. I believe this engaged me in taking a more critical stance in analysing the participants' responses but I hope the audit trail provided in the sections below and Chapters Four and Five generate a sense of trustworthiness and agreement from those who read the thesis including the participants.

Braun and Clarke's (2006) six stages of reflexive thematic analysis is commonly used in qualitative research and it provided me with an evidence informed base to undertake the data analyses processes. I followed Braun and Clarke (2022) most recent guidelines providing an overview of the recursive six phase process below and examples of my actions in each stage in the following sections.

Figure 3. 4 Braun & Clarke's (2006) six stages of reflexive thematic analysis

3.7.1 Phase One: Familiarising oneself with the data

Braun and Clarke (2022) describe phase one of reflexive thematic analysis as familiarising yourself with the dataset. Throughout the data collection process, I actively engaged in the process of data familiarisation in a variety of ways. For example, I made brief notes after each interview to record how I felt the interview had gone and some key ideas, thoughts and feelings that came to mind during the interview. I transferred each transcript of the semi-structured interviews and focus group interview into a word cloud generator online program, 'Monkey Learn' with my parts of the interview deleted. The program created "images composed of texts where the size of the word/phrase represents it frequency" (Mathews et al., 2015, p.26) used by each participant. The purpose was to highlight keywords that relate to each interview as reference point for familiarising myself with the data. An example of the notes and word clouds are provided in Appendix Nine. The documentation of initial thoughts formed an important part of analysis as the foundation of initial ideas that were then formed into overall dataset familiarisation notes.

3.7.2 Phase Two: Generating initial codes

The full data corpus consisted of transcripts from ten semi-structured interviews and two focus group interviews that created a total of 65,236 words to analyse. I started the next phase of generating initial codes and used semantic codes that represented the explicit meaning (Braun and Clarke, 2022) and latent codes to capture the implicit meaning (Braun and Clarke, 2022). I made analytic memos (Saldana, 2013) to record initial thoughts and made links to research and theory as in the moment.

An example of participants’ responses (raw data) that generated an initial code of difference:

“I’m an Apple iPhone, Neurotypicals are android” (autistic student)

“I’m not popular, I’m different” (autistic student)

“…that’s how my brain works – on totally different train tracks” (autistic student)

“…people with autism can see things in different ways” (educator)

“you’re an orange; I’m an apple – deal with it” (autistic student)

This process also highlighted that often one particular group had more to say about the code, in this case it was the autistic students who referred to being different more than the teachers did. Potentially, this linked to their lived and sustained experience of feeling different and being labelled different. This type of hypothesising was linked to the next stage in the analytic process where a range of code were associated with broader theme, for example beliefs about autism and autistic identity, The quotes shared by the students were more aligned with autistic identity whereas the educator’s quote presented as a belief.

A wide range of codes were developed based on explicit meaning, for example in relation to the influence of media the first three quotes below were explicit in nature, whereas those that follow are more implicitly associated with the influence of media.

“There are quite a few teachers who watch the ‘Good Doctor’” (educator)

“And ‘The Big Bang Theory’ doesn’t help with that either” (educator)

“I see a bit on Facebook, sometimes they can be a bit derogatory” (educator)

Some participants’ quotes with more implicit connections to the influence of media were:

“..there was a lot of autistic Yugioh players, “have you thought you might possibly be autistic the same as them?” (autistic student)

Given there is no evidence-base for that the majority of Yugioh players being autistic then this generalisation has highly likely emerged from engagement with a social media game and associated platform.

“Insurance is for your car, your house, your life, not you child?” (educator)

This quote in reference to the NDIS links insurance to other things in life that are constantly advertised on a variety of media platforms.

"…what is an acceptable term for individuals?" (educator)

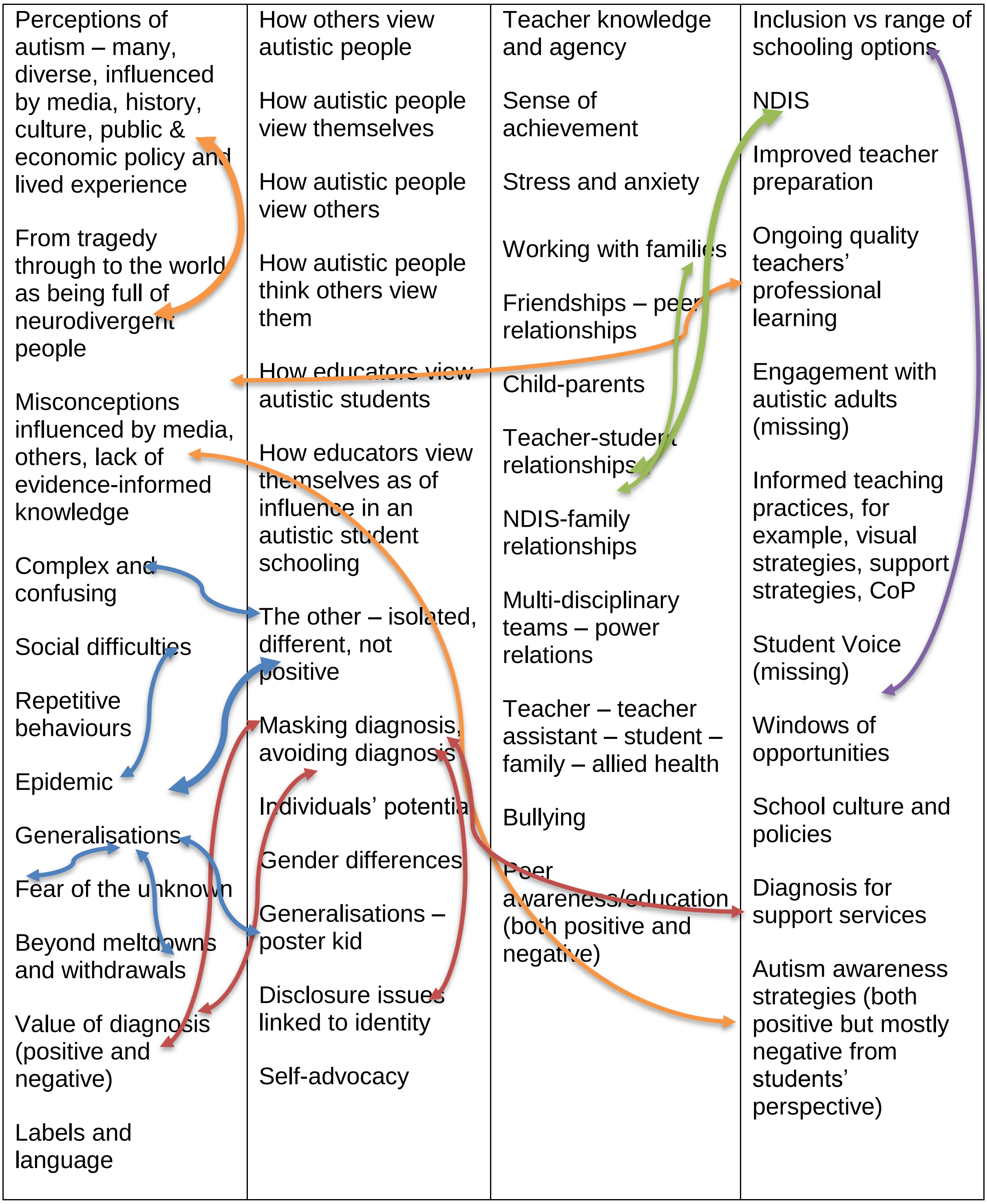
This teacher is questioning what language should be used when talking about autism and of interest it is mainly through social media that language use became an important issue.

"…depends on how you were raised about how autism was talked about" (autistic student?)

This quote is of interest as it could relate to the influence of family, education, media and so forth and as such may have an implicit link to the influence of media but this could also be contested.

The initial process of coding created multiple codes which were then reviewed for connections between them. An example of initial codes from the data are located on the following page in Table 3.1. The codes in Table 3.1 formed the foundation for Phase Three of the analysis process, searching for themes, with the coloured lines explained in the following section.

Table 3. 1 Example of initial codes generated in the analyses process



Perceptions of autism – many, diverse, influenced by media, history, culture, public & economic policy and lived experience	How others view autistic people	Teacher knowledge and agency	Inclusion vs range of schooling options
From tragedy through to the world as being full of neurodivergent people Misconceptions influenced by media, others, lack of evidence-informed knowledge Complex and confusing Social difficulties Repetitive behaviours Epidemic Generalisations Fear of the unknown Beyond meltdowns and withdrawals Value of diagnosis (positive and negative) Labels and language	How autistic people view themselves How autistic people view others How autistic people think others view them How educators view autistic students How educators view themselves as of influence in an autistic student schooling The other – isolated, different, not positive Masking diagnosis, avoiding diagnosis Individuals' potential Gender differences Generalisations – poster kid Disclosure issues linked to identity Self-advocacy	Sense of achievement Stress and anxiety Working with families Friendships – peer relationships Child-parents Teacher-student relationships NDIS-family relationships Multi-disciplinary teams – power relations Teacher – teacher assistant – student – family – allied health Bullying Peer awareness/education (both positive and negative)	NDIS Improved teacher preparation Ongoing quality teachers' professional learning Engagement with autistic adults (missing) Informed teaching practices, for example, visual strategies, support strategies, CoP Student Voice (missing) Windows of opportunities School culture and policies Diagnosis for support services Autism awareness strategies (both positive but mostly negative from students' perspective)

3.7.3 Phase Three: Searching for themes

Phase three of reflexive thematic analysis is described as searching for themes, moving from the "micro detailed scope of the coding process…(to)…macro scale, for connections and alliances" (Braun and Clarke, 2022, p.76). It is an active, iterative and recursive process of examining the codes and dataset as a whole, moving back and forward between the raw data, initial codes and initial conceptualising of themes to identify broader patterns of meaning. The coloured line between the codes in Table 3.1 highlight the emergence of themes, for example, stereotypes of autism is highlighted by green arrow connecting codes including, generalisations, repetitive behaviour, social difficulties, isolated and othering. The orange arrows links codes associated with the issue of diagnosis including both the positive and negative value of a diagnosis, disclosure issues, masking a diagnosis and diagnosis for accessing support services. Another theme represented by the green arrow linked to sources of information whereby lived experiences, historical and cultural factors, the media, others and professional learning were all mentioned by participants as sources of information in the development of their conceptualisation of autism. The linking of codes as noted in Table 3.1 is a brief example of the many connections between initial codes and the search for theme. Several codes linked to autistic identity, but this proved to be a large and all-encompassing theme that didn’t allow for a more detailed understanding of how issues such as diagnosis, isolation and quality of relationships influenced participants’ conceptions of autism. The final theme from the data are provided in Table 3.2. Others may see different themes in reviewing the codes from Table 3.1 however, I was mindful of representing the essence of the original quotes from participants in these themes.

Table 3. 2 Refinement of themes

- Sources of information
- Stereotypes of autism
- Popular media
- Misconceptions
- Difference
- Stigma
- Being labelled autistic/Autism diagnosis
- Belonging

- Educator-student relationships
- Educators’ roles
- Educator development (professional learning)
- School context
- Inclusive education
- Co-regulation
- Access to funding and services
- Role of the National Disability Insurance Scheme (NDIS)

During this phase of the analysis process I developed four overarching themes of relevance to the research questions. These were beliefs about autism, identity and the relevance of an autism diagnosis, relationships, and practices & policies. The initial codes from stage 2 of the analysis process have been included in the table with data poems linked to these codes and themes shared and discussed in Chapter Five.

3.7.4 Phase Four: Reviewing themes

Phase four of reflexive thematic analysis involved the reviewing of initial themes through additional processes of refinement and reflexivity and considering whether these adequately captured the explicit and implicit issues generated by the three previous stages. At this stage, I also reflected on two key issues at the forefront of my thinking, the first being the connection between the themes and the Circuit of Culture and second, whether the themes dissipated the voices of participants. For example, how does a theme of “Diagnosis” adequately capture the complexities and emotions evident in the participants’ actual quotes. While I aimed to respond to the research question through the use of thematic analysis I was also very keen to honour the participants’ voices. At this phase of reviewing the themes and how to best represent these in the findings chapters I explored the use of poetic inquiry as a potential process for reflecting the themes in a rich and meaningful way.

Poetic inquiry is defined by Faulkner (2017, p. 210) as ‘the use of poetry crafted from research endeavours, either before a project analysis, as a project analysis and/or poetry that is part of or that constitutes an entire research project. The key feature of poetic inquiry is the use of poetry as/in/for inquiry. In 2020 Faulkner proposes that may different terms such as data poems, research poems have been used and all form part of the broader poetic inquiry.

Lietz et al (2006) propose that “generating and presenting of this type of data is to inspire an empathic, emotional reaction, so the consumer of research can develop a deep, personal understanding of the ’subject’ of the data” (p. 25). This was an aim I valued in generating this thesis given the impact the participants’ contributions had on enriching my own knowledge.

I also felt the use of data poetry aligned with the notion of images which permeated my thinking before the formal research process commenced and then featured in my literature review and research design. The use of poetic inquiry also allowed me to investigate how different participants interpreted a similar concept or experience as this was central to my research questions. As Schwartz-Shea and Yanow (2012, p.41) note, “…it is precisely those difference that are of analytic interest to the researcher as they suggest what is significant – what is *meaning*-ful – about the event [or concept] to each person speaking.” The comparing and contrasting of the data poems provided a window into the participants varied perspectives on issues including beliefs about autism, and at the same time allowed me to review the relevance and intent of the theme generated in Phase 3 of the analysis process.

I applied the poetic inquiry process to the dataset as a whole and constructed 152 poems. I printed the data poems onto A4 paper and cut the individual poems into sections. I then grouped the poems into themes on large posters into groups under headings of themes

Appendix Ten). I did this in a way that I could move the poems into different theme groupings to determine if the initial theme could be further refined. This process occurred in conjunction with thinking about how the themes and data poems connected with the Circuit of Culture's five processes. It was at this stage that I noted the initial themes connected with more than one of the five processes highlighting the interactive nature of the five processes. The links between the themes and the Circuit of Culture five processes are reported on in Chapter Five drawing on a range of data poems.

To assist in the audit process of how data poems were constructed from the data and reflected themes is provided here as an example of my analyses processes. The following data poems was created from an educator participant's reflection on their beliefs about autism linked to their selection of the visual images of railway tracks:

Brain is like the rail tracks
they all have a purpose and are going somewhere
flick of the switch they can go in a different direction
autism might look like a big jumbled mess
but in actual fact
there is purpose in each of the lines
can see things in different ways
what they focus on
influences the way they see things
they are more black and white
lineal
in a box in their thinking
they need to be more flexible

This data poem clearly aligns to the railway track visual image but expands on the concrete images to add further beliefs linked to generalisations about autism. Whereas the following data poem from one of the student participants, who also selected the railway tack image, links to beliefs about autism but from a first-hand perspective. Of interest, the student also refers to being put in a box, being characterised as needing additional support because of teachers' perceptions when hearing the diagnosis of autism. The subtle links and differences between these poems provided an opportunity to generate themes that were not based on similarities in responses but allowed for analysis of why similar language may be used by participants, but quite different perspectives were held. These differences were of importance on propositions arising from this research.

They expect me to be less independent
people just assume a lot about me
if they hear the word autism
teachers trying to put me into a box
oh, she's going to need a lot of extra support

The use of the data poems allowed for a more in depth understanding of specific themes, and how the same poem may reflect different but related themes. For example, these two poems could be linked to the theme of misconceptions and stereotypes of autism. These two themes could be combined as one but they also represent slightly different foci with misconceptions often an outcome of limited knowledge and stereotypes an outcome of generalisations.

3.7.5 Phase Five: Defining and naming themes

This phase involved the defining and naming of themes and the development of detailed analysis of each theme. Chapter Four aims to introduce some of the themes but the major focus in on sharing findings from participants' responses to the word autism and the photo elicitation process. Again, it is hoped this chapter provides evidence of how defining and naming of themes was an iterative and reflexive process that allowed for further defining and exploration of each theme to occur in Chapter Five.

3.7.6 Phase Six: Producing the report

The sixth phase of reflexive thematic analysis is described by Braun and Clarke (2022) as producing the report. The report in this research is the thesis but with a particular focus on outcomes detailed in two findings chapters with the final discussion designed to weave together an analytic narrative which responds to the key research questions and extant literature (Neuendorf, 2019).

During the production of the discussion chapter, I was keen to capture the richness of the findings in ways other than verbal representation. As visual representation was a key element of my research design, I pondered on the opportunity to represent findings with a visual form supporting the discussion narrative. I met with artist, Amy Hamilton, and discussed my research process and outcomes from individual codes through to themes and the Circuit of Culture processes. Amy read some of the data poems and following a process of ongoing interactions and feedback on her initial illustrations, a final visual representation of key outcomes was created. The image is included in Chapter Six, the discussion chapter and purposefully takes a popular media design to highlight the interactive nature and influence of the Circuit of Culture processes on the research participants' conceptions of autism.

3.8 Research bias

I recognise that I bring my own bias to the research. Trialling stimulus images used in semi-structured interviews with a group of peers (adult doctoral students) was done to reduce potential bias and an alternative to the researcher solely choosing these images as discussed in Chapter Three. Evans (2021) recommends this practice when creatively developing research tools for use with autistic students. The consistency with which participants chose the same images to represent autism suggests that these images have a degree of social validity. Despite these efforts however, it has to be admitted that some risk remains that images used in this study would not have been independently chosen by the sample of students and educators interviewed in semi-structured interviews.

I have worked for many years in the autism field, and therefore these practical experiences have shaped my viewpoint and influenced all my interactions with the research participants as well as the lens that I use to analysis the data. My research bias has been further influenced by formal study and professional learning about autism and disability, undertaken over many years. By utilising reflexive thematic analysis, I am acknowledging my own subjective position and in this way am part of the research design and outcomes. However, I am hopeful that the explanation of the processes I engaged in to design, conduct and report on outcomes of this research is presented with enough transparency to allow for consumers of the research to follow my analytical processes and subsequent propositions. These processes are introduced in this chapter but displayed in more depth in the following three chapters. I acknowledge others with different lived experiences may interpret the data in different ways with different outcomes but in publicly sharing this thesis I am hopeful that it speaks to others in ways that promotes reflection on whether we can be doing more to be on the same track when conceptualising autism.

3.9 Summary

This chapter explains the essence and justification for employing a qualitative research paradigm. The research design and methods are also explained along with details of the reflexive thematic data analyses processes. It is hoped the chapter and associated appendices provides evidence of the soundness and trustworthiness of the research that generated the outcomes that will be reported in the following two chapters. Chapter Four will focus on the participants’ responses to the word and photo elicitation method and Chapter Five explores in more depth the outcomes of the semi-structured interviews that formed the foundations for the generation of themes.

CHAPTER FOUR: FINDINGS- EVERY PICTURE TELLS A STORY

“Meaning depends on the relationship between things in the world – people, objects and events, real or fictional – and the conceptual system, which can operate as mental representations of them.” (Hall, 2013, p.4)

4.1 Introduction

The opening quotation from Hall (2013) is of significance to the focus of this chapter, given that the chapter explores the research participants’ initial conceptualisations of autism through their meaning making of the word ‘autism’ and their interpretations of linkages with the photographic images. Hall (2013, p.18) contends that, ‘Our shared conceptual map must be translated into a common language, so that we can correlate our concepts and ideas with certain written words, spoken sounds or visual images.’ All participants used the English language as a shared medium for exploring their mental conceptions, but it is the similarities and differences in their conceptualisations, along with potential explanations for these, which is the focus of this chapter.

Educators and autistic students share school-based contexts. Relationships and cultural aspects of the school may influence their thinking; however, they may have developed their conceptions about autism from beyond the school context. Hall (2013) suggests if people interpret things in similar ways, then shared meanings and shared ‘conceptual map’ will provide a foundation for creating a social and cultural world that all involved can inhabit with ease. In the school context, this would support the importance of educators and autistic students being ‘on the same track’ in their conceptual understanding of autism and their capabilities to foster conditions in which all can function with successful outcomes. Saggers (2015) highlighted inhibitors to autistic students’ positive experiences at school, such as ‘negotiating difference’ in all areas of the schooling experience. Shared understandings may not develop in schools, as in any workplace or subsection of the community, for a variety of reasons, such as differing language/cultural backgrounds (Baker et al., 2021), or differing political beliefs and values (Holbein et al., 2020). In the case of autism, shared meanings between educators and autistic students may be driven by external influences, individual beliefs and values, and lived experiences, which may generate quite varied mental representations of autism. Hall (2013, p.3) summarises that representations are made up ‘not of individual concepts, but of different ways of organizing, clustering, arranging and classifying concepts, and of establishing complex relations between them.’

The diagnostic criteria for autism (American Psychiatric Association, 2022) and the research on double empathy (Milton, 2012) both highlight that autistic people process information and social cues in different ways to non-autistic people. My research explored the notion that there may be differences in conceptions of autism between the research participant groups, that is, non-autistic educators and autistic students. In addition, the research reflected on the significance of any variations in conceptions and if there exists an explicit need for educators to seek to understand their autistic students' conception of autism. This will be further explored in Chapter Five, which expands on the data from the semi-structured interviews. The final choice to present the participants with pre-selected visual images and the single word 'autism' for the photo elicitation, was designed to create a shared starting point, the same word and images, to see how these were interpreted and subsequently represented by the different research participants. Participants' meaning or conceptualisations align with the 'representation' element of the Circuit of Culture (du Guy et al., 2012) however, 'consumption' of experiences and information, potentially influenced by lived experiences of autism and/or autism popular culture, intertwine to form these representations and ultimately ongoing 'production' of representations.

This chapter reports on the outcomes of the initial inductive analyses of the varied responses and representations of the participants, commencing with a focus on participants' responses to the word autism Hall's (2013) theory of representation, in which representations can be viewed as reflective, intentional, or constructionist (see Chapter One, p. 17), are employed in this chapter as well as in Chapter Five to analyse in more depth the responses of participants. Reflective representations account for responses that capture existing meaning, something that is already known to others: for example, that autism may be defined differently by different people but with general agreement that it is a lifelong neurologically based condition. Intentional representations are those unique to individuals even though they are sharing the same language codes.

The participants in this research are engaged in intentional representations by purposely sharing their personal meanings, but within their intentional representation there may be examples of both reflective and constructionist representations. Hall (2013) contends that we need to pay close attention to how language systems are used to construct meaning; for example, the visual images used in the research don't have inherent meaning on their own. Rather, it is how the participants use language to construct meaning that generate constructionist representations and meanings from the photo elicitation. This thesis itself is a constructionist representation of the research participants' conceptions of autism. In the following section, my constructionist representations of the transcribed responses from participants are presented and aligned with representations from existing research (reflective representations). Key ideas from this process will be extended in Chapters Five and Six.

As explained in Chapter Three, four autistic adults were invited to participate in the research as critical friends and to share in elements of the research process. Their role was to comment on the choice of visual images and also to respond to them. While the initial focus of the research was to consider educators' and autistic students' conceptions of autism, the contributions of the autistic adults proved of great relevance to the research and as such, their responses have also been included in this Chapter. All participants are identified by pseudonyms, with the six teachers named: Martha, Sylvia, Jane, Mary, Tina, and Rose. The four students are named Sarah, Bob, Jim, and Wendy, and the four autistic adults are Tom, James, Alice, and Michelle. The Chapter commences with the educators' responses to the word 'autism,' followed by the autistic students' responses, prior to exploring all participants' responses to the photograph images.

4.1.1 Educators' responses to the word 'autism'

In response to hearing the word 'autism,' Martha focused specifically on her experiences as a classroom teacher and her current employment, which had a strong component of mentoring and support for other teachers. There was an emphasis in her response to the word 'autism,' that autistic students needed support to 'cope' at school. This was not surprising, as there is overwhelming evidence that many autistic students require additional support to cope with the various social, environmental, and academic demands of formal schooling (Saggers et al., 2016). Martha highlighted the importance of taking a team approach to supporting autistic students and their families. Interestingly, Martha described autistic students as 'coping with *their* autism,' as if 'autism' was separate and outside of the individual, a view that arguably reinforces the 'othering' of autistic students (Michael, 2021). This idea of autism representing 'difference' is:

> The first thing that comes to my mind is around my work, in that part of my work is to help teachers help kids with autism. That is the first, the immediate response that I have…. the next…thought would be around, how do we and how does that person that we are referring to at the time, how are they coping with their autism and how are people supporting them? I think back to when I was actually teaching kids with autism in my class, with fond memories and always brings back good memories of the fun that we used to have. How we used to work together to form a team around the kid to help in the class. How we would try and help the family and the students at school.

Martha repeatedly used the word 'help' to describe the support needs of autistic students, as well as characterising families of autistic students as in need of 'help,' and teachers also as needing 'help.' My conceptualisation of this idea is that it problematises autism and autistic students as causing difficulties or issues that require assistance of some kind, which is provided by teachers and support staff. As captured in the literature review, the narrative of autism as a problem with inherent difficult or challenging behaviour is prevalent (Lindsay et al., 2013). Throughout the interview, Martha did not expand on what constituted 'help,' and aside from teacher aid support, she did not explain what this help might practically look or sound like.

The view that autistic students and their families needed 'help' was shared by another teacher, Sylvia, who reflected on her personal experiences when she heard the word 'autism. In addition, she described an associated feeling of heartbreak for families and the challenges she thought that autistic individuals experienced. This may reflect the narrative that autism is a tragedy (Pripas-Kapit, 2020), defined by challenges and difficulties experienced by the autistic individual and their family. This 'tragedy model' is perpetuated by the media campaigns (Saunders, 2018) of many disability organisations that leverage off this narrative, often infantilising autistic people as children (Stevenson et al., 2011) to attract more funding and charity donations. The tragedy/charity discourse (Walz, 2012) is at the heart of the commodification of autism (Mallett et al., 2016) and it is now like a runaway train or juggernaut. It has gathered so much momentum now that is hard to stop or derail, despite the best efforts from autistic advocates.

Sylvia's response to the word 'autism' was:

> Probably an experience rather than anything else, and that is the experience of working with children on the autism spectrum and how difficult it is for them and their families, I suppose it is for acceptance. It is a feeling more than an experience…the challenges and heartbreak for the families and all of those sorts of things that I see.

Both Martha and Sylvia reflected immediately on their teaching experiences, which influenced their representations of autism. Although Martha spoke of having fun with her students, these teachers' personal experiences led them to view autism as 'difficult.' It could be proposed that if educators view autistic students as difficult, it may influence how they reproduce ongoing representations of autism. Wood (2018) talks of the 'looping effect,' that is, the more an idea about autism is discussed, the more it gathers validity, even if it is not true.

Sylvia touched on the idea of *acceptance*, which is increasingly reflected in campaigns from autism organisations that initially focused on raising autism *awareness,* to now focussing on autism acceptance. This was demonstrated by Autism Spectrum Australia's (2014) campaign to 'drop the D' which meant to stop referring to autism as a disorder and move from autism awareness to focussing on acceptance and positivity through their ‘A Different Brilliant’ campaign (Autism Spectrum Australia, 2022).

Jane similarly reflected on her professional experience in her initial response to the word ‘autism.’ Jane had different views to the other teachers, focusing instead on the misconceptions of others as well as the perceived ‘challenging behaviours’ of autistic students, and particularly her experiences with young children. She stated:

> I think there are lot of misconceptions, from an educator’s point of view and I would say challenging behaviours. An image as such, the first image is just young children, I don’t know why, but then again, I have been in autism field for a long, long time and I have worked with a lot of younger children with autism.

While she stated that her first mental image of ‘autism’ was young children, she started her response with a focus on the misconceptions around challenging behaviours. It appears there was a flow of thoughts between one idea and another, with misconceptions potentially indicating that autism is generally associated with challenging behaviours. However, it is difficult to determine if she was adhering to this view or was attempting to present another. Jane finally settled on a focus on younger children but failed to add any detail about them: for example, why she saw them as representative of autism? Like Sylvia, Jane’s response was clearly aligned with her teaching experience, which she reported as ‘extensive.’ However, given her focus on challenging behaviours, it raises the question of whether she was drawing from her own experience, or whether other factors were involved in shaping her responses and conceptual understanding of autism. For example, it appears she situated challenging behaviour within the child rather than within her response to the child. Therefore, the question of the quality of her experiences and professional learning is worth further interrogation to determine what factors are at play in her immediate responses to the word ‘autism.’

These three educators’ experiences of teaching autistic students were a primary focus for their conceptions of autism, suggesting responses came from personal lived experience of teaching, and that lived experience, while eliciting concerns for students and their families also generated a perception that autism aligns with ‘difficult.’ While drawing on lived experience to conceptualise autism is to be expected, perhaps it is the quality of those experiences that need further interrogating to further explore how they are of influence. For example, what did they view as ‘challenging behaviours,’ how did they respond to these, and what were their levels of access to support for enhancing their self-efficacy as educators of autistic students? And further, what may assist in shifting the educators’ perceptions that autism is associated with difficulty?

Jane’s conflation of autism with challenging behaviours is not uncommon. Other researchers also report that educators use terms like ‘maladaptive behaviour’ or ‘deviant behaviour’ to describe autism (Javaid et al., 2020; Verehoef, 2012). Verehoef (2012) asked: if autism is described as a series of deviant behaviours, then how can we ever see it as natural? The concept of deficit is reinforced and is also squarely situated within the child’s behaviour and actions, as opposed to educators’ responses to the child (for example, in their understanding of the autistic child’s communication or learning style).

In the focus group interviews, James, one of the autistic adults, explained that members of his family thought he had grown out of his ‘juvenile autism,’ as they mistakenly believed that it was not possible for him to achieve success at university if he was ‘still’ autistic. Similarly, one of the other autistic adults, Alice, shared that her extended family had said she had also ‘outgrown’ her autism due to her success as an independent adult. This is an issue commonly reported by autistic adults, who often describe feeling ‘invisible,’ as a result of a sociocultural disbelief that autistic children are still autistic when they develop into adulthood (Rabba et al., 2022).

Mary, the fourth educator’s, response focused on the impact of autism on other people, and the difficulty she believed other people experience when trying to understand the complexity of autistic people. Mary used the term ‘hard work’ to describe the experience of families and teachers trying to understand autism:

> It is complex, and there isn’t a one size fits all and it’s very difficult for our teachers and our parents and other kids to understand. I also think it can be very emotional. We have a little boy with autism and Downs (syndrome) and just to see their journey is hard work. It is hard work and people don’t understand, they think they are naughty… and sometimes they are (laughs). The complexity is the thing that comes to me the most.

Mary did not mention any behaviours or characteristics that are often associated with autism. Mary highlighted misconceptions that others may have of autistic children being ‘naughty.’ This linked with Jane’s response that challenging behaviours are situated within the child, rather than considering the learning environment and the role adults may have in triggering such behaviour. Mary explicitly linked her representation with being emotional, aligning this to the hard work of watching families’ experiences. There are extensive examples of autism popular culture drawing on the emotional work autism demands of families (as shared in Chapter One and Two) but it appears Mary’s responses were again drawn from her lived experience as an educator of autistic students and her interactions with their families.

Tina, a fifth educator participating in this research, initially connected autism with repetitive behaviours. This highlighted a link to generalised information about autism but also potentially to the deficit model view of autistic students, (that behaviours that don't fit within a teachers' behavioural expectations can be prominent when thinking about autism). Tina went on to say that in her experience, many parents blame autism for their child's behaviour. This is an extension of her original view that autism is to blame for challenging and repetitive behaviours. However, she shifted direction and expressed frustration that in her view, many people did not understand that autism is a different way of learning or a different way of looking at the world. This perception suggests a link with the wider public's potential misconceptions about autism. And while she expressed concern at the public's misconceptions of autism she drew on generalisations in her first responses to hearing the word autism. However, Tina went on to explain her belief that autism was not a 'true disability'. As with the previous teachers, Tina emphasised that her teaching experiences were of major influence in her response, but she was the first teacher interviewed to express a perspective that connected with the neurodiversity paradigm (Jurecic, 2007) and the social model of autism. However, her response indicates a separation of autism from the child which appears to work in contrast to a neurodiversity paradigm.

> I would say repetitive behaviour, that would be the first thing. The fact that, I suppose, parents blame autism for their child's behaviour instead of looking at: 'ok, that is a behaviour I don't want,' not that you want to always change it but you may want to adjust it or modify it. Learning in a different way, apart from that, yeah frustration, that some people believe that autism is an intellectual disability and it's not. I don't even see it as a true disability. To me, for those people with autism who don't have an intellectual disability part of it, to me it is just a different way of learning, a different way of looking at the world. There is a lot of frustration as a teacher when I see and hear people say, "he has autism, he doesn't know." No, he does have autism and he can know, you just need to take a bit more time or show him or her a different way. Yeah, that would probably be my first thought but then it just delves so much deeper.

Rose, the sixth educator participant, identified sensory processing issues as her primary association with autism, and went on to describe the diversity in the presentation of skills and behaviours in autistic people, although not in a negative way. Her responses were strongly grounded in her professional role and a sense of accountability for understanding children's unique needs. Rose shared later in the interview that she is also a parent of an autistic child, but that did not become apparent until much later in the interview. However, these dual roles may have influenced her responses, which were slightly different to those of the other teachers. Rose shared a greater focus on her role in meeting the needs of her students, rather than expecting her students to meet her need for a calm orderly classroom:

> Sensory difficulties, a student that normally would like structure and routines. Visuals, the use of visuals, they need visuals to help support their learning. They are all individuals, they vary, just because they have autism they are not all the same and all have their unique needs. I would say when I think of autism yeah, they have strengths, some students on the spectrum are very high functioning, some, ones who can't communicate as well, it varies, I don't put them all in one package, they are all so completely unique. Many of the students in our school, when I think of the students in our school, their assessments, what level they are placed on according to their psychologist. Breaking down that diagnostic assessment and analysing each key point and working out what are their needs in their learning. So yeah, the first thing that stands out to me is the sensory, yeah, the sensory issues.

The six teacher participants in this research were all experienced teachers and it is interesting to note that all refer to their experiences of teaching autistic students and working with their families in articulating their initial responses to the word 'autism.' Key concepts often associated with autism in research literature were evident in the teachers' responses, including reference to sensory difficulties (Jones et al., 2020), the need for visual supports (Saggers et al., 2016), challenging behaviours (Pluquailec, 2018), strengths-based approaches (Davey, 2020), and diversity and unique needs. These align with both their personal and lived experience as teachers, but could also be associated with their professional learning. Perceptions of autism for this group of teachers were filtered through their professional lens in reflecting on their work as teachers of autistic students and the emotions that these experiences evoked. However, during the interviews became aware that Sylvia and Rose also had personal experiences relating to autistic and neurodivergent family members.

4.1.2 Autistic students' responses to the word autism

The responses from the four autistic students to the same question 'describe the first feeling, memory or image that comes to mind when I say the word *autism*' were quite different to the responses from the educators. This was to be expected on the basis that the students were all aware of being autistic, and reflected quite different lived experiences to those of educators.

It was interesting to note that one student, Sarah, took a broader perspective and stated, 'it depends on what viewpoint you are talking from.' This was a powerful statement that challenged the belief held in research literature that autistic people are unable to take the perspective of others (known as the 'theory of mind gap') (Baron-Cohen, 1997). This statement indicated that Sarah was aware of the perspectives of others. As highlighted in the literature review, the work of Milton (2012) proposed that in fact it the so-called 'theory of mind gap' was a 'double empathy' problem (as referenced in Chapter Two). Milton argues that autistic people are able to communicate effectively and easily with each other, just as non-autistic people are, with issues of understanding only occurring between the two groups. Sarah stated:

> It depends on what viewpoint you're talking from. To be honest with you for a lot of people I think it has negative connotations. It does for me. Because I think, a lot of kids, are maybe a really socially awkward kid, or – whereas, it's not always like that. Even if it is like that, it's not really. Some kids just can't help it. I mean, one of them is my other friend [who is autistic]. And you know, that's sort of a negative and positive thing. He's a human being, you know what I mean?

Sarah described 'autism' has having negative connotations for her and described her autistic friend as simply 'a human being.' This statement was aligned with the neurodiversity paradigm that sees autism as a part of the human condition rather than a separate entity. Sarah, in reflecting on her friend as a total being, rather than a being with the addition of autism. However, she is acutely aware that autistic people are viewed as socially awkward or somewhat different by others, in effect 'othering' them. This indicates the social context is working as a barrier, as there is a lack of a shared conceptual map about awkwardness. For autistic people it's who they are, and it is the social context that labels them as 'awkward.' For others, their conceptual map goes straight to 'different,' potentially without recognising that the social context is of influence to their conceptual map.

Jim, another autistic student, presented a very intentional representation of autism that displayed an explicit constructionist representation, the use of analogy to extend meaning. Jim's analogy of being autistic is likened to the Apple iPhone, noting the Apple iPhone works as a whole rather than as separate entities. Jim referred to this analogy throughout the interview, describing the iPhone iOS as a different and better operating system than an Android phone (neurotypical people) as a way of explaining his perspective of autism:

> I'm an Apple iPhone. Apple is the superior brand. And also, it was designed by someone with autism. So, it's proven as a much better brand than everyone else…A better way of thinking in some ways. Well, a lot of people who have invented very good things out there are on the spectrum. So … you can see the evidence out there with a simple google search.

These types of analogies of autistic people being on different computer operating systems compared to non-autistic people are not uncommon as described in Chapter 2: Literature Review. Jim's response indicates a sense of pride in being autistic and indeed that the world has benefitted from the capacities of autistic people. However, the key idea being produced here is one of difference or othering. This feeling of being 'othered' was shared by Wendy, another autistic student, who responded 'they think you're different to everyone else.' By the use of the word 'they,' Wendy is referring to non-autistic people and educators. By the use of the word ‘you’re,’ she is not separating herself from autism but viewing herself as a person who she clearly recognises is seen as different by others.

The fourth autistic student, Bob, described his response to the word ‘autism’ as simply, ‘it’s just a word – that people sometimes take advantage of.’ This pause in his response was of interest as it may have reflected that he recognised the word related to him, but he was not keen to be defined by it. However, he then proceeded to note it can lead to people being categorised by the word ‘autism,’ and taken advantage of. Perhaps this was an intentional representation based on a recent (or often) lived experience of being autistic. He didn’t explain further (to describe taken advantage by whom), but his response indicated a sense of being ‘othered’ and potentially not in a positive way.

The key themes from the students’ responses was of ‘othering.’ There was an awareness from all the students that other people see them as different. There was a sense from three students, Sarah, Bob, and Wendy, that being different was negative, created a sense of stigma, and was linked to experiences of feeling ‘less than’ others. Jim, in contrast, presented a more confident sense of identity and pride in being autistic and indicated a conceptual map that autism was part of him rather than separate. - Sarah described autism as “only a small part of me’, and Bob described autism as 'just a word' - that implies that it is not so much inherent to him, but something he doesn't accept (i.e. it's just a label). It was unclear what Wendy believed as much of her interview was concerned with other students’ perceptions rather than her own. This is in contrast to the educators’ who all shared the conceptual map that autism is viewed as separate to the students and potentially the autism is addressed in preference to addressing the individual student. Variations in conceptual maps are explored further through the photo elicitation outcomes in the following sections.

4.2 Photo elicitation to explore participants thoughts about autism

As described in the methodology chapter, the use of twelve black and white photographs were incorporated into the semi-structured interviews. The educators and autistic students were invited to select an image (or more than one) that they believed represented an aspect of ‘autism.’ The twelve black and white photographs were also used with the autistic adults in the focus group interviews but in a different way. Initially this was designed as a consultation with the adults to determine whether the images would be appropriate to use with the students. The focus group participants agreed the photographs were suitable, and then provided several responses to some of the images of interest to them as a group. These responses have also been included in this chapter, as they provided interesting perspectives. The selections of photo images and reasons for the selections by participants are shared below. Responses reflected examples of Hall's three elements of representation: reflection, intentional, and constructionist.

4.2.1 The train tracks

From the 12 photographs presented to participants in the study, the image of the train tracks (Figure 4.1) was the only photograph selected by every teacher and student, and the focus group members. The participants' varied responses to this image will be shared with discussion about their responses concluding the section.

Figure 4. 1 photograph of train tracks

Martha, an educator, stated:

> Well, this reminds me of the synapses of the brain and the part of the brain, how the brain are like the rail tracks and they look 'oh my god' but they all have a purpose and are going somewhere and for want of a better word, with a flick of the switch they can go in a different direction and how people with autism…To people who don't understand autism it might look like a big jumbled mess, particularly with all that scaffolding at the top, but in actual fact there is purpose in each of the lines.

Martha's response highlights the medical understanding of autism as a neurological condition, and in turn the view that autistic people can be misunderstood by others. Her description of autistic brains as a 'jumbled mess,' and autistic people as being misunderstood is related to the dominant medical representation of autism. In Western society, autism remains heavily rooted in this belief system as discussed in Chapter Two: Literature Review. This has the effect of describing behaviours or characteristics, rather than a whole person.

Sylvia also stated that this photograph led her to think of a sense of 'confusion,' but that it also caused her to think about the metaphor that life is a 'journey,' and that life is about the journey rather than the destination. She noted the destination in this photo appears somewhat bleak but was hopeful of positive outcomes for all.

> This one to me is again about confusion. There are so many roads leading to a destination and some people can take one path through and get there really quickly, whereas for other people it is a really difficult way to get there and they get really confused about how the journey is going to go. Hopefully we all get to a really good destination, but this does look a little desolate at the end. But this is more about the railway tracks than it is about the destination.

Jane shared a similar thought about the tracks showing ‘confusion,’ and the minds of autistic people being very ‘busy.’ Jane referred to an understanding of autistic minds that is linked to neurology and the medical model of autism. Jane related to her role as a teacher and the broader profession, trying to teach autistic students’ social rules, and how that is difficult for autistic students to learn. There was some reflection that the teachers may be adding additional pressure and confusion for autistic students:

> …I have also chosen the many train tracks because that reminds me… it’s very complicated, very busy and I think that often children with autism… their minds are very busy. We are trying to teach them social rules and they are not always getting it… and which path do they take, sometimes they take the B choice and not the A choice. This busyness of all the different railroads ‘do I take this track or do I take that track’ as the decisions that we are sometimes putting on children, or choices and it can be confusing for them so that is what that reminded me of.

Mary, reflected on her role as an educator when she chose the train tracks. The tracks represented her own confusion and the different aspects of support that she has been required to provide during her career. Mary considered in her response that autistic children grow up to be adults, and the railway lines made her think of this:

> That is the railway lines, and they are all criss-crossing over and you can change in directions, and that is how it feels sometimes with our students with autism. We get something sorted and then you have to change track, and change track, and change track just to keep them going in the same direction. Sometimes it feels really confusing but we keep them going forward on the tracks…. See there are tracks and we are going forward, but it’s not like a normal railway line you might go down this track and deal with this, and then you deal with this and you might just get that sorted, then they grow up and they change and you have got the social stuff, emotional stuff, educational stuff and behavioural stuff so that is why I thought that one.

Tina related the photograph of the train tracks to the autistic brain and tried to imagine what autistic students may be thinking. Her guess was that it was ‘chaotic.’ Interestingly, Tina started by saying that she wouldn’t choose the tracks even though she could see why some people would. Tina then went on to speak about the tracks in detail:

> Most of these I wouldn’t pick because as there is too much chaos and movement, and a lot of kids I know with autism, that would drive them nuts because there is no order…The ones with the tracks and the lines and all that, I can see how, especially the kids with the intellectual disability, how that would be how their mind is. There has to be a line there somewhere, but which line do I follow, which one do I cross? There is so much going on and sometimes you can see by the expression on their face, you think, I would love to know what is going on? When they sit there, and they just laugh for no reason. You know that they are laughing at something that they are seeing or hearing or something like that. You think, “what are you laughing at?” So, you wonder sometimes, even with our mainstream kids, what do their minds look like inside? They haven’t made any real connections or sense and it just feels like absolute chaos. We are trying to get them to do a thousand and one things every week, what are we asking them to do in some ways?

Tina’s response generated several interesting points of discussion that will be explored in more detail at the end of this section, but it appeared she was trying to reflect that she is an experienced educator who will avoid generalisations. However, in her description she put forth a sense of not really knowing her students or what they may be thinking. She also questioned the impacts of school on autistic students in relation to the demands placed on them over the course of a week.

Rose, the sixth educator, was more empathic about the students in her class. She related to the tracks as showing information overload related to the classroom environment and teaching methods, rather than the students themselves:

> When I look at that, sometimes in the classroom is an overload of information there is too much going on, they can’t sit and concentrate, it is too overwhelming. Sometimes it is because the teacher needs to break down instructions, or it is the language used, or it could be too much background noise, air conditioners, or music playing in the background that the teacher hasn’t realised. There is a lot going on in that picture and sometimes that is how it is for our students in the classroom, it is very overwhelming and just too much.

Rose’s description is reflected in accounts from autistic people about their experiences at school (Williams, 1992). In accounts from high school students, the classroom environment and related feelings of overwhelm and anxiety were commonly experienced (Saggers, 2015).

Each teacher brought an intentional representation to the selection of the image of the train tracks, with nuanced variations from seeing the image as representing the autistic brain through to the complexities of the learning environment. The link to learning environment reflected the educational context in which the educators work, however the comments about how the autistic brain functions suggests this information has come from elsewhere, such as professional development, other professionals, the family, and/or autism popular culture.

There appeared to be limited questioning of the knowledge about brain functioning, implying a ‘taken as truth’ reflective representation and a willingness to reproduce this concept. The following section presents the students responses, noting several differences in conceptions.

Sarah connected the image of the railway tracks to her personal approach to making connections, and that while she may sometimes jump to conclusions, she can think about many things at once:

> Sometimes even immediately I jump to conclusions or think about a lot of different things all at once. My brain is just kind of …. (laugh). I just make connections. You know what I mean when I’m trying to think about a problem. Sometimes I think of a lot of things at once and make connections.

Sarah’s description still reflected thinking styles or neurology but as a strength rather than ‘chaos’ or being problematic. Sarah focused on capability, seeing the ‘complexity of the tracks’ as a strength.

Jim related the train tracks to thinking creatively, perceiving himself as an Apple iPhone, compared to neurotypical people as an Android product: ‘I don’t think an android would really work that out. But then, you can see, they’ve got the switches, so you can swap them all around.’ He later went on to say that he had ‘superior thinking’ and came back to the iPhone analogy a number of times throughout the interview.

Bob chose the tracks ‘because, my brain’s just a maze.’ He didn’t attribute this negatively or positively, rather as a statement of fact. He didn’t share where the understanding came from: others’ interpretation of how he functioned, or his own reflection.

Wendy related the image of the tracks to ‘kids giving me crap. Yeah, literally that. Well, I go into flight or fight.’ Her awareness of ‘flight or fight’ modes indicates she understands she may respond differently at different times, depending on her social engagement with other students. This demonstrates evidence of strong self-awareness, in contrast to the educators’ perceptions of the autistic brain and thought processes as ‘chaotic’ or ‘a jumbled mess.’

The response from the autistic adults focus group were of interest as some reflected the students’ responses and others the educators. Michelle said; ‘Oh, that’s how my brain works – on totally different train tracks, going a thousand different directions a thousand times a day.’

Michelle doesn’t indicate if this is a positive or negative thing, much the same as Bob. It’s their reflection on the way their brain works, without an added judgement. This response links to Tina and Jane responses about the busyness of the track and the potential for this to lead to confusion, but Michelle and Bob don't talk about being confused, so the conceptual maps aligned to the concept of brain functioning vary between the educators and the autistic adults. Tom related the tracks to a number of concepts and feelings:

> The whole thing feels very dark, very negative – war camp stuff, you know? That's how I feel about it. But I don't relate that to MY understanding of autism, or to my experience…Certainly, train tracks are very commonly associated with autism. We feel one-tracked and yet we are bombarded by so many.

Tom's representation of autism acknowledged that others may view autism from a negative perspective, but this does not connect with his view. He did not share what his view of autism is, but he was seeking to challenge commonly held assumptions. Again, it's not clear where his assumptions about other's perspective of autism have emerged from. Of interest he reflected on being 'one-tracked' but overwhelmed by other tracks. This generated a sense that even though he contests generalisations of autism, he acknowledged the challenges he faces in some environments.

The railway tracks photograph was the only image to be selected by all participants, which generated the title of this thesis, framing the central question about whether educators and students are on the same track in their representations, consumption, and production of 'autism.' The response to this photograph and the word 'autism' presents some evidence to indicate the participants were not always 'on the same track' in their conceptual maps. The educators referred to the image of the train tracks as representing their perception that the autistic brain is chaotic, jumbled, and disordered. Conversely, the autistic students talked about the tracks representing their superiority of thinking, their ability to think about multiple things and make connections quickly, of being an 'Apple iPhone' rather than an 'android phone.' This simple example is quite powerful in exploring differences and conceptual maps. As Hall (2013) suggests, without shared conceptual maps, people are at risk of not understanding the cultural norms, beliefs, expectations, and practices of a group in which we share a social space and relationships of importance to success in life. If educators and students are unable to share aligned conceptual maps, then interactions, relationships, and sense of identity may be compromised.

The following section will explore the reasons behind the selection of different photographs and any further connections with variations in conceptual maps between the research participants.

4.2.2 Photograph of abstract block design with face images

Another image chosen by multiple interviewees was the photograph of an abstract black and white block design that appears representative of faces (Figure 4.2). Seven participants including three educators, two students, and two adults from the focus group chose this image.

Figure 4. 2 Photograph of abstract face images

Martha, an educator, said:

> I really like this one because depending on what you concentrate on, as in what you see and you can see a funny shape T with bits sticking out or I see two faces and that people with autism can see things in different ways and what they may focus on influences the way that they see things, they are more black and white, more lineal, more in a box almost, so is their thinking and they need to be encouraged to be more flexible.

Martha's reference to 'black and white thinking' is commonly used by professionals to describe autistic thinking. Her description was definitive in problematising a perceived lack of flexibility in autistic thinking, and in her view, one that needs to be changed. Her response to this image appeared to contrast with her response to the train tracks where she described autism as a jumbled mess, while here she is indicating her view that autistic brains are overly ordered. Tina, another educator, shared a similar view:

> Everything is black and white, very rarely is there a grey area, especially when they are way down the end of the spectrum. It's got to be "this" or "this," there is no "maybe."

Tina's description of 'way down the spectrum' reflects a linear way of thinking about autism in terms of 'low' and 'high' functioning that is being challenged in the literature (Anderson-Chavarria, 2021). Tina's response to this image highlights the use of the 'spectrum' metaphor, which is indeed part of the diagnostic label Autism Spectrum Disorder (American Psychiatric Association, 2022) has proliferated in the autism industry but is now being questioned. Tina's conceptual map of the 'spectrum' appears to overlook how the environmental and social contexts may influence the presentation of some autistic characteristics at given times for some individuals. What is not clear is what has been of influence on her mental representations that connects autism with black and white thinking and the spectrum.

Sylvia's interpretation differed to Martha's and Tina's representations. Sylvia challenged the assumption of 'black and white thinking' as a characteristic of autism, although this clearly indicated she is also aware that 'black and white thinking' is often associated with autism:

> … it is one of those images that you can see things from different ways. Some people may see little images, some see a face or just the T or the shapes themselves. I think for me, in working with kids with autism and looking at things from their perspective, sometimes we see things in different way and maybe those images don't always match up in terms of what we're thinking and they're thinking and with what they see and what we see and it is trying to get the balance. The fact the images are black and white as well, even that, as it is not black and white. We often hear the term they are so "black and white" in their thinking, I don't actually agree with that at all. I think maybe it's people who don't have autism who are black and white in their thinking that everyone with autism is the same…That is what I think about that one.

Sylvia posed an interesting hypothesis, highlighting stereotypes that neurotypical people often hold and the generalisations they make about autism. She suggested neurotypical people may have rigid perceptions and an inability to really understand the diversity of autistic people. However, from the first three teachers' responses, it is clear that the concept of 'black and white thinking' was quite familiar to them, whether they adhered to the belief that it reflects autistic people or not. The question of why people associate autism with 'black and white thinking' is of interest in that it has clearly been produced, reproduced, and consumed, and from a Circuit of Culture (Du Guy et.al 2012) perspective, so much so that it has become a culturally embedded representation of autism. Contributors to the production of this cultural representation may be researchers, the media, educators, families of autistic people, and autistic people themselves. It is clear that it has passed these teachers filters to form part of their conceptions of autism.

The students' responses also reflected an understanding that the 'black and white thinking' concept is linked to autism, though they took a slightly different perspective when explaining their reasoning for the selecting the image.

Tom, from the adult focus group, reflected an understanding that the 'black and white thinking' concept is regularly linked to autism. He stated:

> You could say people have black and white concepts of autism that were very black and white thinking people, that were very literal. You could also say things like, it happens that a lot of autistic people apparently identified as those who were pattern thinkers. I’m certainly not a pattern thinker.

Tom’s response reflected on how neurotypical people may have a restricted understanding of autism. He then moved on to indicate that autistic people may connect with this image, not due to the black and white concept, but due to the connection Tom is making with pattern thinking, although he indicates he is not a pattern thinker. Of interest, his response to the train tracks image suggested he didn’t connect with this way of thinking about autism, but he was aware others did. Although Tom is living the life of an autistic adult and is self-aware of his style of thinking, he is also very aware of how others, including autistic and neurotypical individuals, conceptualise autism. This reflects one example of how autism popular culture has impacted on autistic people’s lives, whereby perceptions, representations, and consumption continue to reproduce conceptual maps that have little to do with the lives of many autistic people.

One of the students, Jim, responded with quite a different representation of this image. He perceived the image as:

> Two people talking. They’re different heights… it is a weird image, it reminds you of how some people – like everybody looks different – no two people are the same, which is kind of what that shows.

Jim did not mention the ‘black and white’ concept; he focused in on the representation of people talking and that they are different heights. This led him to describe the image as ‘weird,’ although is not clear how this connection was made and whether it linked to his individual experiences in life or his observation of others. He again connected the image with difference, perhaps linking back to his conversation about the difference between autistic and neurotypical people (for example, his Apple iPhone analogy). It may be that he was also challenging the stereotype that no two people are the same, regardless of a shared diagnosis of autism.

Sarah, another student, initially linked this photograph to NAPLAN testing. In Australia, the NAPLAN tests are the National Assessment Program – Literacy and Numeracy (NAPLAN) tests, which are a series of basic skills tests administered annually to Australian primary and early secondary school students. These standardised tests assess students’ reading, writing, language, and numeracy, and are administered by the Australian Curriculum, Assessment and Reporting Authority (ACARA). The annual NAPLAN tests are a way that student learning is nationally regulated. Sarah may have linked these images to NAPLAN due to the image looking like a test item or puzzle to be solved. The NAPLAN report sent to families with the students' results has similar looking graphs so maybe that is part of her association with the image?

> This reminds me of the NAPLAN really specifically. I know that's really specific. I was really good at reading. And I know there's the connotation that some people with autism have particular struggles or particular strengths with one or another thing.

For Sarah, this image generated a very specific and personal link and for others it may be difficult to make sense of her response as there is limited awareness to why this proved significant to Sarah. It may be that she had recently sat the test or that the media was reporting on outcomes of the NAPLAN assessment (which they do in a large-scale way). The response is far from a literal description of the picture which was presented by Tom, and it indicates her lateral thinking capacities. However, it is important to note she challenged again the preconceived notion that autistic students are either very good or very poor at things. Her reference to the 'spectrum' model indicates that Sarah is also aware of the many generalisations made about autism. The view that autistic people have extraordinary strengths, or in some cases 'superpowers' is regularly promoted in the media and continues to be of influence in many people's conceptualisations of autism.

One other person in the adult focus group, James, made a brief comment about the image following Tom's comments. He said, 'it gives me an abstract of face-blindness.' Face-blindness, known as *prosopagnosia* in the literature, is characterised by a difficulty recognising faces, particularly when out of context, and is cited by Minio-Paluello et al.., (2020) as prevalent in autistic individuals. This experience is often mentioned by autistic adults, with concerns that their difficulties recognising faces are often judged by others as rude, without any understanding of the challenges it can present. The concept of face-blindness does not appear to be well understood or recognised by the wider community, and it certainly doesn't hold the status of 'black and white' thinking in autism popular culture. This example suggests that autistic adults still lack a voice in challenging some of the representation in autism popular culture, while less commonly understood issues that may expand on people's conceptualisation of autism are overlooked.

While all the photo images presented to the participants were in black and white, the abstract face images generated a specific focus on the concept of 'black and white thinking' as representing autism from the educators' point of view, whereas the students in both their literal and lateral thinking responses did not connect with the 'black and white thinking' generalisations. The 'black and white thinking' generalisation from multiple contributors to this autism popular culture concept reproduces the notion of a 'spectrum model' of autism.

As Sarah suggested, this model promotes the view that autistic people have either great strengths or great weaknesses. The educators appeared to adhere to this model, while the students recognised their difference from neurotypical people but did not appear to accept the ‘spectrum model.’ As Jim stated, ‘no two people are the same’. It also highlights, that educators and students, once again brought different representations to the same image, indicating that they were not ‘on the same track’ in their conceptions of autism.

4.2.3 Photograph of a shoreline

The photo image of a shoreline (Figure 4.3) was selected by only two educators, so there was no opportunity to compare similarities and differences between the views of educators and the autistic students and adults. However, the educators brought quite different perspectives to their selection of the image, which indicated varying factors of influence, such as their professional experience and educator identities, on their conceptualising

Figure 4. 3 Photograph of a shoreline

One teacher, Sylvia, reflected on the image as, ‘this to me is about a divide in the way that people with autism are perceived, and that often we sit on two sides of a fence.’ The other teacher that selected this image, Mary, said she chose the photo because it ‘is how I would really like it to be’:

> You know peaceful…that is how I would love it. It’s not determined, you can see things melding in with each other and it’s not a straight line you know it’s got the wiggly, I don’t know whether it’s the coastline or whatever? That is how I would like it to be for families, for the kids, for the staff at school, but I don’t think it ever will be for staff.

The variations in the two educators’ perspectives presents an important example of seeing the same thing, but in quite different ways. Even though both share a similar professional role and work within school-based cultures, their lived experiences and interaction with autistic students, adults, families, professional learning, and the media all influenced how they filter and respond to events and information. Sylvia suggested the wider community holds diverse perspectives about autistic students and people that creates a potential divide between understanding and actions. Potentially, Sylvia has experienced different professional opinions about the best ways to support a student or she is aware of differences in opinions between autism advocates, families, and educators' beliefs, noting it can be difficult to find common ground. While the divide presents a disappointing view about current educational settings, it is very important to acknowledge this perspective as it certainly indicates there is a still a long way to go until all are 'on the same track.'

Mary's comments reflect an aspirational view to find a way in which everyone works together in harmony, melding their knowledge and skills together to achieve the best outcomes for students and families. However, her final comments are reflective of Sylvia's notion that all is not well in educational settings. Mary has no expectation for educators to achieve a sense of harmony in their work but it is not clear whether this arises from school-based conditions, working with families or even policy demands. Understanding the barriers to more effective outcomes for all were explored in more detail in the semi-structured interviews, with further exploration of themes presented in Chapter Five.

4.2.4 Photograph of sand drawing

The photograph of an abstract pattern in the sand (Figure 4.4) was chosen by two teachers, Sylvia and Rose.

Figure 4. 4 Photograph of sand drawing

Sylvia said of this image:

> This one is about confusion, and maybe about pathways, about the way we think. The way our young people and even adults on the spectrum think. They are trying to find the right way through things and sometimes things are really confused.

There was a sense from her description that Sylvia felt that autistic people were trying to find their way, and there was a warmth in her reference to ‘our young people.’ Her description of the sand pathways as ‘confused’ reinforced the perception that autism is a disorder. This was similar to her description of the train tracks (Figure 4.1), which she also described with the word ‘confusion.’

Rose, in responding to this image, also referenced the railway tracks image (Figure 4.1) and its relation to autism: ‘Same with that one there, it is similar to that (train track), they just lose focus, and their thoughts go everywhere’.

Both teachers appear to have deeply held beliefs that autism is associated with ‘confusion.’ They attribute ‘confusion’ to the way autistic students and people think, and there is a difference in their capacity to focus and process information in the way neurotypical people do. Holding the perception that autistic students have ‘confused’ thinking suggests they assume that neurotypical people process information in a linear and efficient way.

4.2.5 Photograph of a person in the shadows

The photograph of the person behind a shadow (Figure 4.5) was the only photograph that presented a more realistic depiction of a person. This image was selected by two teachers and two secondary school students.

Figure 4. 5 Photograph of a person in the shadows

Sylvia, an educator, had a very emotional reaction to this photograph. Her response highlighted the outsider perspective that autistic secondary students don't fit in, and that they are, in her words, 'trying to find their way':

> This image of the man with the shadows across his face, sometimes I think for some of the teenagers I work with it, they see a lot of darkness in their life, they don't see a lot of hope, and it is almost like they are trying to lookout and see a space, that they can find their way. It must be really challenging …. this is really hard for me, I find this really hard I find this really heart breaking (cries).

In contrast Rose, who is also the parent of an autistic child, focused on processing issues and the challenges this can present in classrooms. However, there was a sense of empathy for students in her comments, suggesting she recognised there are many barriers for autistic students in mainstream classrooms. She said:

> … when I look at that, I think, sometimes they are looking and they are just trying to focus so hard, that the images of people just go distorted, they can't stay focused. It all becomes blurry they have lost their train of thought as there is too much information for them to take in, in the classroom.

The two students' responses aligned more closely with Sylvia's experience of teaching adolescents. Bob said of this photo that it reminded him 'that sometimes people don't really understand it, and it (autism) makes you feel isolated.' Wendy added that the photo reminded her of a feeling of being 'isolated and misunderstood.' This feeling of being misunderstood, of being the 'other' is a strong theme that was identified by the teachers as well as the autistic participants in response to this image. In addition, all comments tended to reflect an understanding that school contexts can present many challenges to autistic students, both socially and educationally.

4.2.6. Photograph of tree trunk

The image of the tree trunk (Figure 4.6) was chosen by one teacher and one focus group member, with each describing very different conceptual connections. Jane, an educator, spoke about 'autistic space' as a positive concept, although this concept touched on the stereotypical idea of autistic people 'being in their own world.' In her view, this 'world' is a peaceful and happy place:

> I have chosen the image with the fallen log, or fallen tree, in the paddock. I think that sometimes children are in their own world when they are on the spectrum. You know that is their world and might even see it as a bubble and it looks peaceful. I think sometimes you know when they are in that phase, they are peaceful and generally happy. It just sums up that nice peaceful own world space.

Figure 4. 6 Photograph of tree trunk

However, for Tom, from the adult focus group, it generated a very different response. He said that non-autistic people might see ‘where there’s a bare kind of tree, lifeless almost, dead actually – some people identify with that possibly as ‘all that mental health, lack of life.’ Tom projected how other people might respond to this image, which he did when responding to previous photographs. He considered how others might respond to the pictures, and this is understandable as the original role of the focus group was to comment on the appropriateness of the images for use with other research participants. However, his response indicated that he believes others see autism as aligned to a lack of quality of life, ‘lifeless almost,’ with a link to mental health challenges. These contrasting perspectives and somewhat emotive responses highlight the complexity and diversity of people’s conceptualisations of autism.

4.2.7. Photograph of fern

The photograph of the fern (Figure 4.7) was chosen by three participants: two educators, Mary and Tina, and one student, Sarah. All referred to ‘growth and possibilities’ when discussing this image. Mary, one of the educators, saw the fern in terms of possibilities, and in the context of autism, related it to the fact that prognosis is difficult to predict. She said that she loves to be proved wrong about her autistic students:

> …I picked that one for some of our students, some of the people I know with autism their growth, you can see them turn into these wonderful people and you didn’t think they would ever get there and do things you thought [they] would never do and I love that.

Figure 4. 7 Photograph of fern

Tina talked about the developmental nature of autism and individual trajectories, relating the fern to a pathway along which all people grow and develop:

> This one again with the sameness, as every frond of the fern has to uncurl like that, but they all uncurl at different rates, but they will all eventually get there.

Sarah, responded to the image of the fern in terms of her own growth and development:

> I guess in an abstract sense, this can represent growth. And also, growth in terms of the way I interact with people as I've gotten older.

The three research participants appeared to bring similar conceptual understandings that the development of autistic individuals occurs over time. Sarah was quite specific about her development or growth, focusing on an improved capacity to interact with others. The two educators were less specific about the type of 'growth' that occurs. Both teachers used the words 'get there,' indicating there is somewhere to arrive at or something to achieve, but it is not clear what they believe constitutes successful growth. It is not surprising that the educators were focused on a successful developmental trajectory as this aligned with the professional expectations of their work. Educators are charged with supporting their students' development both academically and socially and clearly both have had experience of observing autistic students achieve positive outcomes. Of interest was Mary's response that she is often surprised that her autistic students turn into 'wonderful people' who achieve things beyond her initial expectations. The concern here is that she had an image of what a 'wonderful person' is, potentially an autistic person that is able to fit in with neurotypical people. Younger students may not be described as 'wonderful' as they haven't yet developed the skills to effectively 'fit in.' Even Sarah's response that her growth is associated with being more effective in her interactions with others suggests that 'fitting in' with the neurotypical world is expected as part of achieving successful outcomes. It is not clear what has been on influence in the development of such a conceptual map relating to growth and success of autistic individuals, but for educators it may be linked to their sense of professional identity. They may consider it their responsibility to help students ‘fit in.’ For Sarah, her sense of identity may also be linked to her capacity to ‘fit in.’

4.2.8. Photograph of robot

The photograph of the robot (Figure 4.8) was chosen by one educator and two autistic students.

Figure 4. 8 Photograph of robot

Tina associated this image to the communication style of autistic students that she has taught. In particular, she connected the image to a perceived flat affect and monotone of autistic students:

> …the number of kids I know, who talk with that robotic sound that monotone. Not that they are robots, but they do have that robotic, you know that monotone sound, sort of thing with their voice. With some of them there is no expression.

Sarah’s description of this image was linked to support at school, some of which is not helpful, or can be confusing. She also linked it to a sense of being controlled or reliant on others:

> This is going to sound bad – because it’s a robot it has negative connotations for me – oh, not necessarily bad, but just even needing support or something. I think that’s a keyboard, with the robot typing – or playing the piano? It reminds me of either getting support, or a child getting support or having child support services; or being told – with their learning – told to do something, not specific, or not

> specific enough, and getting confused and then needing that extra help…. The strings – are kind of like being controlled. Not necessarily in a negative sense, but even seeking out support services – like that's kind of like help I guess. That's what the strings remind me of – I don't know why – because it's not like they're attached or anything.

Sarah's response was emotive and clearly connected to her personal experience. She indicated that the image of the robot generated negative connotations for her, and while not directly linking this to other's perception of autism, there appeared to be an awareness that others may view autistic people, including herself, as 'robot-like.' Tina's response is certainly an example of such an association. Such beliefs from others and self-awareness of these associations may have an influence on students' sense of identity development. Sarah's indicated a level of frustration with the type of support she received in the school context. She explicitly referred to the strings in the image, linking these with other people trying to control her, looking over her shoulder all the time, and perhaps linking the robot to a sense of feeling 'programmed' by others.

Jim's description of the image of the robot was more literal. He did not provide a specific description of how that the image related to autism, just that it was a photograph that he liked.

> Old-school robot – automaton… It's like a wind-up robot. And it plays music and stuff. Automaton stuff. No, *Automatone* is a musical instrument. It's an Automatone.

This image selected by three participants generated two responses that clearly aligned with personal experiences of influence to their intentional representations while the third appears to be more closely associated with personal interest suggesting, a reflective representation of autism generated from existing knowledge.

4.2.9. Photograph of empty warehouse

One teacher, two students, and one focus group member chose this image of an empty warehouse (Figure 4.9).

Figure 4. 9 Photograph of empty warehouse

Jane, the educator, described the old warehouse in terms of institutionalisation, barriers, and communication:

> … I have chosen the picture that looks a bit like a jail cell or old warehouse with fences all up and grids. This reminds me of institutions; a long time ago we had a lot of children and adults in institutions with autism. I guess looking in on that, [it] also represents sometimes how they might feel struggle. There is always barriers to what they are trying to get across or communicate or make people try and understand there are usually walls that stand up in the way of getting there all of the time.

Sarah, one of the students, also considered the image in terms of institutionalisation, which for her related specifically to school and special classes (segregated learning):

> This – just reminds me of isolation. So, I guess, if you're thinking about autism – in the past, this is another negative thing…I'm just thinking of connections, personally. Teachers trying to put me into a box, in the sense that they'll – I remember at (NAME of SCHOOL) there used to be a learning centre…they would sort of try to put all the kids that had maybe even a slight disability, together in this one building sometimes. And isolate them from other people; and people talked really badly about the learning centre just because there were obviously negative connotations – anyone who had a disability at (NAME of SCHOOL). So basically, if you went there you would get bullied for it. And I didn't like how the teachers had to box off anyone who had a disability from everyone else just for them to get support. I don't think that was okay. Or even just isolation from other people, because someone has autism.

Focus group participant, Alice, also referenced institutionalisation in relation to this photograph and the Autism Speaks video referenced in Chapter One of the thesis:

> To be honest only one of them makes me think something to do with autism. And, it's not autism itself. It's that one, right there! Just reminded me of all those stories, you know, about autistic people being locked in cages and stuff like that (image of warehouse) …the other thing it reminds me in general, because of the black and white, is that horrible autism video, by 'Autism Speaks'…Hopefully high school students have not seen that if they're autistic.

Jim, the other student, also referenced a sense of isolation from this image, although this had more positive connotations:

> It’s like in one of those abandoned concrete buildings? With the open walls, where people tend to make skate parks and that – that’s what it reminds me of. And a lot of people with autism ride scooters and skateboards.

Both Tina’s and Alice’s responses aligned with reflective representations of autism, drawing on their existing knowledge about historical responses to autistic people. Alice refers directly to the ‘Autism Speaks’ video, indicating its influence on her response. This was the only example in the participants’ initial responses to the word autism and selection of photo images that explicitly referenced a resource external to personal experience, even though there were certainly representations that alluded to the influence of external sources of information.

Sarah’s response was an intentional representation of her personal experience which also aligned with the notion of autism as a disability that resulted in barriers and isolation from others. She also conceptualised that these barriers created or produced generalisations about autistic people that have negative connotations. School-based practices, that some may view as being supportive of autistic students, were viewed by Sarah as producing more stereotypes and potentially leading to the ‘othering’ of autistic students. Jim on the other hand made no reference to school, but rather to skate parks, which he connected to interests of autistic people. This suggested that Jim was also making a generalisation about autistic people, potentially based on his own interests and observations of like-minded people. He did not present the same emotive connections to the image as the other three participants.

4.2.10. Photograph of spider web

This image of the spider web (Figure 4.10) was chosen by one educator and one autistic student. Tina, the educator, referenced that this image brought to mind her observation that autistic people preferred routine and sameness:

> Basically, patterns, routine, there is so much similarity and all that sort of thing in the spider web, it is all the same, which is why I chose this one. People with autism, generally like sameness, routine and all that sort of thing.

Figure 4. 10 Photograph of spider web

As an educator experienced in working with autistic students, this observation was most likely generated from her professional role rather than other sources such as popular media, however the selection of the image indicates the concept of patterns and routine was at the forefront of her thinking. She did note that autistic people ‘generally like sameness,’ suggesting some awareness that this is not always the case, but her selection of the image indicated it is clearly part of her conceptual map.

Jim, the student, in many of his previous responses initially identified elements of the images, for example, the robot and empty warehouse, prior to adding a more abstract connection. In responding the spider web, he went straight to an abstract connection. saying, ‘it reminds me of neurons firing in the brain.’ This response reflected a constructionist representation, similar to his Apple iPhone analogy, and potentially connected to generalisations about the functioning of autistic people’s brains as different from those of neurotypical people.

4.2.11 Photographs of outer space and Indigenous cave drawings

The images of the outer space (Figure 4.11) and Indigenous cave drawings (Figure 4.12) were not selected by any participants. These have still been included below for reference.

Figure 4. 11 Photograph of outer space

Figure 4. 12 Photograph of Indigenous cave drawings

4.3 Summary

This Chapter shared the research participants' initial responses to the word 'autism' and the photographic images they selected as being connected to the conceptions of autism. The participants' responses included reflective, intentional, and constructionist representations (Hall, 2013) of autism. In the initial analysis, these were generated from personal experience, but were also aligned with external influences, including generalisations potentially driven by autism popular media and the commodification of autism. Alice was the only participant to make an explicit reference to an external influence, the ‘Autism Speaks’ video (highlighted in the introduction of this thesis). However, comments such as those relating to ‘black and white thinking’ are unlikely to emerge from educators’ professional roles alone. Whether external influences are consumed and then reinforced by personal experience, or whether personal experience produces a concept that is reinforced by other external representations of autism, is difficult to determine from these initial responses of the participants. There is certainly a sense of interaction between information sources and personal experience reflective of the Circuit of Culture interactions, particularly production, representation, and consumption. The participants responses, although often varied in nature, were reflective of generalisations prevalent in autism popular culture.

The use of the same photo images allowed for some initial inductive analyses of similarities and differences in the participants’ conceptual maps. Several images generated different conceptual maps particularly between the educators and autistic students. Of note was a distinct difference in the way autism was understood as a separate entity to students by the educators, but was viewed as intrinsic to the autistic students. This creates a scenario whereby educators were often focused on characteristics of autism, perpetuated by generalised views, rather than focusing on autistic students as unique individuals. Students were focused on who they were as a total entity, not separate to autism, with one student noting, ‘no two people are the same.’

Other conceptual maps from the participants’ initial responses included a reference to differences between autistic and neurotypical people. This notion of difference was reflected across the participant groups, but educators viewed the differences as challenging and as a barrier to student success, while students viewed their differences as a strength that heightened their capabilities in a range of ways. These differences in conceptual maps require attention and further exploration, as Hall (2013) has explained: without shared conceptual maps, people are at risk of not understanding the cultural norms, beliefs, expectations, and practices of a group in which we share a social space and relationships of importance to success in life.

There was some evidence of similarities in conceptual maps between the three groups. For example, isolation and stigma were referenced by several participants across the groups as closely associated with autism, with many noting that school contexts were often environments that perpetuated isolation and stigma. One educator responded emotionally to the heartbreak she felt for her students ‘trying to find their way,’ while adults also indicated that autism is isolating due to misunderstanding from others. There was also evidence from educators and a student that growth and development was certainly possible for autistic students, but interestingly, this appeared to be associated with ‘fitting in’ to the neurotypical world. Even the student that commented that she had grown in her capacity to interact with others, indicated a greater capacity to ‘fit in.’

The propositions from this Chapter include the pivotal nature of personal experiences of educators’ and autistic students’ representations of autism, noting these experiences occur in relationship with others and are socially constructed in school contexts. However, there is also evidence of external influences, potentially including generalisations from autism popular culture. Historical references to autism were made by two participants but no participant referred to regulations, policy, or legislation as being of influence in their initial responses. There was certainly evidence of reference to identity, both from educators reflecting on their professional roles, and from autistic students reflecting on their conceptions not only of themselves but how others viewed them as well. This capacity to identify how others viewed them contrasts with popular generalisations that autistic individuals lack a capacity to understand others’ thoughts and feelings, (Milton, 2012) as referenced in Chapter Two.

The participants’ initial response to the word ‘autism’ and the set of black and white images provided evidence of the interaction between elements of the Circuit of Culture, but also reflected Hall’s (2012) notion that the language (codes) we use to express meaning and representations is an outcome of our social conventions. These codes are crucial for meaning and representation. They do not exist in nature but are the result of social conventions. These codes are a crucial part of our culture – our shared ‘maps of meaning’ – which we learn and unconsciously internalise as we become members of our culture. This constructionist approach to language thus introduces the symbolic domain of life, where words and things function as signs, into the very heart of social life itself (Hall, p.14).

As noted earlier in the Chapter, Hall indicated that shared conceptual maps are critical to harmony in shared social spaces. He also noted that our conceptual maps are ‘unconsciously internalise[d] as we become members of a culture’ (2012, p.14). However, in reflecting on the outcomes of this Chapter it appears that the educators were internalising conceptual maps about autism from their professional roles and from their school-based work cultures, while the students were internalising conceptual maps both thrust upon them by school-based cultures and from seeking their own autistic identity.

Chapter Five provides a more in-depth exploration of data from the semi-structured interviews, which serves to extend the initial proposition in this chapter. Understandings of autism through word elicitation and photo elicitation were shared openly by the participants. This highlighted the importance of first-hand experience in shaping understandings of autism, and the interconnectedness of factors such as media and interactions with others to socially construct autism.

CHAPTER FIVE: FINDINGS - INFLUENCES ON CONCEPTIONS OF AUTISM

“Representation is the production of the meaning of the concepts in our minds through language. It is the link between concepts and language which enables us to refer to either the ‘real’ world of objects, people or events, or indeed to imaginary worlds of fictional objects, people and events.” *(*Hall, 2013, p.3).

5. 1 Introduction

Chapter Four reported on the findings from the research participants’ initial responses to the word ‘autism,’ and a series of pre-selected photographic images. This process was designed to generate immediate responses, with a view to analysing any similarities and differences between the three participant groups. Chapter Five presents the outcomes of the remainder of the semi-structured interviews, which were designed to provide participants with the opportunity to share more in-depth responses to the semi-structured interview questions (see Appendix Eight, with a specific focus on sources of information that were of influence on their conceptions of autism. These responses were analysed using reflexive thematic analysis (Braun & Clarke, 2006), which has been outlined in more detail in Chapter Three. The thematic analysis was initially completed without consideration of the five Circuit of Culture processes (du Gay, et.al., 1997), but the themes were then reviewed for any alignment to the five areas of representation, production, consumption, identity, and regulation. The focus of much of the data in the previous Chapter connected with the first three Circuit of Culture processes, with a particular focus on representation, however the interviews generated connections to all five areas. In this Chapter, the findings have been presented with the support of specific quotations and data poems. I shared my reasons for using and creating data poems in Chapter Three.

I have specifically chosen not to use individual participants’ names in this chapter as I was seeking to present a more holistic understanding of potential differences between educators’ and autistic students’ and adults’ conceptions of autism. I have also highlighted in bold and italics the initial introduction of the theme generated as an outcome of the analyses processes and as detailed in Table 5.1 in this chapter.5.2 Overview of themes aligned to the Circuit of Culture processes.

In Chapter One, I introduced the Circuit of Culture, and provided examples of factors associated with autism from my personal experience and observations (see page 17). Table 5.1 in this chapter presents themes generated from the reflexive thematic analysis of the data as they align to each of the five processes of the Circuit of Culture. The alignment of the themes to one process alone proved challenging, and this is not surprising, given that du Gay et al, (1997) highlight that the processes are interactive and at times, interdependent. The theme allocation was somewhat reflective of the adage about the ‘chicken or the egg.’ At times it was challenging to determine what was driving participants’ conceptions of autism. This led to the questions: was it the consumption of information through popular culture media and/or professional information driving educators’ conceptions of autism? Or was it their work and learning experience with autistic students that produced specific practices that shaped their understanding of autism? In essence, it was probably a combination of the interactions between the five Circuit of Culture processes. As such, several of the themes have been allocated to two or more processes given. They also generate slightly different foci, depending on the content of the data and the specific process. For example, a diagnosis of autism links specifically to ‘identity’ for some participants, but also to ‘regulation,’ whereby the diagnostic label ‘autistic’ or ‘autism’ provides access to funding and services.

The allocation of the themes was, in part, designed to determine which Circuit of Culture processes featured most, and how, in the participants’ responses. However, it becomes evident through the ongoing reflexive analyses processes and the writing of this chapter of the chapter the allocation of themes across processes didn’t effectively capture the highly interactive and interdependent nature of the five processes. And while the chapter is structured to focus on one process at a time, commencing with Consumption, this is more to do with providing an opportunity to explore in more depth the different themes emerging from the data. The summary section will draw together the findings presented in this chapter in a figure designed to represent the holistic and interdependent relationship between the themes and five processes of the Circuit of Culture (du Gay et al., 1997).

Table 5. 1 Research themes and their alignment to the Circuit of Culture processes

Consumption	Production	Representation	Identity	Regulation
Sources of information Stereotypes of autism Misconceptions Educator development (professional learning) Popular media	Stereotypes of autism Misconceptions Popular media Difference School context Inclusive education	Stereotypes of autism Misconceptions Difference Stigma Popular media	Being labelled autistic/Autism diagnosis Belonging Educator-student relationships Educators' identity School context Isolated Stigma	Being labelled autistic/Autism diagnosis Co-regulation Access to funding and services Role of the National Disability Insurance Scheme (NDIS) School context Inclusive education

5.2 Consumption

One of the aims of this research was to determine influences on different cohorts' conceptions of autism. In seeking to understand these influences for the different groups of research participants, the questions posed to educators, students, and adults varied a little. The autistic adults provided input into the type of questions that should be posed to the students, and while it was deemed suitable to ask educators about information sources of influence this was not appropriate for the students. In essence, it would be akin to asking people how they accessed information about themselves. However, students would be clearly aware of the significant and varied information available for consumption by others, and they were invited to share anything they saw in the media or through their school about autism and their thoughts about this information. The students provided very little reference to anything in the media, however they focused quite specifically on school-based information sharing and their responses to this. Not surprisingly, their responses reflected little about their personal consumption of information sources. However, there was evidence of how production and regulation of information influenced their sense of identity, and therefore themes from the students' responses were aligned with the processes of production, regulation, and identity. As such this section on consumption is mainly informed by the educators' responses.

Educators' responses to ***sources of information*** of relevance drew specifically on a range of professional learning workshops and materials, with comments made about the quality of these. For example, one educator referred to an organisation's professional learning as being a "101" introductory level course, but they appreciated that this group was constantly updating their information and that their resources were evidence-based. Several educators referred to 'Positive Partnerships' (a national government funded professional learning provider), and a popular private provider of professional learning and University courses and qualifications as being of influence on their learning. Of interest, the following two data poems from two different educators highlighted that while they engaged in learning external to the school, this was often not always relevant to their school context. They also described the importance of whole-of-school involvement if autistic students were to be successfully included and supported:

[My] Education is going to influence the way I work with those children.
Graduate Certificate in Autism was excellent
Positive Partnerships course that was very practical
hands on strategies
I wish I had at beginning of my career in autism
I found [private provider] really useful.
Working with students' therapists,
Lots of different courses and individual specialists
helped me to get a better bank of knowledge.
the key, they have to be used consistently
not just in one room
you need the whole entire sub-school working on it
whether you are on yard duty or in the classroom
consistent language and consistent approach
using the lanyard and the flashcards
visual schedules have been invaluable in the classroom
the visual schedules are really important

The second educator also acknowledged the importance of consistency within the school context and highlighted the challenges faced by engaging all staff in 'evidence-based' practices:

I thought I don't know anything
I need to do something to find out
I started my Masters.
I did the Grad Cert in Autism
when you come back from training and development
doesn't really fit in our school
doesn't work doesn't fit in our context,
doesn't fit our kids,
what else can I do?
good having theory underlie what I knew worked.
we have allied health professionals who come in

we have a lot of conversations with them
we work together with them well and that helps.
you just need a small group of supporters
start with them
we work really closely with the ones who seem to get it
then some of the others start to get it.
it's the older people (teachers)
who are the most difficult
get stuck in their ways.
For some teachers the concept of using visuals
you would think we were asking them to teach Japanese
using visuals has always been linked with Special Ed
but actually, it helps every child
why would you not do it?

While both educators acknowledged that engagement with allied health professionals was supportive to their learning, at no stage did these educators mention learning about autism from students themselves or their families. Courses were accepted as formal ***professional learning***, through which evidence-based strategies and theory was accessed, but learning from students, families, and teaching experience was not perceived as a formal information source. The following data poem generated from another educator highlights the value in learning from a colleague who was a parent of an autistic child. The learning here was more focused on the student as a holistic being engaging in life, rather than on specific teaching strategies such as the use of visuals central to the focus in the previous data poems. The sources of information for this educator were captured as:

Various trainings and workshops
biggest influences when I worked over at the Special School
the SSO[3] had a highly autistic son
he used to go to the special school, he now works
seeing how far he has come
what she had done for him
the sort of person that he is,
what she has taught him to do
has made me more aware
what autism is and what it can be like
some parents today will say
oh no my child has autism they can't do this or that
I see some parents who really baby their kids
I just think 'oh you know they are capable of learning so much more'.

This educator's source of information varied from the other two educators' responses, in that the learning was on-site and sustained over time and also involved

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[3] SSO refers to School Services Officers, who are support staff for educators and students either working directly with students or in collaboration with educators to provide additional support for student learning.

authentic experiences and examples. The consumption of information in this way, over time in context, has generated conceptual representations about the capacity of autistic students, as opposed to being more focused on specific approaches to the support of autistic students' learning. Both are important, and an ***educator's identity*** is certainly aligned to responsibility for ensuring pedagogical practices are evidence-based. However, learning from autistic students and families about what works for individual students would seem to be an important information source. Fortunately, many educators did highlight that their understanding of autism has been significantly influenced by their experiences of teaching autistic students. In essence, experience is both consuming information and producing it as well. For example, in the following data poem the educator reflected on learning from her experience and how she produced her practice for others to learn from. She did not specify what she had learnt but indicated that experience had been key to her sense of confidence in re-producing the outcomes of her consumption of knowledge for others to learn from. She presented as an experienced and confident educator but highlighted the value of working in collaboration with families and others to achieve positive outcomes. The data poem captures the interaction of consumption and production of knowledge between groups of people working in a specific context. However, once again, autistic students were not acknowledged as being part of the information sources for educators, but as a problem to be solved.

With experience you get better
I do a lot of work with teachers
I get called in when things go wrong
building capacity of teachers
I felt really ill- equipped myself
I help others to improve their practice
a community of people who understand and can work with our kids
you can't do it all yourself
it's not about you
it is about building capacity
.

Educators, along with students, were asked whether they had noticed anything recently in the media about autism and if so, what were their responses. Media is a significant source of information, and as noted in Chapter Two, the autism industry is rife with both helpful but also sensationalised information about autism, so I was interested to see how educators and autistic students and adults consumed and responded to media-generated information. The following data poem from an educator highlighted various sources of information, noting that some information may be helpful, while other information made her 'cringe.' She challenged the way information is presented in the media, but she is clearly a consumer of ***popular media***, with her final comment referencing the television program, *Atypical*.[4]

Facebook
Autism SA[5] cranks up a lot with autism awareness month
Autism SA is accessing a lot of autism friendly sessions
at Bounce[6], movies, 'BrickAdelaide[7]'
just normal everyday stuff, more practical
everyday life that people like doing
rather than just information.
On the media,
I always just cringe
I say 'they are people'
not just because they have autism
or not because of mental health
they say that they shot someone because they have mental health.
No mental health doesn't mean you shoot people
the way they portrayed
that is the reason.
Have you watched 'Atypical'?

The following, rather lengthy data poem, generated from one of the educator's responses highlights her consumption of information from the television program *The Good Doctor*, and, whether consciously or unconsciously, her perpetuation of autism popular culture generalisations with the unfortunate comparison to one parent's communication style. The educator moved between challenging ***stereotypes of autism***, but then replicated these stereotypes herself in her suggestion that the character of *The Good Doctor* reflected all autistic people with his monotonal voice, refusal to look people in the eye, and dislike of physical contact. This presented an example of how popular media is consumed and may influence people's conceptions of autism.

I watch The Good Doctor because everyone does!
Good Doctor has autism
he doesn't have an intellectual disability
they portray him with amazing skills
Why don't they just portray him as a normal human being
who has autism
who happens to be a doctor?
I don't know?
they portray him
not looking anyone in the eye
not liking to be touched
the way he talks,

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[4] *Atypical* is a comedy drama television series about an autistic teenager who wants to find a romantic partner.
[5] Autism SA is the peak autism association in South Australia
[6] Bounce is an indoor trampoline and adventure play park
[7] BrickAdelaide is an interactive play and Lego® exhibition held in Adelaide that usually runs over a few days

whoever the actor is
he got that down pat
we had a parent
she is quite autistic
she talked to me exactly the same way
she would flick her head
look at me this way and that.
The first thing I thought of was
“wow, you are exactly the same as the ‘Good Doctor’”.
he talks in the monotone voice
he hates people hugging and touching him
those aspects they have got down pat
why make a big deal of him being a genius doctor?

Of interest, in this educator’s response, is also evidence of how the creators of *The Good Doctor* are making use of an autistic character as a product. *The Good Doctor* is a product that is consumed by the public, including educators and autistic people. The proliferation of movies and television programs featuring autistic people or characters is consumed in a variety of ways. For example, ‘Julia’ in *Sesame Street*, not only features in television episodes but is available to purchase as a plush toy and as a character in *Sesame Street* children’s books, such as *Celebrate You, Celebrate Me!* (2017), *The Runaway Egg* (2018) and *Family Forever: A Julia Storybook* (2018). This could be viewed as positive for young autistic people to see themselves reflected in a character in an internationally renowned television series. This could also be seen as an example of the commodification of autism, and how the consumption of such products reinforces autism in a particular way that in turn influences people’s representations of autism.

Another educator, in responding to the question of information sources of influence, indicated she did not watch a lot of television. However, she referred to Facebook, with particular reference to using the social media platform for seeking information. Like other educators, she commented on some of the quality of information she found on this platform, suggesting it could lead to ***misconceptions*** about autism by the wider public. However, she went on to say she also used Facebook as an ‘outsider’ to understand the challenges faced by parents of autistic children. She indicated this assisted her to be more understanding and empathic. She did not indicate whether families were sharing positive or negative experiences on social media, and it would be interesting to understand why she chose to use Facebook as a source of information rather than speaking to her own students and their families. She may also do this, but she referenced Facebook as a source of information ahead of her students and families. Once again, this may suggest educators don’t view their students and their families as primary sources of information.

I see a bit on Facebook.
I use Facebook not as a social tool
provides insight into parent struggles
what they are finding challenging
nice to see as an outsider
try to improve my practice
be a bit more understanding and empathetic
sometimes derogatory
people put things up
don't have the best understanding of autism
can be quite negative
for someone who is not educated autism
fed that kind of thing off the media or the internet
you could get quite a misconception about autism

Key findings from the educators' responses to information sources of influence on their conceptions of autism included recognition that through social media others are exposed to stereotypes and misconceptions, although in some instances they did not appear to recognise their own continued framing of stereotypes. They valued evidence-based professional learning, which appeared to translate to the use of specific teaching strategies and confidence in teaching others to use these. However, professional learning focused on teaching strategies, and resources may have served to focus educators on responding to 'autism' rather than responding to the individual student. This focus in training and professional development may have unwittingly reinforced the notion that autism is an entity separate from the student.

Educators clearly engaged with popular culture and used this to support their previous conceptualisation of autism or to access new information to shape their professional practices. While educators mentioned parents as being a valuable source of information, at no point did any educator reference students as a primary source of information. This is an important finding which will be addressed in the discussion Chapter Six. Educators' consumption of information about autism involved varied sources and included stereotypes and misconceptions. Some of the information was challenged by the educators, while other served to reinforce existing representations with little evidence of personal reflection on the nature of information being consumed and that they reproduced for others in professional and school-based settings.

5.3 Production

Key themes aligned with production processes include stereotypes, misconceptions, and popular media, which all featured in the previous section on consumption and again in representations. This highlights the interactive, and at times, interdependent nature of the Circuit of Culture processes. The interaction between production, representation, and consumption is clearly evident in popular media, such as the example shared in the previous section about the program, *The Good Doctor*. The example highlights how the production of a character that draws on generalised autistic characteristics serves to reinforce stereotyped representations of autism, for example, gifted or highly intelligent individuals with very poor understanding of social skills and protocols. This representation is then consumed by an often-unquestioning audience, perpetuating generalisations and stereotypes. This circuit of interaction also occurs in many other contexts beyond popular media, although it may not be as explicit as *The Good Doctor* example. In this research, the ***school context*** and ***inclusive education*** were identified as themes of relevance to the production of autism popular culture, with the students themselves often being the product to be consumed and represented by others. In Chapter Four, the issues of 'othering' and 'difference' was evident in participants' responses, and this theme continues in this section.

Students were invited to respond to how autism was discussed in their schools, and while responses indicated that it varied across school contexts, there was evidence that autism was again seen as a separate entity and as a product associated with 'difference.' Students themselves reported feeling different, and this will be discussed in more detail in the section on Identity. Students shared their frustration that schools latched on to autism as an issue or problem, when indeed it was often other things that should have been the primary product of focus. For example, students described bullying as a problem in school settings, and often for reasons other than having autism. The following data poem reflects this frustration:

Autism Talk Day – personally I don't appreciate that
they shouldn't mention 'autism'
like this sort of annoying thing.
once kids hear the word 'autism'
they're like *ohhhh*
I don't think they understand until they're older,
when they're not in the judgmental phase.
better off talking about bullying and acceptance,
better approach than specifically saying 'autism'
they should mention other things that kids may get bullied for,
because an overall accepting community is better for everyone

This student's response indicates that autism is clearly viewed as a product to be understood by other students in the school context, but in doing so with events such as 'Autism Talks Day' (another example of production), autistic students are also viewed as a product with characteristics that are different to others. The student questioned why the focus needs to be on the product of autism as ***difference*** or challenge, rather than the bullying. Schools may believe they are trying to be more supportive of autistic students, but in doing so they are contributing to the creation of autism as a product of difference.

The autistic adults engaged in a discussion about their own schooling experiences and the question of whether to disclose an autism diagnosis. Disclosure of a disability diagnosis is viewed by schools as an opportunity to access additional support, but it can also lead to 'othering' by staff and peers. One adult's data poem captures that complexity:

At Primary School
parents or teachers made the decision
to let the class know about the diagnosis
the child is fine with that at Primary School.
Then they get to High School
don't want to stand out
becomes really difficult.

The concept of disclosing a diagnosis of autism is closely intertwined with autism as a product, something that attracts additional funding and services (regulation), but as indicated in this adult's response something that creates an impact on autistic students' identities. Again, this highlights the interactions between the Circuit of Culture processes, this time being production, regulation, and identity. Being viewed as a product, as also proposed by Autism Industrial Complex theory, will clearly influence one's sense of identity. As the student's data poem noted, people can be judgemental, and during adolescence young people are particularly susceptible to other's opinions, asking questions such as, 'How do I see myself?' and 'How do other people see me?' Autistic students shared that they often reflected on how other people viewed them, and even though the following data poem indicated this student was not concerned what others thought, it identified that the school context produced and reproduced 'othering:'

The popular kids
all are jerks to people
I don't want to be that person
I only want to be myself
be accepted for who I am
not putting on this persona to be popular

This student stated a desire to be accepted for himself, but at the same time acknowledged the option of 'putting on a persona' or masking to achieve greater acceptance from others. School contexts are complex, as they bring together a diverse range of students, usually in contained classrooms with an educator who is charged with supporting students' academic progress and in recent years, their mental health and wellbeing. Collins (2009), in his review of social reproduction theory across decades, suggests that 'social reproduction theory argues that schools are not institutions of equal opportunity but mechanisms for perpetuating social inequalities' (p.33). He goes on to say that social reproduction theory has been contested and was largely abandoned in the late 1990s. However, new approaches which included a greater focus on agency, identity, and the voice of individuals over larger organisations, generated an ongoing call to "understand how social inequality results from the interplay of classrooms, schools and the wider society" (p.33). These comments resonate with the findings from this research, in which the interplay between popular media production of autism and autistic culture, together with interactions between students, and students and educators, each of whom bring varied representations of autism to the school context, serve to create 'othering' of autistic students rather than including them. Of significance is that the autistic students are clearly aware of being viewed by others as different, which also contests the generalisation that autistic students have a lack of awareness of other people's thoughts and feelings proposed in the concept of poor theory of mind. From this research, it is very evident that they are well aware of how other people think about them. And literature suggests that that they are explicitly informed throughout their schooling experience.

The South Australian Department for Education (SA DfE) (2022) advertises its desire to be part of the Autism Friendly Charter,[8] an initiative of Autism SA, to educate schools and businesses about creating inclusive environments for autistic students and people. The SA DfE notes on its website that by signing up to the charter, educators will be more effectively 'equipped with knowledge, principles and support to be truly autism-friendly' (SA DfE, 2022). Autism SA is in the peak body for autism support in South Australia, and the Charter has been created through the support of the National Disability Insurance Scheme funding with a genuine desire to support the autistic community. One might hope that the production of the Charter and its use by public schools in South Australia may go some way to creating schools more inclusive of autistic students as the Charter is implemented in 2023 and beyond Yet, this currently does not seem to be the case from the perspective of either students' or educators' participating at the time in this research. Multiple participants' responses in this research have already highlighted both students' and educators' angst about experiences in the school context. The following series of short poems from educators captures how the members of a school community perpetuate, rather than reduce, social inequality. While these educators may have good intentions in mind, for example, ensuring a student is supported with social skills development so they are more able to 'fit in,' each one of these participants used language that reproduces autism as challenging for others, either

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[8] Details of the Autism Friendly Charter can be located at this site https://autismfriendlycharter.org.au/

through autistic students’ inability to meet mainstream school norms or their parents’ failure to be ‘honest’ about their child’s needs. The message being produced is that schools have a great deal of work to do to help the autistic child fit the school and the wider community. There is little evidence of a consideration of how autistic students could be more effectively included as they are.

If they are socially acceptable
understand the social norms
then everything else is much easier
secondary is easier as they move classes every lesson
not a whole day with the child
some kids with autism cope really well
they love changing classes
gives them that break
If they are not having a great time with that teacher
they know that they only have to last 45 minutes
and she is gone
I wish people would open their minds
special schools are not so prominent anymore
sometimes parents aren’t very truthful
what they disclose about their child
what they say about their child
very different in the school setting

Although the following educators’ poem commenced with a focus on the value of inclusive education to other students in the school, the use of the words ‘compassion’ and ‘empathy’ suggests that inclusive education is this school context is producing an environment in which autistic students are a product to be pitied and shown compassion. This also establishes a power imbalance whereby those providing compassion are generally in a position of power seeking to support others to achieve beyond their current status.

The poem goes on to highlight the benefits for autistic students of a mainstream education, in contrast to a special school setting in which their ‘quirky behaviours’ may be reinforced. The underlying message continues here with a suggestion that parents need to see their children in a different light, and finally, reinforcing the view that an autistic student is a product who can attract more funds to the schools and more staffing, which benefits the child and family. Others may interpret this educators’ response as one of advocating for inclusive education and the benefits for the student and families but in taking a critical lens to the comments through a Circuit of Culture perspective, a significant concern for educators’ capacities to think critically about the use of their language emerges.

Inclusive education teaches other students’
compassion and empathy
students with autism in mainstream school setting
learn better social skills and social rules

what is appropriate and inappropriate
in a special school setting
pick up on other negative behaviours
add to their bank of quirky behaviours
not going to see that as much in mainstream school
it's good for parents to have their eyes opened
huge benefits from inclusive practices
including all children in schools
funding that can be attracted
higher ratio of teacher aides in that classroom
your child is going to benefit from that as well.

It appears that a vortex of production processes occurring within, and beyond schools, even with the best of intentions in mind, still fails to make inroads into autistic students' feelings of being included for who they are, rather than for who they should be within their school context. The focus on autistic students' identity, and identity as a cultural process, will be explored in a future section of this Chapter. However, it appears there are multiple influences that result in educators, often unknowingly, contributing to the production of autism generalisations and stereotypes, and autistic students as products of autism. In the following section on representation, educators' responses appear to come from a genuine desire to challenge these stereotypes and generalisations, but in practice they continue to contribute to the interaction of processes in the Circuit of Culture, thereby continuing the 'othering' of autistic students.

5.4 Representation

Chapter Four focused in detail on the research participants' representations of autism in relation to photographic images, whereas this section serves to summarise key themes from the semi-structured interviews. There is a noticeable overlap in the findings from both Chapters in relation to representations of autism. As noted in Chapter Four, there was diversity in the research participants' interview responses to representations of autism, but all participants commented about stereotypes or referenced stereotypes, generalisations, and/or misconceptions. All participants were clearly aware of stereotypes such as the 'black and white thinking' concept discussed in Chapter Four, and in this Chapter the notions of 'poor social skills' or 'special interests' were also raised. Of interest was how these stereotypes and generalisations developed and were represented by the research participants. What were their sources of information, and how were these consumed and then reproduced or challenged? This section analyses some of the participants' comments for their conscious and unconscious representations of autism prior to reflecting on how these representations developed and varied among participants.

The following phrase, ‘poster kids for autism, they tick every box,’ was used by one of the educators on several occasions, indicating there is a checklist of characteristics that define autistic students. This ***stereotype*** may be linked to the established criteria for diagnosing autism via the DSM-V-TR (American Psychiatric Association, 2022), but it also suggests educators may see the characteristics before seeing the student. For example, another educator said, ‘if you have a special interest in something, or if you see someone whose social skills aren’t that good, it is assumed they must have autism.’ This educator went on to acknowledge that such assumptions are not useful because autism is much more complex than that. However, she also referred specifically to *The Good Doctor* as a reference point that her colleagues used to describe autism. This reference highlights the potential influence of popular culture on educators’ thinking, and while this educator is mindful that stereotypes are problematic, she doesn’t elaborate on how these could be challenged. Without challenging stereotypes, they will continue to be consumed and re-produced.

The following data poem created from an educator’s response to how other educators view autistic students is interesting because it stated that educators think of autistic students as unique and different, but she categorised autistic students as needing visuals and structure. This use of language indicated that there may be unconscious generalisations about autistic students, related to teaching strategy recommendations, rather than a focus on the dispositions of individual students. She also used the term ‘high functioning,’ which is a historical term used to categorise autistic individuals, described in Chapter Two.

When you asked staff
what do you think of our students on the spectrum
they would say
they are all so unique and different
In our school we have those who are very high functioning
they may need visuals and like structure
there are some who struggle with education.

The language educators used in their responses to the research questions reflected an awareness of stereotypes, but either consciously or unconsciously they continued to reproduce stereotypes in their representations of autism. For example, the following data poem from an educator, represented autism as a ‘tragedy,’ as sensationalised by the media, as involving ‘meltdowns’ due to too much noise, and emphasised the importance of ensuring young autistic children are exposed to the ‘real’ world.

We need to stop this idea
‘oh my god he’s, got autism you poor thing’,

no,
not just the sensationalised way they do it in the media.
Yes, this child may have a meltdown in the supermarket
because of the noise
too much for them,
I am going to pick up this child
while they are screaming
take them somewhere quiet until they calm down
then we are going to try it again
don't give up the first time they have a melt down
and then never do it again
do it right from a young age.
the real world is not quiet, dull,
and boring with nothing walls.

This educator was sharing her beliefs about the best way to support young children with autism, and while initially contesting stereotypes she also continued to reproduce them in her representation. This educator presented as confident in her knowledge, noting her vast experience of teaching autistic students. However, there was also a sense of 'power' in her reflections, demonstrating her need to take control of a situation because she believed that she knows what is best.

The educators in this research clearly drew on their experiences of working with autistic students, and this ideally should have assisted them to develop more holistic understandings of their students. However, their representations of autism, described in the previous data poem, reflected an information base that appears to have been influenced by stereotypes, generalisations, and ***misconceptions***. Another educator's reflection suggested that it is *other educators* who have misconceptions about autism, but she continued to represent autistic children as 'being in their own world' and interpreted that 'world' as a 'nice peaceful' space.

There are lot of misconceptions
from an educator's point of view
quickly judge students with autism
'oh, this child is so challenging'
challenging behaviours
challenging but in a nice way
you learn a lot when you work with students with autism
children are in their own world
when they are on the spectrum
their world, a bubble and it looks peaceful
a nice peaceful own world space.

Tom, one of the adults from the focus group, shared his thought on the challenges created by misconceptions. He noted that the scope of misinformation was now so widespread, ‘it’s mind-blowing.’ There is a sense that it is ongoing hard work to try and correct the information bases of others.

A lot of misconception
about what autism is.
even though you might be giving out the right information
people are already coming from
a certain base of understanding
it’s hard work
it’s mind-blowing.

Chapter Four highlighted some of the differences in representations between the educators and autistic students and adults. These differences were also evident in analysing the data poems. Tom was concerned about the quality of information people were consuming when building their understanding of autism, whereas the educators appeared quite confident about their own knowledge bases. They did question their colleagues’ perceptions, and noted some of their misconceptions, but they did not question their own information bases. There is also a notable difference in one of the students’ responses when asked about teachers’ beliefs about autism. Her data poem revealed that teachers make generalisations about autistic students, putting them ‘in a box,’ and this attitude generated a negative view for herself and others.

Autism – in the past
a negative thing
teachers trying to put me into a box
put all the kids that had even a slight disability
together in this one building
isolate them from other people
negative connotations
bullied for it
teachers had to box off anyone who had a disability
for them to get support
not okay
isolation or divisions

This student’s experience of being ‘othered’ for having autism is also linked to feeling more isolated, a theme that will be explored in the section on Identity. However, together with the findings reported in Chapter Four, it is evident that representation processes interact with consumption and production and vary between educators and autistic students and adults. The variations in the research participants’ conceptual maps (Hall,1997) generates an environment whereby educators and students are ‘on different tracks’ and are potentially working at cross purposes.

There appears to be value in educators taking more time to understand their autistic students' lived experiences of school. One of the autistic adults commented that autistic people are often overlooked as a valuable resource of support for both educators and students in schools, stating, 'once schools' cotton onto that, they'll cotton onto a gold mine because we are very productive people.' Of interest, the term 'productive people,' suggests an awareness that others do not view autistic people as 'productive,' again highlighting a flawed representation of autism.

There are multiple examples in this research of autistic students and adults challenging how others represent them. They used the language of other people, demonstrating they are quite capable of understanding other peoples' perspectives, but at the same time they recognised that the representations of autism are now so generalised and reinforced by autism popular culture that they find themselves needing to challenge these, with limited power to do so. In essence, this creates an example of Anderson-Chavarria's (2021) predicament model, with the predicament that autistic people are classified by others and do not have a strong voice to contest these representations. The autistic community is seeking to take back some power and challenge popular autism cultural representations, but it appears from this research that autistic students have limited capacity to achieve this, and clearly this has an impact on their sense of identity.

5.5 Identity

The Circuit of Culture 'identity' process is defined by du Gay et al., (1997) as the lived cultures and experiences that create discourses: in this case, the discourses of autism. In Chapter Two, I described the emergence of autistic culture and the work of autistic self-advocates, which stressed that autism is not just a set of clinical characteristics or deficits, but is a human experience uniquely experienced by autistic people.

Chapter Four shared participants' responses about identity. Autistic students and adults viewed autism as intrinsic to an individual's identity, while educators viewed autism as separate to students. This section explores in more depth how the process of identity reflects not only how autistic students and adults see themselves, but how they think others see them. A key theme of the participants' responses was ***autism diagnosis*** and the decision of whether to disclose this to others. During this chapter pseudonym will not be used, reference to either an educator, student of autistic adult has been used intentionally to further anonymise the data.

Other themes from a focus on identity, and addressed in this section, includes the influence of educators' professional identity on their understanding of ***autistic identity***. Identity is influenced by our social, historical, political, and cultural experiences, but as this research connects with the school context there is a more specific focus on the social interaction and ***relationships*** between educators, autistic students, and other students in the school context. The professional identity of educators appears to shape responses to, and interactions with autistic students, noting how relationships can serve to enhance or undermine an autistic students' sense of identity.

One of the students referred to being autistic as generating negative connotations for her, as she was unaware of what was 'socially acceptable' to others. She went on to acknowledge that she needed to learn how to interact more with others, suggesting she was experiencing some sense of doubt about her identity fitting other's expectations. Such a response indicates she aligned her identity with the need to fit in with others, and through either interacting with others or responding to advice from educators and/or parents, she felt the need to develop her interaction skills in an effort to mask her autistic self. She had yet to value her autistic identity and potential, as she was seeking to 'fit in' with others in the school context.

[Autism]…it has negative connotations.
It does for me
I didn't know what was socially acceptable
I think over time I learned
tried to change the way I interact with people
how to start conversations
I've gotten better.

The same student referred to her beliefs about the ways in which her peers perceived her and other autistic people, and how she perceived other autistic students too. Her comments indicate she was aware of behaviours that could irritate others and she sought to contain these in her interactions, but certainly recognised them in others. Research highlights that autistic people have poor theory of mind: that is, they find it difficult to understand how others are thinking. However, this student, and many of the other autistic participants in this research, showed evidence they understood how others often responded to autistic people. Her response indicated she actively seeks to mask her autistic characteristics to avoid annoying her peers and to create an identity that is accepted by others.

How do they know me?
someone who can get emotional sometimes.
Other than that,

I don’t really think they see many differences from other kids.
Maybe they can find me annoying sometimes
I try not to go on about things for too long
I know that can be annoying
there are some other kids with autism
who tend to go on about stuff
I don’t think she understands
it can be quite irritating.

The autism literature highlights masking as a commonly occurring and exhausting part of many autistic people trying to fit in with societal expectations and norms. One of the autistic adults added, ‘people can hide it pretty well. And I think that’s what people don’t understand. A lot of people hide it or aren’t as obvious.’

The theme of disclosure and identity was raised by a number of participants. One autistic student explained that she was not defined by her diagnosis, ‘autism is only a small part of me,’ and went on to say ‘I wouldn’t want everyone on the street to recognise that I have autism. It’s just unnecessary…. I wouldn’t scream at people – “I’m one! I have autism too!” That’s what it’s like walking down the street and saying, “Hello, nice to meet you. I don’t know you. I know I’m not talking to you, but I HAVE AUTISM.’ The student’s response is interesting in that she has suggested autism is a part of her and while she did not disclose whether she has an opinion about this, she did not see the need to disclose her diagnosis to others. This projects a sense that this student viewed autism as something that is personal to her, and therefore not something that needed to be the focus of attention. In essence, he may have been suggesting that the average person doesn’t introduce themselves in a way that discloses information they don’t wish to share, or that seeks to categorise them. However, there appears to be an expectation that autistic people disclose their diagnosis at the earliest convenience. There also appears to be an increasing use by others of the phrase, ‘I think they may be on the spectrum,’ indicating that personal identity is often aligned to autism rather than to the individual. This issue will be discussed in further detail shortly in this section, in relation to an educator’s response.

The idea of not being defined by autism was explained by one of the autistic adults, who said that “lots of high school students that I’m familiar with don’t accept their autism – they see it as a very negative thing”. This is opposed to many autistic adults who on the contrary state that autism does define who they are, rather than something that they ‘have’ (Bury et a;., 2020). This is not surprising given that adolescents are often focused on developing friendships and creating positive impressions in the school context. As noted in the students’ responses in this research, masking characteristics of non-autistic or ‘neurotypical’ people to fit in was viewed by many autistic students as a necessity. However, masking and trying to fit in is often challenging, given the nature of many school contexts.

One of the students spoke more broadly about the fear associated with difference and identity. He said:

> People are afraid of something or
> someone who is different to them.
> White people were afraid of black people
> because they were different.
> Same with Nazis and Jews.
> Different.
> They were more or less afraid of them.
> People fear the unknown,
> even once known, people still fear.
> It’s human nature.
> People think just because they’re different
> they can treat them like shit.

This student has clearly been treated poorly and ‘othered’ for being different. The complexity for schools and educators is a desire to share information about autism and students’ specific approaches to learning and social interaction, in the hope that more information may reduce ‘fear of the unknown’. However, this can also serve to reinforce autistic identity as different and therefore to be avoided, consequently reducing the opportunity to come to know the student rather than the label assigned to him or her. Again, this creates a predicament for educators, autistic students, and families. For example, what may be appropriate in some situations may not be in another. The important issue is to ensure educators and those in positions of power do not assume what is best for an autistic student without consulting with them first. However, educators’ professional identities are associated with being responsible for students’ growth and development and their accountability to others, including families and education systems, and this often results in them making decisions based on their prior experiences and conceptual understandings of autism. This research highlights how these conceptual understandings often contrast to those of autistic students.

One educator’s reflection on students she has taught suggested that autistic students struggle with a sense of self-worth in a school setting. She personally found this ‘heartbreaking,’ but she did not expand on what she or others in the school context could do to make autistic students feel more hopeful and positive. The school context appeared to work against a sense of pride in an autistic identity.

> Some of the teenagers I work with
> they see a lot of darkness in their life

they don’t see a lot of hope
it is like they are trying to lookout and see a space
find their way
it must be really challenging
I find this really hard
I find this really heart breaking.

A common response generating from the expanded coverage of autism in popular and mainstream media is the concept that we are ‘all on the spectrum.’ This concept dispels or weakens the notion of autistic identity and, not surprisingly, autistic adults have expressed their frustration at this very surface level understanding of the autistic experience. Such generalisations are reflected in two further data poems below that reference the ‘spread’ of autism, suggesting influences of media-driven myth. The first educator questioned the increase in number of autism diagnoses but then indicated a future in which autistic people would outnumber neurotypical people and become the ‘norm.’ Such beliefs reinforce autistic identity as not normal and reflect the need for a more critical stance in understanding the influence of media on conceptions that position autism in such generalised ways.

Some of the kids you see with a diagnosis
you think really?
Where?
In another generation what are we going to end up with?
All those people with autism are going to have kids.
Is society going to shift
in 2 or 3 generations time?
The ones without autism
are going to be the ones who are different
Is autism going to be the norm?

The second educator also presented another generalisation about autism, by suggesting that ‘everyone is autistic in some way.’ While her intention may have been to reduce the ***stigma*** for autistic people, this viewpoint actually fails to acknowledge the unique identity of autistic people. She then suggested that we co-exist in ‘a horrible place,’ that makes life difficult for everyone. In this context, she was not sure how to best assist autistic students, but she felt that perhaps her support was better than nothing. One might question whether these pessimistic beliefs would be helpful to her adolescent autistic students, who are in the process of developing a strong sense of identity as capable young people with the right to a place in the community.

You can see the spectrum in everyone if you look for it
students who have social and communication blockers
the world is such a difficult horrible place
how can I make a difference?
sometimes you feel like you are working alone
it is better than having nobody.

The comment by this educator that she felt she was ‘working alone,’ could refer to limited engagement with others and her observation that her students were not truly included in the school context. She was certainly reflecting on her professional role, and on her need to be more successful in supporting students. However, her conceptualisation of autism and understanding of autistic identity may work against educational practices that could make a positive difference.

The previous three data poems suggest that the educators were aware of the many challenges faced by autistic students in the school context. While it is positive that they understood this, they also expressed a sense of helplessness about what they could do to make a difference. Educators need to be advocates for their students. While it was evident the educators contributing to this research were genuinely committed to supporting autistic students in the school context, their responses often suggested that the quality of relationships between educators and students would benefit from educator take a more reflexive approach, considering how their framing of autism and autistic students reproduced an autistic identity to be pitied and further stigmatised. If educators are framing their students from a ‘pitying’ representation then it is not surprising that autistic students reported feeling different, isolated, and stigmatised in school contexts.

‘Being different’ was a significant theme reported in Chapter Four. For example, students commented: ‘I’m not popular, I’m different’ or ‘You’re an orange, and I’m an apple.’ As discussed in the section on production, inclusive schools are designed to embrace difference and to ensure that all students feel a sense of ***belonging*** within the school context. However, this seems to be far from the case for the participants in this research. The educators and students participating in this research were all from mainstream schools, and while the students presented evidence of feeling ‘different’ within this context, educators reported a sense of frustration about their own professional roles and identities. One educator referenced an interaction with a parent, positioning the parent, who had a goal to move her child to a special school setting, as subversive. The educator appears to be positioning herself in the role of champion of this child and does not acknowledge that the parent may have more knowledge of the child’s capacity or past experiences in education. The data poem captures the complexities of interactions between families, students, and educators, noting the role of identity in decision making and assumptions. Building respectful and genuine relationships between families, students, and educators is paramount to achieving positive outcomes for all.

She hates the idea of him being integrated into a mainstream class

she will say he is a lot lower than that
why are we trying to push him?
Because that is our job
She sees autism as a disability.
I feel like I am not doing my job properly for that child
people who don't value what we do here at school
they almost use us as a babysitting service

Throughout the focus group interviews, the autistic adults also reflected on their interactions with families of autistic children. They expressed a level of frustration with parents or families who had tried to provide information or support their understanding. These reflections focused on parental responses that may have shaped their autistic child's identity, acknowledging that identity is shaped in many ways and many contexts. However, the adults' reflections indicated that they are an underutilised resource in building understanding about autism.

I've had parents say to me
how upset and angry they were
because I was speaking about autism
and their child was *definitely* autistic.
I'm very able to speak for autism – and I said,
I'm only speaking for me;
I'm not speaking for all the autistic people everywhere.
I'm only speaking for me;
I am only speaking from my experience
as well as what the research is showing us.
What you take from that is up to you.
I don't claim for other people.
I do tend to speak for autism and I know I can do that
not just personal experience
family experience, grandkids, my own kids are all on the spectrum.
Very challenging for you – I don't claim that it isn't

Identity as a Circuit of Culture process is complex, with scope for further exploration of the role of families in shaping identity. However, this is beyond the aims of this research, as the focus is more specifically on how educators and autistic students develop their conceptions of autism. These conceptions are clearly influenced by the shaping of autistic identities in the school contexts, with evidence that diagnoses, educators' experiences in teaching autistic students, and their framing of autistic identity, all interact to generate their representations of autism. In addition, the autistic students' experiences in 'inclusive' school settings, and of being ***isolated*** and **stigmatised**, often unconsciously, by educators and peers, generates an identity of feeling ***different***, of not belonging, of needing to mask to fit in. The quality of relationships between educators, students, and families also seems problematic, with many assumptions made without any level of critical reflection by educators about how they are framing autistic students. Rather than supporting students to develop and take pride in their autistic identities, there appears to be a desire for them to be more like other students in the school, as it is assumed that this will make their lives easier.

5.6 Regulation

The final process in the Circuit of Culture, Regulation, can be viewed from two perspectives: 1) external, macro-level regulation, including political and economic influences on individual's perspectives of autism; and 2) regulation as a meso-level process, whereby people interacting with each other regulate behaviours. For example, autistic students masking to fit in with others, or 'othering' of autistic students by educators and peers, which results in autistic students seeing themselves as different. This Chapter will focus in the main on the first perspective, noting the influence of policies and funding on educators' and autistic students' and adults' conceptions of autism. However, the following section provides a brief reflection on the second perspective, highlighting the strong links to identity and its influence on the regulation of autistic identity.

In this research, the interaction between identity and regulation processes highlights how autistic students continue to be positioned as 'different,' even in a school context that is perceived by educators to be inclusive. In essence, the interaction of these processes could be viewed as ***co-regulation**,* whereby the influences of a diagnosis of autism and autism popular culture frames a range of responses from educators, autistic students, and school-based peers. These responses serve to reproduce representations of autism which are evident in actions and language used in the school context. For example, the following response from a student reflects how the interaction between him and an educator generated co-regulation of behaviours. In this example, the student suggested there was no common conceptual maps between the educator and student, with each working against one another to establish control of the issue at hand:

> One teacher in particular likes picking on me
> for the slightest of things
> they think I'm answering back
> I'm just asking a question.
> Like, why?
> Even when I'm not in the wrong.
> I'm not breaking any policies that he thinks I'm breaking.
> He's literally changed the rules that many times
> because I tried to say something's against the rule
> it's not and I pointed it out to him
> he literally went and changed the policy several times
> because I kept on pointing it out

The students' perspective of this scenario suggests his behaviour of contesting the educator's action was driven by the educator's 'unreasonable' behaviour, but he possibly failed to understand how his own behaviour may have been at the heart of the educators' responses. What is evident is an example of the co-regulation of behaviour that occurs in school contexts, subsequently re-producing the autistic student and educator identities. In this case, the identities are in a struggle for power which may have been generated from a previous poor relationship between educator and student, or the meaning each attributed to the other's role and rights. This link between regulation and identity processes is potentially less explicit in the preservation of conceptions of autism by educators, students, and peers alike in the school context.

The quality of ***educator – student relationships*** was explored in the previous section on identity and while it was viewed as important to improved outcomes for autistic students there was little evidence that educators reflected on the issue of co-regulation. There was only implicit reference to how an autistic student might regulate an educator's professional practices but there appeared to be multiple mentions of how educators were required to regulate student's behaviours for the benefit of the student. In essence, this one-sided co-regulation may be an outcome of an educator's sense of professional responsibility, but it could also be linked to the regulations imposed by the ***school context***, regulations which have become more complex with the influence of the National Disability Insurance scheme. The following section focuses more specifically on the influence of macro-level regulations, but educators' responses indicate that these regulations processes are influential to their conceptions of autism as well.

The National Disability Insurance Scheme (NDIS), as introduced in Chapter One, was referenced multiple times throughout the interviews as both a gateway to ***funding and support services***, as well as a source of stress for families. Russo et al., (2020) undertook a systematic literature review regarding parents' experiences of the NDIS and highlighted stress and feelings of overwhelm associated with the NDIS process. This stress on families was acknowledged by the educators indicating their sense of accountability to supporting families in accessing support from a highly regulated authority. The extent of the regulation associated with the ***role of the NDIS*** reinforces the concept of autism as a disability requiring special support and services delivered by professionals beyond the school context. Funding is not designed to support the successful inclusion of autistic students in schools as it is deemed school receive sufficient funding to meet students' needs. However, the proliferation of external 'health-related' professionals now providing services to autistic students in school-based settings suggests schools are no longer capable of meeting the needs of all students all the time. Another perspective on the intersection of NDIS funded services being provided during school times is not the inability of the school professionals to support autistic students, but that parents prefer for the services to occur during the school day to avoid organising out-of-school hour visits to external professionals. Either way, the NDIS, has an influence on both educators and autistic students and their families with the multiple regulations involved contributing to the research participants' conceptions of autism. One educator shared her experience of the increased engagement with external providers:

Before the NDIS you may have the occasional child going out to speech
Now, especially in the junior primary classes
almost every child has either someone coming to see them
or they miss a bit of time
going out to see a therapist
most days someone coming in to see one child or another
they are used to it
they don't bat an eyelid
these classes were built with a space, a quiet room,
speechies and OTs can use
be in line of sight for the teachers

The need for extensive support from external professionals suggests the concept of ***inclusive education*** continues to have gaps in truly meeting the needs of all students. Yet, the responsibility for the child's development and even the monitoring of the provision of that service lies with the educator. These regulations and NDIS driven services appear to reinforce that 'autism' will bring with it increased demands of teachers hence influencing their conceptualisation of autism. Once again, they are viewing autism as separate from the student and in many cases in need of specialised external services. However, of interest, educators did not indicate they used these professionals as a ***source of information***. Indeed, it appears from the following data poem that the educators were the source of information for parents seeking to achieve positive financial packages from NDIS.

In the following paragraphs it is evident that educators, in particular, recognise the role of the NDIS in perpetuating autism as a difference needing special support and attention. The data poem that follows indicates the influence that the NDIS has on an educator's professional observations which add to her beliefs that autism needs funding beyond what schools can offer.

The NDIS is good
great that the Government is funding it
but there are still massive disadvantages
in the way they are doing it.
Huge waiting list
eventually get that support on board
some families have been waiting a year

they finally get their planning meeting
and they don’t know what to ask
or the person doing the plan has no experience at all.
The child ends up missing out
it hasn’t been put in the plan
they need psychological help with behaviour
or specific equipment like sensory blankets
if it’s not in the plan it’s not funded
who is supposed to come up with the money?
Some of students have been having ABA therapy
then the money stops
children still need support.

On educator suggested that since the introduction of the NDIS, there had been an increase in autism diagnoses in order to access NDIS supports. She highlights that the NDIS in raising the nature of its work has created a greater focus on ensuring a ***diagnosis of autism*** to access funding.

National Disability Insurance Scheme
brought a lot more to the surface
NDIS has brought things into the media
Schools thinking,
‘why have we got so many more students with needs? ‘
Parents more active in getting a diagnosis
trying to access funding.
Funding doesn’t directly go through to schools with the NDIS.

An autism diagnosis does not automatically mean access to the NDIS, as access is based on functional impact in a range of life skills. The process of gaining access has been reported as stressful. Another educator commented, ‘It is hard work, and you have to push against so many things, you have to access so many services, and I reckon that is what the NDIS seems like for many of our parents. I have parents come into me and they say ‘I can’t do it, all they will say is no to me again, and I can’t ask another question because they will just say ‘no we can’t do that’.’ This educator response explicitly links the influence of the NDIS on schools and educators with relationships between families and educators extending to trying to support families to access funding.

The increase in disability service providers and professional experts vying for a share of the NDIS funds engages educators as advocates not just for the autistic student and their family but for themselves too. Although NDIS funding is not designed to support school-based education, educators in this research expressed the value of families receiving NDIS funds to support their child. However, to gain maximum funding, the application for the NDIS needs to focus on the problems of the participant. Educators noted a tension for families in completing applications for funding as they had been encouraged to focus on the strengths-based neuro-affirming capacities of their child by educators yet needed to revert to deficit-based language and perspectives if seeking to achieve sufficient funding. As explained by an educator,

Parents don’t want to write anything bad,
as a parent you don’t want to write about
the worst day with your child,
so, they don’t…
then when you read the report you say,
oh, there is nothing wrong with your child.
That is why I get parents to bring it in,
as it is also going to benefit us,
if they don’t get the support then it is hard work for us.
Parents just don’t understand why they need it,
they look at it and say it is an insurance scheme.
Why do I need insurance?
Are they going to die?
Insurance is for your car
your house
your life
not your child.

This data poem, though focusing on regulation processes, also highlights that educators are consumers of NDIS information who seek to maximise benefits for families, autistic students and themselves through producing a representation of the autistic students as in significant needs of additional services to ensure their quality of life. The multiple interactions between the Circuit of Culture processes perpetuates an autism identity and culture of difference that requires sustained support. There is also reference to parents being confused by NDIS language and regulations and with limited awareness of why they need to access such funding. Educators appear very aware of the NDIS as a source of funding while questioning families’ understanding of the organisation. This positions educators as having authority over families and their child which reinforces their sense of expertise in understanding autism and the needs of their autistic students without any critical consultation with families or students. Educators’ knowledge of the NDIS system and processes may result in assisting families to access a funding package that does enhance the lives of the autistic student and their family and while this may generate positive outcomes it can also position the educators as a ‘saviour’ to be listened to as the expert rather than families seeing themselves as the experts. The suggests the NDIS has proved to be a regulatory process that continues to position autistic students and families as needing the support of experts to manage their lives. Educators may not purposefully view themselves as in positions of power but the evidence shared by the participants in this research suggests this may be the case.

In addition to the NDIS, educators in the research also focused on the need for more explicit focus on autism in pre-service teaching degrees and professional learning for qualified educators. Once again, this positions them as experts in the provision of advice for others about autism. While there are multiple regulations for pre-service education degree courses and an expectation that fully qualified educators will engage in regular professional learning, educators in this research suggest this is still not enough to be an effective educator of autistic students. One educator commented:

Teacher training needs more work
in the area of students with autism,
intellectual disability
diversity around student learners
how they learn
still taught as a one size fits all,
it is definitely not a one size fits all.

This educator's use of the phrase 'teacher training' suggests she is referencing a very dated perspective of education in which 'training' was a commonly used word. Quality professional learning and pre-service teacher education has moved well beyond on the concept of 'training' people with one person presented as the expert to 'train' others. The 'educator as expert' identity is evident in this data poem and reinforces a consistent finding of educators identifying as experts, yet without a sense of critical questioning about their beliefs and roles. It may certainly be that graduate and experienced teachers would benefit for a greater focus on knowledge and skills to more successfully include autistic students in mainstream classrooms however, a valuable starting point may be to ensure they see their autistic students and their families as experts they can learn from.

Another educator also commented on the lack of quality preparation of graduate teachers noting the increase in autistic students in mainstream schools. This educator initial blames universities for poor preparation but them shifts blame to families for not being truthful about their child. She finally ends with noting the challenges for educators with the increase of diversity in classrooms. Her response reflects a number of issues associated with regulatory processes but the 'educator as expert' identity is still evident.

When they come out from University
Teachers aren't prepared
what autism is and how to deal with autism
teachers need to be better trained in autism
from a University level
not just in autism
all kinds of kids with different needs and learning styles
a greater focus at University level

there are more and more coming in mainstream schools
special schools are not so prominent anymore
sometimes parents aren't very truthful
what they disclose about their child
what they say about their child is very different in the school setting
not necessarily the parents not revealing the true picture
just different environments, and dynamics.
teachers find it difficult to accommodate the needs of one child in the classroom
when there are 20 others to think about
finding that balance can be quite challenging
extra work involved, extra meetings
teachers get overwhelmed
'Oh, I have so many more meetings'
'I have to do an ILP'
I have got to do this'
there are a few challenges
they can be worked through

The current school context in which there are legal rights for parents to request an inclusive education for their child appears to be compromised from educators' perspectives citing graduate and experienced teacher lack knowledge and skills to effectively include autistic students in their mainstream classroom. However, another educator in this research expressed a belief that education system may be at fault as, "they just don't have the time to go and do extra training". This comment and those above suggest that expert knowledge comes from within individuals or from an external source but certainly not from the autistic student or family.

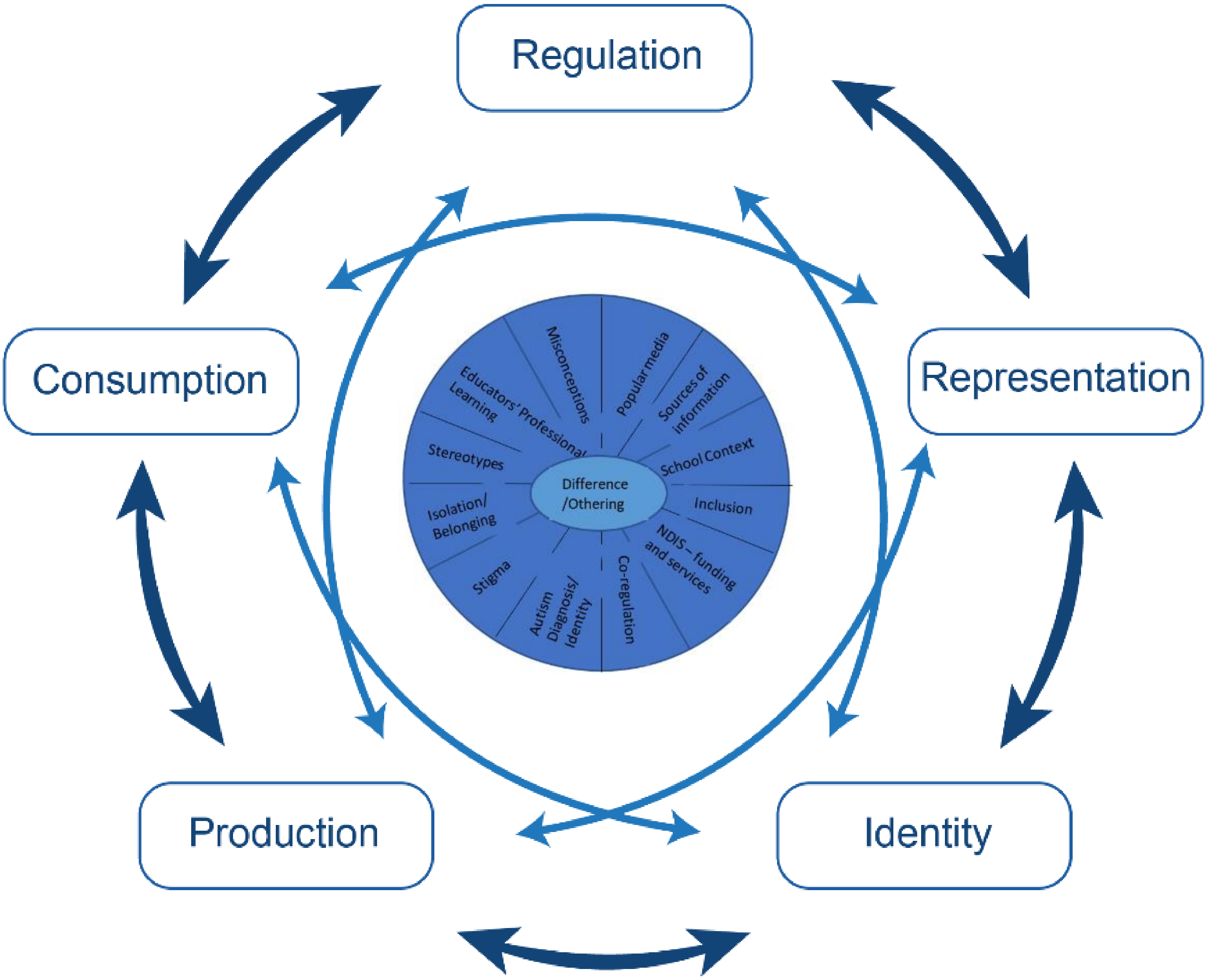
The key foci in this section on regulation was on the NDIS and educators' pre-service qualifications or continued professional learning however, once again, examples of how the five Circuit of Culture processes interacted to reinforce a scenario in which autism is positioned as a difference with the need for expert support and additional funding but in which families and students held very little power in decision making processes, indeed one educator indicated parents could not be trusted in the information they provide. Of importance is the finding that educators' beliefs and practices, and subsequently conceptions of autism, have been explicitly and implicitly influenced by the NDIS.

5.7 Summary

The Circuit of Culture (du Gay et al., 2012) has provided a valuable framework to analyse the research participants' conceptions of autism noting how the five processes interact and are often interdependent. These interaction and interdependencies are at the heart of reinforcing conceptions of autism and subsequently an autism popular culture in which the themes identified in this research all served to create 'othering' of autistic students. Although the themes were initially allocated to one or more of the five Circuit of Culture (du

Gay et al., 2012) processes (see Table 5.1) it became evident that the themes often connected to all five processes. Through these interactions a central theme of difference or othering emerged. The centrality of difference or othering as an outcome of interactions of the themes and five Circuit of Culture processes is represented below in Figure 5.1.

Figure 5. 1 Centrality of difference/othering to research themes and Circuit of Culture processes



The central circle highlights the various themes generated from the research process with difference/othering as a central point. In essence the circle could be viewed as a spinning wheel that reflects different elements of the research participants' conceptions as they align with the five different processes of the Circuit of Culture. However, what remains central is that autistic students are represented as different often by themselves and others. The students in this research were quite accepting of who they were and found being in their home context a safe haven, but it was quite a different matter when in the school context. Multiple factors interacted to perpetuate a scenario of autistic students as being different and othered by peers and educators. Educators also positioned themselves as experts with little evidence of critical reflection on how they developed their conceptions of autism and how these beliefs and practice positioned autistic students in the school context.

The reflection on how to more effectively represent the themes situated within the Circuit of Culture (du Gay et al., 2012) framework and the analogy to a central spinning wheel created ongoing inductive analyses of the outcomes that is taken up in the final discussion chapter. During this stage, I met with an artist to share my reflections on the research outcomes with the aim of generating a pictorial representation of overall outcomes, given the use of visual images and data poems, as a more creative approach to reporting on research outcomes. Chapter Six will revisit the four research questions drawing on findings from Chapter Four and Five and share the visual image that captures my representation of overall outcomes of the research.

CHAPTER SIX DISCUSSION

"'Autopia' - a vision for autistic acceptance and belonging in a future dimension" (Beardon, 2022, p.159)

6.1 Introduction

This research explored educators', autistic students' and adults' conceptions of autism and whether these conceptions varied or aligned. I was particularly interested in whether the commodification of autism influenced how the research participants conceived autism. This chapter will discuss the outcomes of the research and consider the implications of the research findings. The chapter commences with responses to the four research questions and introduces the visual representation of my overall analyses of the research findings and related literature. Key findings to be discussed in more detail in the following sections including the persistent 'othering' of autistic students, particular in the school context. The influence of the autism industry and autism popular culture in perpetuating autism stereotypes and how to authentically include the voices of autistic students, their families and autistic adults in reframing education policies and practices to create more inclusive schools. This could be seen as utopian or as quoted at the beginning of this chapter by Beardon (2022) 'Autopia' meaning acceptance and a sense of belonging for autistic people.

6.2 How do educators and autistic adolescents and adults conceptualise autism and what influences the development of their ideas?

Autism was conceptualised in various ways by the research participants as noted in their responses to the word 'autism' reported in Chapter Four. Common phrases used in response to the word 'autism' included 'different thinking styles', 'neurodiverse', 'complex', 'difficult', 'challenging behaviours', 'repetitive behaviours', 'social difficulties', 'sensory issues', 'visual learners' and holding 'negative connotations. In general, most participants conceptualised autism from a deficit perspective with one educator viewing it as a tragedy for families making use of the word 'heartbreaking.' One student indicated it was just a word but noted that sometimes people take advantage of this. He didn't elaborate how but went on to say, "they don't really understand it". And perhaps this may be at the heart of some of the challenges in conceptions of autism. This is further supported by autobiographical account written by autistic people who describe feeling misunderstood by their non-autistic peers (Jackson, 2002; Peers, 2003). The multiple sources of information available to all through research, popular media, government and non-government agencies and/or lived experiences has created an ‘infodemic’ whereby non-autistic people are influenced by the many generalisations associated with autism.

The educator participants in this research were all highly experienced in working with autistic students and yet there was still a very deficit perspective of autism. While one educator suggested she did not see autism as a ‘true disability’ she went on to say this was because it was not an intellectual disability, “just a different way of thinking.” Educators conceived ‘autism’ as difference and complex even though there was a genuine belief they were knowledgeable and well prepared to include autistic students in their classroom. In a recent study by Devi et al., (2023) gaps in autism knowledge and feelings of unpreparedness were commonly experienced by pre-service teachers as well as well as new graduates working in the field. Commencing an educator-student relationship from a deficit perspective is problematic as it positions the autistic students as needing intervention.

The research identified a range of factors of influence on the research participants’ conceptions of autism. Lived experience was a primary driver of all participants’ conceptions but these lived experiences varied for participants and involved both explicit and implicit influences on representations of autism. For example, educators referred to explicit engagement in professional learning, experience of working with autistic students and families, their work as leaders of other educators’ learning and as advocates for families. These experiences contributed to conceiving autism as difficult and complex. Of interest they did not appear to recognise implicit influences such as the commodification of autism through initiatives such as the NDIS on their conceptions of autism. Chapter Five provided examples of how educators needed to lead families in the development of deficit-based applications to achieve funding and services for their child. Such practices would only serve to reinforce autism as difficult and complex but without critical recognition of its influence on the representation and re-production of autism as a deficit. It was of interest that the educator appeared to be critical consumer of policies such as the NDIS but showed less capacity to be critical examiners of their own discourses when reflecting on autism and autistic students.

Autistic students’ lived experiences in a school context were of influence on their conceptions of autism as difficult and having negative connotations. Students cited being bullied, marginalised and misunderstood. They acknowledged differences in their thinking styles and responses to situations and identified these issues as creating a sense of isolation in the school context. They highlighted the need to mask their autistic characteristics if they wanted to ‘fit in’. However, even though they viewed autism as having negative connotations they also reflected that it was a part of who they were and for some participants they viewed this as an advantage rather than a deficit. The students appeared more focused on micro-and meso-level influences on their conceptions of autism, and this is not surprising given their adolescent ages. However, there were certainly examples of where macro-level external influences were evident. For example, one student commented, “the culture of a school really affects how you learn, some kids are just mean.” School culture could be viewed as both a meso- and macro-level influence.

6.2.1 Tragedy/medical model

Even with a growing focus on a social model of disability, for educators in this research, autism continues to be viewed from a medical model perspective. This is potentially an outcome of their sense of identity as a professional with responsibility for educating their students. However, due to the influence of their teaching experiences they conceive autism as challenging with a need to ‘intervene’ to support the autistic student to ‘fit in’ with others. These dominant themes of challenge and difficulty align with the tragedy and medical models of autism, in which autism is a difficulty to be fixed.

In the photo elicitation of the train tracks these dominant themes were clearly reflected with Martha’s view of autistic brains as a jumbled mess being similar to Jane’s view of autistic minds as confused. Mary talked about her own confusion in understanding autism, whilst Tina talked about her needing to guess what autistic students were thinking and described this as chaos. Sylvia also talked about confusion and a bleakness but that there is hope in the future along the journey. Rose’s thoughts reflected that the tracks could be representative of the sensory challenges provided by the classroom for autistic students.

Experience is clearly a powerful reference point in the development of these educators’ conceptions of autism, and their mental representations appear to be firmly situated within a school-based context. However, it is possible popular media may have been of influence in their responses without explicit recognition of these influences. For example, do television representations displaying the rapid and unusual processing of information such as in the Good Doctor have an implicit influence on the conception that autistic students’ brains represent a ‘jumbled mess’. The concept of black and white thinking was also raised by educators and some of the autistic adults indicating that generalisations about information processing continue to be of influence on educators’ conceptions of autism. While there is evidence that suggests sensory processing of information may vary for some autistic people, and the research participants, both students and adults made comments about their own information processing, linking autism with ‘chaotic’ thinking reflects a myth more than a reality. The ‘reality’ for one of the students in this research indicated his brain was far more efficient, functioning as an ‘iPhone’ as opposed to an ‘android’. Conceptions of brain functioning in this research appears to reflect a popular culture perspective generating an educators’ ‘reality’ that may be quite different to that of their autistic students.

6.2.2 This is who I am

The representations of the six educators varied to a degree however, the educators all used language in way that separated autism from the student, indicating a shared conceptual map that autism was an entity in itself that resided in students and created challenges for them, their families and their educators. This shared conceptual map suggests these educators, all conceived autism as a disability.

On the other hand, the dominant theme from the students was that they were whole beings, with their autism simply a part of them and not a separate entity. However, they did feel othered by the way that they perceived their educators viewed autism and also their own insights into their differences from their peers. There was an awareness from all the students that other people see them as different. There was a sense from three students, Sarah, Bob, and Wendy, that being different was negative, created a sense of stigma, and was linked to experiences of feeling ‘less than’ others. For example, Sarah talked about not wanting to wear an autistic pride t-shirt as she did not want to be identified as ‘one of them’. This stigma may be influenced by educator perceptions of autism as a challenge and difficult (Love et al., 2019) and/or peer perceptions of autistic students as ‘less than’. Campbell (2008, p.155) highlights that from an ableist lens “the existence of disability is tolerated rather than celebrated as a part of human diversification… internalized ableism utilizes a two-pronged strategy, the distancing of disabled people from each other and the emulation by disabled people of ableist norms “.

Jim, in contrast, presented a more confident sense of identity and pride in being autistic. However, all the students referenced themselves as ‘whole beings’ and indicated a shared conceptual map that autism was part of them rather than separate. This is in contrast to the educators’ conceptual map that autism is viewed as separate to the students and potentially the autism is addressed in preference to addressing the individual student. The students however, were clear that they had insights into how they could be best supported and should just be asked what they need.

The research provided much evidence that lived experience was a major influence on the research participants' conceptions of autism but in considering the research findings there was also evidence of other sources of information being of implicit influence too. This draws to mind the research of Anderson-Chavarria's (2021) predicament model in which she challenges the 'spectrum' metaphor of autism, with a recommendation to focus on autistic individuality in preference to fitting individuals along a spectrum and/or making comparisons with standards of 'normal.' The autistic students in this research viewed themselves as unique individuals and were able to discuss their strength and challenges, but they were also keenly aware that others viewed them as different and that these conceptions were often related to generalisations perpetuated in social and mainstream media. They were aware that their teachers viewed them as 'having' autism rather than as a unique individual and that their lived realities were greatly influenced by their educators' conceptions of autism.

6.3 How do the research participants' conceptions of autism vary and/or align in response to the Circuit of Culture processes?

The Circuit of Culture was used to frame and analyse the influences on educators', autistic students' and adults' conceptions and experiences of autism situated within school-based contexts. The participants' concepts of autism both varied and aligned for all of the Circuit of Culture processes, consumption, production, representation, identity and regulation. It was clear that different individuals experienced aspects of the Circuit differently. This was unsurprising given the varying lived experiences of the participants. For example, educators responded from a position of expert and power without a critical lens on how they consumed, represented and reproduced conceptions of autism. Interestingly, the autistic students' lived experiences generated an understanding of how others perceived them noting the influence of autism as difference. Autism as difference was a sustained experience for the students emerging from how peers and educators interacted with them. However, these students were very capable of reflecting on their identity and noting it was quite different from the generalisations of others. The students' appeared to be more critical consumer of representations of autism than educators.

In table 5.1 (p. 131), a summary of themes from the data in relation to the Circuit of Culture was presented. Themes were of relevance across the five processes and an important finding was how these processes interacted in reference to particularly themes.

For example, educator-student relationships, identified as co-regulation, connected to all processes with different elements of co-regulation contributing in different ways. However, as noted in the previous paragraph, central to all themes was the conception of difference and othering. When thinking about why these themes remained central to participants' response I noted that educators' consumption was based on their classroom experiences and the professional learning that they had attended over the years with some media influence, *The Good Doctor* and *Rain Man*. Combined together these sources of information continued to reinforce autism as difference. The students also talked mainly about school-based autism awareness talks and information sharing and their responses to these, with just one of the students referencing the *Good Doctor* and *NCIS*. However, there was also evidence that the language used by both educators and students reflected several elements of autism popular culture and media generalisations, particularly in the photo elicitation responses. This ongoing re-production of difference and othering, as reflected in popular autism culture concepts, whether intentional or unintentional, requires challenging particularly in school-based contexts where such language and beliefs serve to further marginalised autistic students.

The students also noted that school-based autism information sessions represented autism as a separate entity, which educators also supported in their conceptions of autism. The students did not support these representations and identity forming cultural practices but appeared to have little to no voice to contest such conceptions of autism. This may also explain why the educators did not view the students as experts in their own autism, to be consulted or collaborated with. In contrast educators did value parental input and referenced the difficulties of parenting an autistic child. Again, this is an area which should be reviewed with both educators and students as a priority.

The use of the Circuit of Culture to explore the themes generated in this research provided an opportunity to look more closely at alignment or differences in the participants' conceptions of autism and it emerged there were more differences than similarities indicating that educators and students were not on the same track. However, even with variations in conceptions, all participants continued to consume, represent and produce conceptions of autism in such ways that an autism identity of difference was firmly entrenched in ongoing regulation and commodification of autism.

6.4 How do media discourses from autism popular culture and the participants’ conception of autism vary and and/or align?

The main findings were that media discourses were shared by the participants but interpreted differently. The two main media representations were that of socially awkward autistic genius, as in *The Big Bang Theory*, *The Good Doctor*, or severely disabled and a burden, as in *Rain Main.* Educators aligned the media discourses with the medical model and the narratives of acceptance, adjustment and adaptation with the classroom. The idea of autism as a burden can be viewed through the lens of confirmation bias in the classroom with autistic students potentially requiring more support than others.

The autistic students and adults mostly interpreted the media discourses as stereotypes and misconceptions and did not necessarily identify with media representations. One of the autistic students reflected that most people assume that autistic individuals are really good at one thing, but that this was a stereotype that she did not identify with at all. These participants talked about bullying a lot, which is a theme within mass media and social media but not mainstream movies or television shows and was not mentioned by the educators at all, despite being featured in the research literature (Rodriguez et al., 2021). The difference in awareness of the bullying of autistic students may highlight personal experience more than media discourse, but also may hint at the different types of media being consumed by the different groups.

6.4.1 The overarching understandings of the impact of autism in school and in the community.

The educators and autistic participants had quite different understandings of the impact of autism and this was brought to life through the photo elicitation and the data poems. It can be seen through the Circuit of Culture that identity and regulation are aspects of the impact of autism, with educators seeing autism as mostly problematic for all concerned and the autistic participants having quite nuanced views.

These views included problematic experiences such as bullying and being othered as well as more positive and strengths-based views such as valuing their own creativity and skills. The autistic adults suggested that autistic teenagers, like most teenagers just want to fit in with their peers and this may be why they did not talk about the impact of autistic pride and focused more on experiences that excluded them. The autistic individuals all talked about interpersonal relationships being able to make life much better or much worse for them, whereas this wasn’t brought up by the educators at all.

They saw my potential.
They bothered and took time.
I'll forever be grateful
Miss S and Miss G… they were called.
I'll never forget them.
They were just lovely
they gave me an essence of feeling valued
which I didn't get anywhere else at that time in my life

This is interesting in light of the need for positive interpersonal relationships between educators and their students to maximise learning outcomes (Hattie, 2012), and is possibly due to the educators viewing the students as challenging and difficult and needing to learn social skills and how to interact.

This creates a problematic dichotomy where the students feel that they know what supports they need to succeed and want to be asked for their input, but educators do not understand that the autistic students are able to and may have insights into their own support needs. This is likely to lead to frustration for both the educators and the autistic students, which may in turn damage the interpersonal relationship between the two. One of the autistic students summed up a possible end point, which was a teacher 'making my life hell'.

6.5 How do the experiences of educators and autistic students in a school context reflect features of the commodification of autism?

Educators talked about raising money for autism and the need for money to improve the educational outcomes and lives of autistic students, reflecting both the commodification of autism and the tragedy/medical model of autism. These experiences may have supported the confirmation bias around autism being problematic and difficult or challenging in a school context.

Whereas for the students, their school experiences of autism as a stigma, being othered and being bullied reflected the commodification of autism as a condition that is complex and problematic and requires remediation. Students used social media memes to both support and counter these views.

In 2022 in South Australia, as part of the 2022 State election campaign, the Labor Party launched a plan that focused on autism and education, and included the following objectives:

- Investing $17.15 million to appoint an Autism Lead Teacher in every public primary school with clear accountabilities of outcomes;
- Seeking to increase the number of autism-qualified staff in preschools;
- Working with service providers, including Autism SA, to offer early intervention services in children's centres;
- Developing a State Autism Strategy that operates with the State Disability Plan and requires all government agencies to sign up to the Autism Friendly Charter; and
- Investing $50 million to fund 100 additional speech pathologists, occupational therapists, psychologists, and counsellors for access in the public-school system.

In March 2022, the Hon. Peter Malinauskas and the Labor party were successful in winning the State election. In August 2022, the Hon. Emily Bourke was appointed as the State Government's Assistant Minister for Autism. The Government began to deliver on its election commitments to invest $28.8 million for an autism lead teacher in every public primary school. This has already led to an increase of $11.65 million in funding, supporting the idea of autism as a commodity. In contrast, there are no other condition-specific Ministers. There is not a Minister for Down Syndrome, or for heart conditions or diabetes. There is not a Minister for Inclusive Education or Diverse Learners. The focus on autism in this context is deliberate and highly political and involves large sums of money.

This decision to create an Assistant Minister for Autism should be understood in a wider Australian context in which autism has taken a more prominent position, politically and culturally. The National Disability Insurance Scheme funds more than half of its overall funds to autistic people and their families. A National Autism Strategy (NAS) is being developed by the Federal Government in response to lobbying from the Australian Autism Alliance, which is comprised of key autism organisations across Australia. Disability Royal commission has over 5000 submissions many of which were autism-related. The Senate Select Committee on autism published 81 recommendations in total, many of which require funding rather than upskilling or attitudinal change. Even though attitudinal change is a pre-requisite for educators who do not currently value autistic voice nor collaborate with their autistic students, to start to do so.

6.6 Are we on the same track?

In Chapter Three reference was made to an illustration that was developed by artist Dr Amy Hamilton during the data analysis that was designed to synthesise the research findings in a visual representation. The image (see Figure 6.1) is visually busy to illustrate how autism is produced and consumed through the autism industry and autism popular culture. The hand in the bottom left corner represents a mobile phone that is a key to accessing a multitude of website, indeed an ‘infodemic’ about autism. The massive amount of information generates both myth and reality and demands those accessing the information are critical consumers which is not always the case. The participants in this research were explicitly and implicitly influenced by the current autism ‘infodemic’.

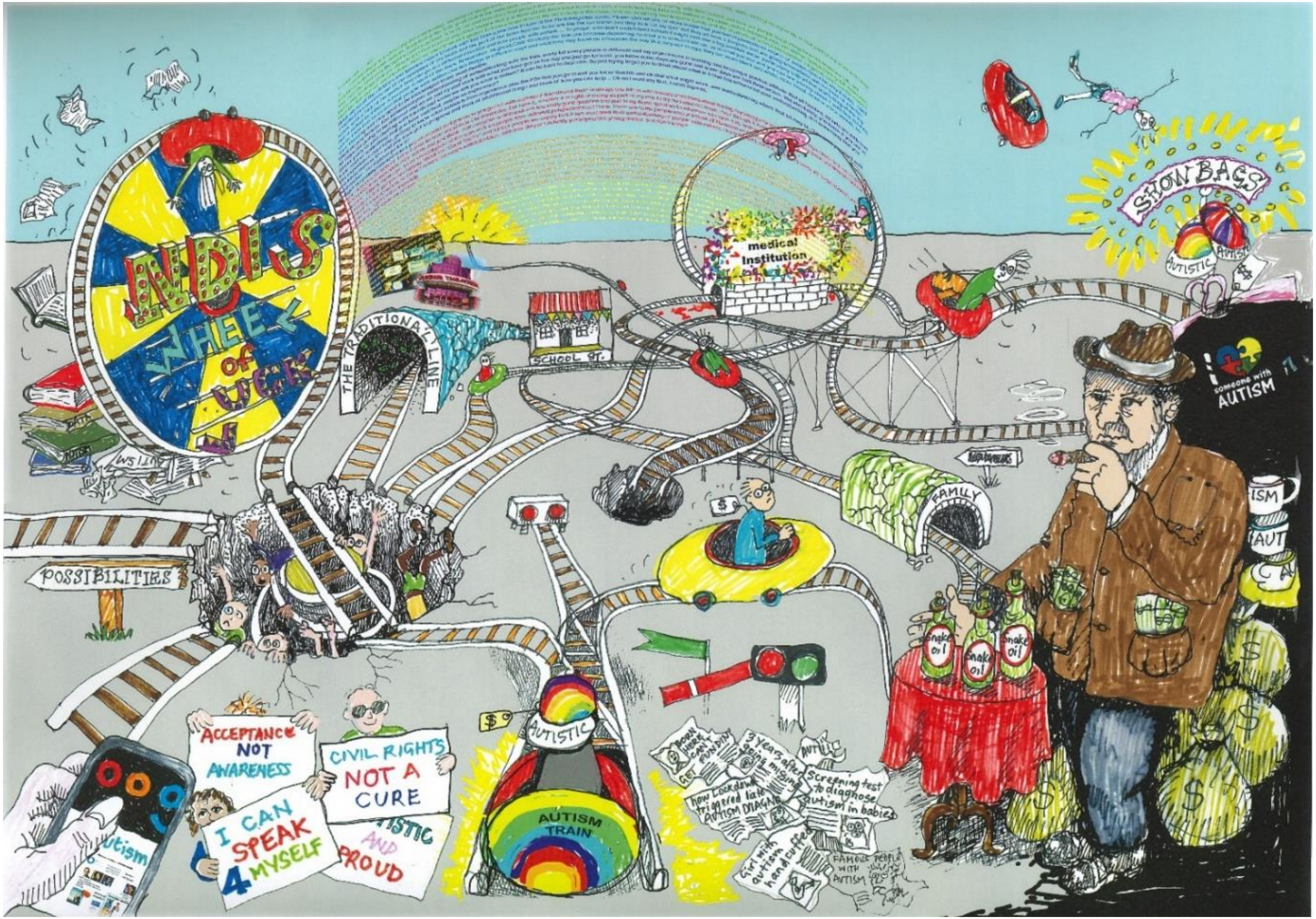
The autistic individual is on the ‘autism train’ and attached to them is a dollar note to depict the commodification and monetary association often reported as a cost or burden on families and government as well as the funding that services can attract to support autistic people. There are the autistic self-advocates advocating, whilst images from newspaper headlines and books about autism are scattered around the tracks, as well as a cinema and billboard referring to autism. The autism train can go in many directions, a rickety turnstile can take the person towards possibilities, or they can fall through the cracks. There are tunnels that represent traditional, medical and family influences that impact the autistic person. The NDIS ‘wheel of luck’ represents that experiences for families and autistic young people are unpredictable. Luck is central to outcomes that can either positive or negatively impact quality of life and sense of identity.

On the right hand-side of the image there is a man selling ‘snake oil’ which is designed to represents questionable therapies and false promises. He is also selling autism t-shirts, mugs, hats and autism ‘showbags’ that represent the commodification of autism and the broader autism industry. In the distance the words and stories from autistic people create the rainbow that depicts diversity, positivity and hope for a better future. Of note some of the autistic people remain on the tracks and others are flung off or fall through the cracks, whilst others remain on the track for a brighter future or other possibilities. I encourage the reader to reflect on what you see in the image and question whether we all on the same track? The implications of not being on the same track or having the same conceptual map create a foundation for continuing to conduct ‘business as normal’ in schools and contribute to creating an autism culture that appears to be more interested in the generation of money than in outcomes for autistic people.

My research findings suggests that educators and autistic students and autistic adults are not yet on the same track, with divergent and opposing views and understandings in several areas including conceptions that autism exists as a separate entity to the student while autistic student see themselves as whole individual, that autistic students need to fit in with others while autistic students would prefer to be accepted for who they are, that autistic students don’t have an understanding of the type of support they would benefit from in schools while autistic students are keen to provide information about their learning preferences. Such variations in conceptual maps would benefit from further research with a larger group of educators and students as it appears an important finding of this research that could be addressed in professional learning opportunities, in particular those that prioritise the inclusion of autistic students’ voices.

As reported in the Senate Select Committee on Autism (2022), some teacher supports for autistic students may be unhelpful rather than helpful, such as having a teacher aide full-time for an autistic student who doesn’t actually want an adult by their side all day. However, educators do learn from experience and this is complicated by the fact that no two autistic students are the same, confirmed by the student participants. The educators did say they want to learn and do their best by their students; however, this can also be contrasted with one of the teacher’s suggestion that her school is attracting ‘too many’ autistic students because they ‘do it too well’ and that this is starting to upset other educators and potentially families as overall NAPLAN and SACE scores may drop.

This research found that educators are still using the medical and/or tragedy model of autism whereas their students and autistic adults are more likely to be using a neurodiversity paradigm, seeing their strengths and supports needs whilst still being aware of their differences from non-autistic people.


NDIS
WHEEL of LUCK
DATA
AUTISM
POSSIBILITIES
THE TRADITIONAL LINE
SCHOOL ST.
medical Institution
SHOW BAGS
AUTISTIC
AUTISM
$
FAMILY
someone with AUTISM
ISM
AUT
Snake oil
Snake oil
Snake oil
$
AUTISTIC
AUTISM TRAIN
ACCEPTANCE NOT AWARENESS
CIVIL RIGHTS NOT A CURE
I CAN SPEAK 4 MYSELF
AUTISTIC AND PROUD
Autism
BORN HERE, CAN'T GET FUNDING
3 Years after going missing
AUT
Screening test to diagnose autism in babies
how Lockdown triggered late AUTISM DIAGNO
Girl with autism handcuffed
FAMOUS PEOPLE WITH AUTISM

6.7 Limitations of this research

With a small sample size, it is difficult to know how much of the findings are more widely applicable and the research would need to be replicated with a much larger sample size to extend on these original findings. It may also be useful to include family perspectives in future research as this would provide an opportunity to understand family's conceptions of autism and how they varied or were similar to their child and/or their educators.

Another limitation is that the educators and students were not from the same schools, so this meant that I could not directly see if attitudes from one directly impacted the other. However, it also meant that all participants felt more comfortable to express themselves openly.

Future research should also include a greater diversity of autistic students, including those who are non-verbal or have an intellectual disability. However, participants in this research were self-selected through a parent group and no-one with additional needs replied to my approach to the parent group. In hindsight, I could have also approached organisations that support autistic young people with complex needs and this would be a valuable inclusion for further research.

6.8 Conclusion:

Educators and autistic individuals of all ages are not yet on the same track, and until they have a shared understanding of the conceptions of autism they are unlikely to achieve positive educational experiences and positive long-term outcomes for autistic students. Supporting educators and autistic students to be more critical consumers of the influences on their current conceptions of autism is recommended along with high quality professional learning for educators that draws on autistic students' voices. Currently the South Australian Government is due to implement their multi-million-dollar autism strategy which includes primary school-based Autism Inclusion Educators. It would seem paramount for educators taking on these roles to ensure they are on the same track as autistic students and their families. The designers of the professional learning to support these educators would do well to highlight the way in which the autism industry plays a significant role both explicitly and implicitly in shaping people's beliefs and conceptions about autism and how educators through their beliefs and practices can continue to perpetuate a medical model of autism.

Role models and mentors for autism tend to be 'created' media representations, such as Sheldon in the Big Bang Theory, rather than individuals living their own realities in a complex world. This can make it difficult for educators to understand the potential of their autistic students and for autistic students to see that they have many varied possible life outcomes. The increase in autistic led autism support organisations in Australia may address some of these issues and further research would be relevant in this area. Using the Autism CRC inclusive practice research guidelines (2016) would ensure that future autism research will be as inclusive and meaningful as possible.

Othering and other exclusionary practices (Graham et al., 2020) are currently barriers to effective inclusion (Done et al., 2021), and were reflected in the comments by the autistic participants, both students and adults. The lack of focus on this by the educators highlights a divergence of thinking about autism and education. Lived experience appears to be is missing in many professional learning offerings and pre-service teacher education, and if autistic people are not visible then how can they be heard. “Right from the start, from the time someone came up with the word ‘autism’, the condition has been judged from the outside, by its appearances, and not from the inside according to how it is experienced” (Williams, 1996, p. 14). Further research is needed into both the concepts of othering, emotional and physical exclusion and their impacts and what is needed for effective inclusion that is accessible to both autistic students and their educators.

The description of clinical features of autism and diagnostic criteria are just words on a page, and yet those words are used to label and, in some ways, limit the perceptions from others about what an autistic person can or can’t do. These criteria help to perpetuate the expectations of autistic students as ‘hard work’ or ‘challenging’ and as a foundation for how we continue to perpetuate an autism culture that appears to be based more on myths than reality. Schools are a critical organisation in our community and in the formation of the young people who will continue to shape our communities. Educators have a role of power within schools and while many would view themselves as advocates for the promotion of greater equality for all, this research highlights that the explicit influence of experiences and implicit influences of autism popular culture has generated a scenario in which young autistic students continue to feel ‘othered’. Adolescence is also a time of significant identity development, so spending this time in an environment in which one’s place in the world is shaped by sustained experiences of being ‘othered’ demands urgent attention from all in the education profession and beyond. As Freia (1998) identified in the publication Pedagogy of Freedom, “One of the most important tasks of critical education practice is to make possible the conditions in which the learners, in their interaction with one another and their teachers, engage in the experience of assuming themselves as social, historical, thinking, communicating, transformative, creation persons; dreamers of possible utopias…” (p.45).

While educators in this research may ‘assume’ this is what they are trying to achieve for their students, from the students’ realities, this is far from the case.

My research reinforces that the way autism is conceived and represented in education matters. The research has found that there is a disconnect between the views of educators and the voices of autistic adolescents and adults. In South Australian schools, autistic students are a cohort that is more often suspended or expelled (Graham et al., 2020), a cohort that is more likely to experience bullying and mental health issues (Lung et al., 2019), and a group of students that is identified by teachers as the most difficult to teach (Jones et al., 2021). This is not acceptable. If autistic students are not understood, and teachers are not equipped with the knowledge (Devi et al., 2023) and support they need to teach autistic students, it can be detrimental for everyone. But if a different approach is taken, and students, teachers and parents are all on the same track together, with a genuinely shared conceptual map, then one would hope for a more respected and positive future for young autistic people.

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APPENDICES

Appendix One: The Autism Speaks commercial I am autism

Transcript was published on the ASAN website https://autisticadvocacy.org/2009/09/horrific-autism-speaks-i-am-autism-ad-transcript/
September 23, 2009 and https://www.youtube.com/watch?v=9UgLnWJFGHQ

I am autism.
I'm visible in your children, but if I can help it, I am invisible to you until it's too late.
I know where you live.
And guess what? I live there too.
I hover around all of you.
I know no colour barrier, no religion, no morality, no currency.
I speak your language fluently.
And with every voice I take away, I acquire yet another language.
I work very quickly.
I work faster than paediatric aids, cancer, and diabetes combined
And if you're happily married, I will make sure that your marriage fails.
Your money will fall into my hands, and I will bankrupt you for my own self-gain.
I don't sleep, so I make sure you don't either.
I will make it virtually impossible for your family to easily attend a temple, birthday party, or public park without a struggle, without embarrassment, without pain.
You have no cure for me.
Your scientists don't have the resources, and I relish their desperation. Your neighbours are happier to pretend that I don't exist—of course, until it's their child.
I am autism. I have no interest in right or wrong. I derive great pleasure out of your loneliness.
I will fight to take away your hope. I will plot to rob you of your children and your dreams. I will make sure that every day you wake up you will cry, wondering who will take care of my child after I die?
And the truth is, I am still winning, and you are scared. And you should be.
I am autism. You ignored me. That was a mistake.
And to autism I say:
I am a father, a mother, a grandparent, a brother, a sister.
We will spend every waking hour trying to weaken you.
We don't need sleep because we will not rest until you do.

Family can be much stronger than autism ever anticipated, and we will not be intimidated by you, nor will the love and strength of my community.

I am a parent riding toward you, and you can push me off this horse time and time again, but I will get up, climb back on, and ride on with the message.

Autism, you forget who we are. You forget who you are dealing with. You forget the spirit of mothers, and daughters, and fathers and sons.

We are Qatar. We are the United Kingdom. We are the United States. We are China. We are Argentina. We are Russia. We are the European Union. We are the United Nations.

We are coming together in all climates. We call on all faiths. We search with technology and voodoo and prayer and herbs and genetic studies and a growing awareness you never anticipated.

We have had challenges, but we are the best when overcoming them. We speak the only language that matters: love for our children.

Our capacity to love is greater than your capacity to overwhelm.

Autism is naïve. You are alone. We are a community of warriors. We have a voice.

You think because some of our children cannot speak, we cannot hear them? That is autism’s weakness.

You think that because my child lives behind a wall, I am afraid to knock it down with my bare hands?

You have not properly been introduced to this community of parents and grandparents, of siblings and friends and schoolteachers and therapists and paediatricians and scientists.

Autism, if you are not scared, you should be.

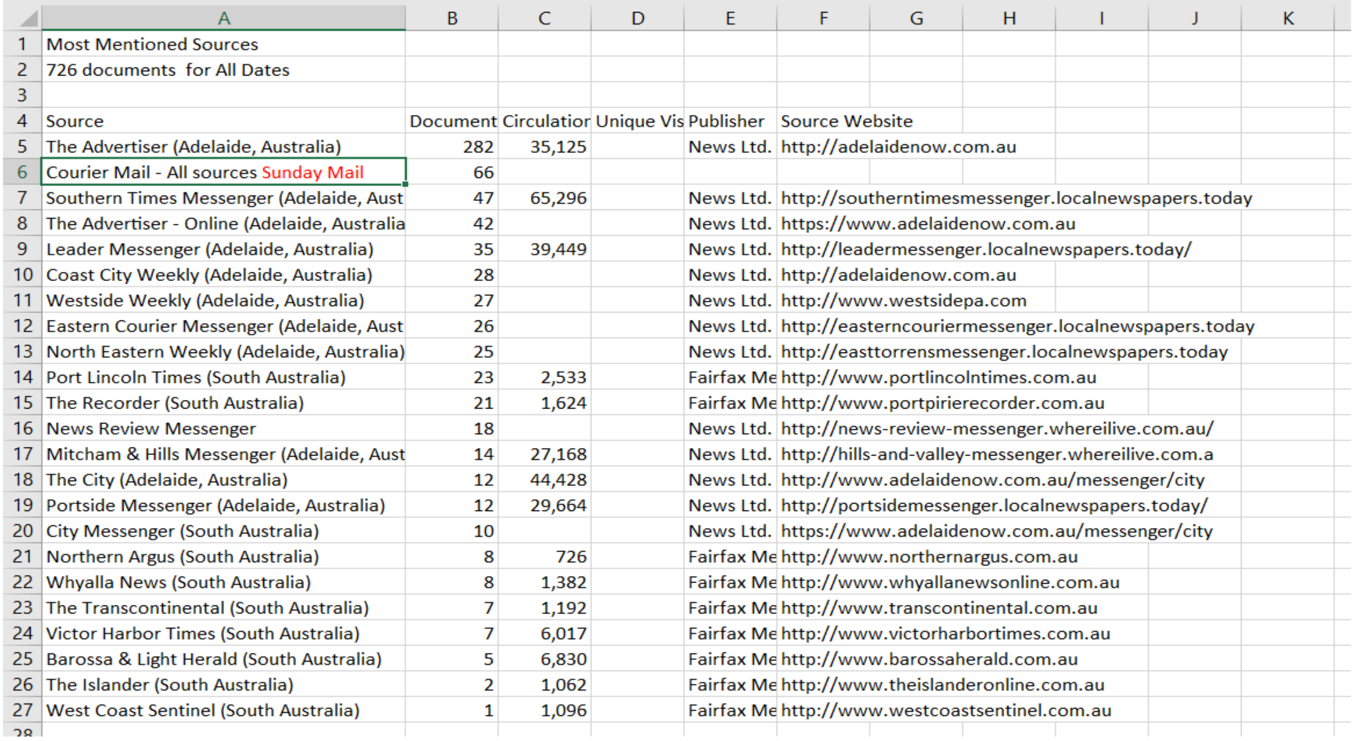
When you came for my child, you forgot: you came for me.

Autism, are you listening?

Appendix Two: Dr Jac den Houting Transcript of TED Talk

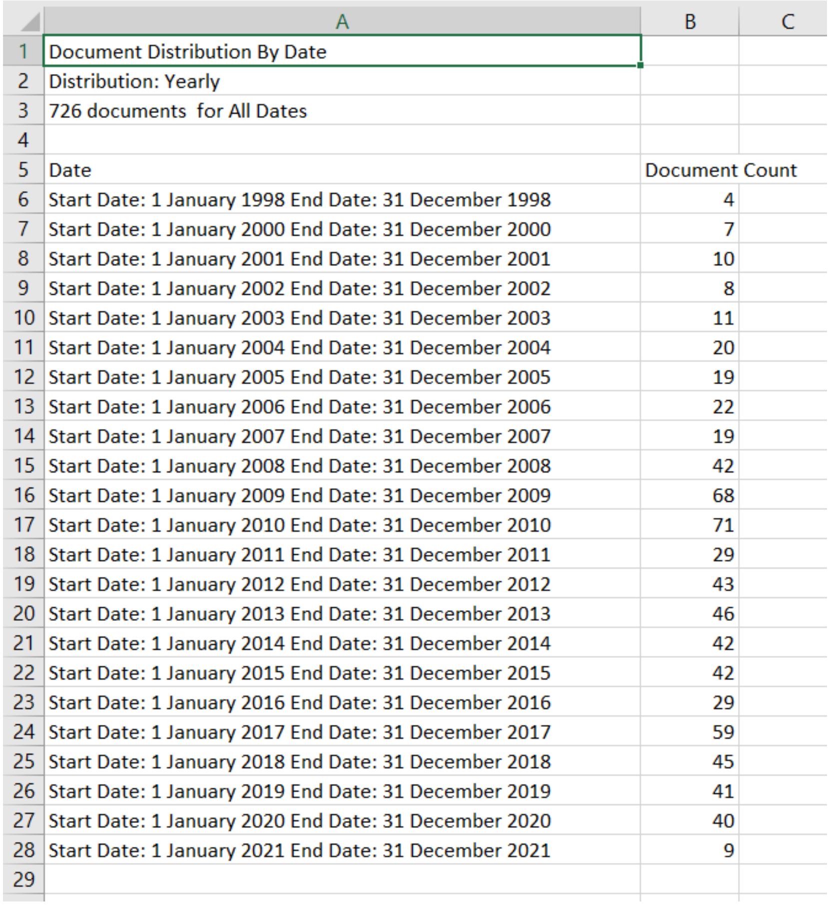
We know that the Earth is round. Everything we understand about this planet is grounded in the fundamental assumption that the Earth is round. But there was a time, not all that long ago, when we knew that the Earth was flat. That's called a paradigm shift. Our basic assumptions about the Earth changed because we had evidence showing that our previous assumptions were wrong. Just like the shape of the Earth, there are assumptions about autism too. Most people understand autism through medical assumptions. They understand autism as a medical condition, a disorder, even as a tragedy. In the medical paradigm, we're taught to believe that there's a correct way to develop neurologically, that there's a right way for our brains to work, the "normal" way, and that any other way of developing is wrong and needs to be treated and fixed. In 2011, when I was 25 years old, I was diagnosed with autism, and it wasn't a tragedy. It was the best thing that's ever happened to me. Finding out that I'm autistic brought me an overwhelming sense of relief. My whole life, up to that point, finally made sense. My paradigm about myself shifted. I wasn't a failed neurotypical person. I was a perfectly good autistic person. After my diagnosis, I did what most of us would probably do, I went to Dr. Google, (Laughter) and I started researching autism. Eventually, I upgraded from Dr. Google. I did my Ph.D. in autism, became a doctor myself, and today, I'm proud to be one of a growing number of openly autistic people working in autism research. But, in those early days, I wasn't running a complex research project, I was just trying to learn more about myself. And learn about myself, I did. I was bombarded with information. I was bombarded with information about my deficits. Autism causes deficits in social interaction, deficits in communication, restricted and repetitive behaviours, sensory processing deficits. For me, that information just didn't make sense. Finding out that I'm autistic had completely changed my life for the better. How could something that was so positive for me be such a bad thing? So, I went back to Dr. Google, but this time I dug deeper. I started to find information about autism that was written, not by researchers or other professionals, but by actual autistic people. I discovered a thing called the "neurodiversity paradigm." The neurodiversity paradigm is an alternative way of thinking about autism. It describes autism as a part of the range of natural variation in human neurological development. At its very simplest, autism is a different way of thinking. Just like biodiversity helps to create a healthy and sustainable physical environment, neurodiversity can help to create a healthy and sustainable cognitive environment. According to the neurodiversity paradigm, there are no right or wrong brains. All forms of neurological development are equally valid and equally valuable. And regardless of what type of brain you've got, all people are entitled to full and equal human rights and to be treated with dignity and respect. Now, that sounds a bit like a panacea, I know. Treating people with dignity and respect ... it just makes sense. You might be surprised, then, to learn that a pretty common way of reacting to this idea is ... "I don't know, I mean, it's alright for you, but it doesn't apply to everybody. What about this person? They're really autistic. They're not just different; they're disabled." Well, maybe you can't tell just by looking at me, but I'm disabled too. I'm not disabled by my autism, though; I'm disabled by my environment. This is another paradigm shift. The way that we're used to thinking about disability is based on a model called the medical model of disability. The medical model assumes that disability is an individual problem. It places disability within the disabled person, within me. For example, I really struggle with shopping malls. They're loud, they're brightly lit, they're unpredictable, they're full of people. The medical model would say that I struggle with shopping malls because there's a problem with the way that my brain processes that input because I'm autistic. But there's another way to think about disability. It's called the "social model of disability." In the social model, disability happens when a person's environment doesn't cater for their individual characteristics. In the social model, we don't refer to people with a disability. Disability isn't something that I carry around like luggage. Instead, we use the word "disabled" as a verb. Disability is something that's being done to me. I'm actively being "dis-abled" by the society around me. When I go to a shopping mall, I don't struggle because there's something wrong with me; I struggle because the shopping mall is designed in a way that doesn't cater to my needs. If we started designing shopping malls that were quiet, dimly lit, predictable, and sparsely populated, well, I'd still be autistic, but I might not be disabled by shopping malls anymore. Almost everything we know about autism stems from research that's based in medical assumptions and the medical paradigm. We spend hundreds of millions of dollars, globally, every year on autism research. And the vast majority of that research conceptualizes autism as a problem. Recently, I conducted a study examining how autism research funding has been invested in Australia over the past 10 years. Here's what I found. More than 40% of funding went to genetic and biological research, trying to find out why autistic people are the way we are and if there's a way to prevent it. Another 20% of funding went to research investigating treatments for autism, most of which are trying to find new ways to make autistic people just act a bit less weird. Only 7% of funding went to research investigating services to help autistic people. Why does this matter? Well, around 1 in 50 people are autistic. About 60% of autistic adults are under- or unemployed. 87% of us have mental illness. Autistic people are nine times more likely than the general population to die by suicide. We have an average life expectancy of just 54 years. And we deserve better. In 2012, an autistic researcher named Dr. Damian Milton proposed a new theory. He called it the "double empathy problem." And what he suggested was this: maybe autistic people don't actually have social deficits. Maybe we just get along better with other people who think like us. Maybe autistic people socialize better with other autistic people and non-autistic people socialize better with other non-autistic people. Maybe the difficulties that we see when autistic and non-autistic people try to socialize aren't because the autistic person has social deficits, but because autistic and non-autistic people are both bad at communicating in ways that make sense to the other. Now, to the autistic community, this made perfect sense. But a lot of autism researchers weren't so keen. I guess maybe they didn't like the idea that the whole history of autism research could be based on flawed assumptions. Luckily, in the last couple of years, a handful of autism researchers have jumped on board with the double empathy problem, and they've decided to test it scientifically. In one brand-new study by Dr. Catherine Crompton from the University of Edinburgh, they did this using a task called a "diffusion chain," which, in Australia, we know by the slightly politically incorrect name of Chinese Whispers. Now, I'm sure you're all familiar with it. You whisper a piece of information around a group of people, one by one, and you try to keep it as accurate as possible. And if you've played, you know that the accuracy part is pretty hard. The first person will whisper a perfectly innocent sentence like, "Today I need to pay my rent and get new tires." But by the last person: "Donald Trump is President, and the world's on fire." (Laughter) Well, in Edinburgh, they played that game with three groups of participants. The first group was all autistic people. The second group was all non-autistic, or neurotypical people. And the third group was a combination of autistic and neurotypical people. The researchers found that the all autistic and all neurotypical groups were equally accurate in their information sharing, but the combined autistic and neurotypical group was significantly less accurate and less clear in their information sharing. That suggests that autistic and non-autistic people communicate equally well. It's the mismatch between those communication styles that causes the problems, exactly as the double empathy problem predicts. We need a paradigm shift in the way that we think about autism. We need to recognize that maybe "acting less weird" is not the best outcome for an autistic person. We need services and supports that will help us to live long, happy, and fulfilling lives while respecting our right to be authentically autistic. And we need the kind of work that I do: research led by autistic people that answers the questions autistic people want answered. Because the Earth is not flat, and I am not a tragedy. Thank you. (Applause)

Appendix Three: Factiva Search-number of articles linked to search terms autism and education.



	A	B	C	D	E	F
1	Most Mentioned Sources					
2	726 documents for All Dates					
3						
4	Source	Document	Circulatior	Unique Vis	Publisher	Source Website
5	The Advertiser (Adelaide, Australia)	282	35,125		News Ltd.	http://adelaidenow.com.au
6	Courier Mail - All sources Sunday Mail	66				
7	Southern Times Messenger (Adelaide, Aust	47	65,296		News Ltd.	http://southerntimesmessenger.localnewspapers.today
8	The Advertiser - Online (Adelaide, Australia	42			News Ltd.	https://www.adelaidenow.com.au
9	Leader Messenger (Adelaide, Australia)	35	39,449		News Ltd.	http://leadermessenger.localnewspapers.today/
10	Coast City Weekly (Adelaide, Australia)	28			News Ltd.	http://adelaidenow.com.au
11	Westside Weekly (Adelaide, Australia)	27			News Ltd.	http://www.westsidepa.com
12	Eastern Courier Messenger (Adelaide, Aust	26			News Ltd.	http://easterncouriermessenger.localnewspapers.today
13	North Eastern Weekly (Adelaide, Australia)	25			News Ltd.	http://easttorrensmessenger.localnewspapers.today
14	Port Lincoln Times (South Australia)	23	2,533		Fairfax Me	http://www.portlincolntimes.com.au
15	The Recorder (South Australia)	21	1,624		Fairfax Me	http://www.portpirierecorder.com.au
16	News Review Messenger	18			News Ltd.	http://news-review-messenger.whereilive.com.au/
17	Mitcham & Hills Messenger (Adelaide, Aust	14	27,168		News Ltd.	http://hills-and-valley-messenger.whereilive.com.a
18	The City (Adelaide, Australia)	12	44,428		News Ltd.	http://www.adelaidenow.com.au/messenger/city
19	Portside Messenger (Adelaide, Australia)	12	29,664		News Ltd.	http://portsidemessenger.localnewspapers.today/
20	City Messenger (South Australia)	10			News Ltd.	https://www.adelaidenow.com.au/messenger/city
21	Northern Argus (South Australia)	8	726		Fairfax Me	http://www.northernargus.com.au
22	Whyalla News (South Australia)	8	1,382		Fairfax Me	http://www.whyallanewsonline.com.au
23	The Transcontinental (South Australia)	7	1,192		Fairfax Me	http://www.transcontinental.com.au
24	Victor Harbor Times (South Australia)	7	6,017		Fairfax Me	http://www.victorharbortimes.com.au
25	Barossa & Light Herald (South Australia)	5	6,830		Fairfax Me	http://www.barossaherald.com.au
26	The Islander (South Australia)	2	1,062		Fairfax Me	http://www.theislanderonline.com.au
27	West Coast Sentinel (South Australia)	1	1,096		Fairfax Me	http://www.westcoastsentinel.com.au

Appendix Four- Factiva Search: Document Distribution by date- 1998-2021



	A	B	C
1	Document Distribution By Date		
2	Distribution: Yearly		
3	726 documents for All Dates		
4			
5	Date	Document Count	
6	Start Date: 1 January 1998 End Date: 31 December 1998	4	
7	Start Date: 1 January 2000 End Date: 31 December 2000	7	
8	Start Date: 1 January 2001 End Date: 31 December 2001	10	
9	Start Date: 1 January 2002 End Date: 31 December 2002	8	
10	Start Date: 1 January 2003 End Date: 31 December 2003	11	
11	Start Date: 1 January 2004 End Date: 31 December 2004	20	
12	Start Date: 1 January 2005 End Date: 31 December 2005	19	
13	Start Date: 1 January 2006 End Date: 31 December 2006	22	
14	Start Date: 1 January 2007 End Date: 31 December 2007	19	
15	Start Date: 1 January 2008 End Date: 31 December 2008	42	
16	Start Date: 1 January 2009 End Date: 31 December 2009	68	
17	Start Date: 1 January 2010 End Date: 31 December 2010	71	
18	Start Date: 1 January 2011 End Date: 31 December 2011	29	
19	Start Date: 1 January 2012 End Date: 31 December 2012	43	
20	Start Date: 1 January 2013 End Date: 31 December 2013	46	
21	Start Date: 1 January 2014 End Date: 31 December 2014	42	
22	Start Date: 1 January 2015 End Date: 31 December 2015	42	
23	Start Date: 1 January 2016 End Date: 31 December 2016	29	
24	Start Date: 1 January 2017 End Date: 31 December 2017	59	
25	Start Date: 1 January 2018 End Date: 31 December 2018	45	
26	Start Date: 1 January 2019 End Date: 31 December 2019	41	
27	Start Date: 1 January 2020 End Date: 31 December 2020	40	
28	Start Date: 1 January 2021 End Date: 31 December 2021	9	
29			

Appendix Five: Example of Information Form

Vanessa Alexander
College of Education, Psychology and Social Work
Sturt Road
Bedford Park SA 5042

GPO Box 2100
Adelaide SA 5001
Tel: 0421 870 506

INFORMATION SHEET

(for *focus group*).

Title: A critical discourse analysis of the dominant representations of autism in education.

Researcher

Ms Vanessa Alexander
College of Education, Psychology and Social Work
Flinders University
Tel: 0421 870 506

Supervisors
Dr Kerry Bissaker
Associate Professor in Education
College of Education, Psychology and Social Work
Flinders University
Tel: 8201 5376

Dr Ben Wadham

Associate Professor in Sociology
College of Education, Psychology and Social Work
Flinders University
Tel: 8201 3358

Description of the study

This study is titled *A critical discourse analysis of the dominant representations of autism in education*. It is a qualitative study involving interviews with teachers, autistic secondary students and a focus group of autistic adults. The study also includes textual analysis of education documents and websites.

Purpose of the study

The purpose of this study is to investigate the ways that autism has been defined, and how these ideas have changed and developed over time to the contemporary field of autism, and are used in the field of education. Furthermore, how these ideas impact on teachers' perspectives about autism, their professional practice and ultimately on autistic subjects lived experience. This project is supported by Flinders University, College of Education, Psychology and Social Work.

What will I be asked to do?

You are invited to attend two focus group meetings. The focus group will have up to 6 autistic adults with the researcher, Vanessa Alexander. The first focus group meeting will discuss the proposed interview process that will be undertaken with autistic secondary students. The second focus group meeting will discuss autism and education. Participation is entirely voluntary. Each focus group will take about 60 minutes. 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.

What benefit will I gain from being involved in this study?

Whilst you will not directly benefit from the study, the sharing of your experiences is valued by the researcher. Your contributions will assist the researcher in their understanding of autism, as well as the design of the questions and process that will be used with autistic students.

Will I be identifiable by being involved in this study?

The nature of focus group means that you will be meeting and discussing information with other group members so you will not be anonymous. However, please be assured that any information provided will be treated with the strictest confidence and none of the focus group members will be identified in the thesis or associated publications. Pseudonyms will be used instead of real names. 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 if I am involved?

Other focus group members may be able to identify your contributions even though they will not be directly attributed to you. The researcher anticipates few risks from your involvement in this study, however, given the nature of the project, some participants could experience emotional discomfort. If any emotional discomfort is experienced please contact *Beyond Blue* on 1300 22 4636 or *Lifeline* on 13 11 14 for support / counselling that may be accessed free of charge. If you have any concerns regarding anticipated or actual risks or discomforts, please raise them with the researcher.

How do I agree to participate?

Participation is voluntary. You may answer ‘no comment’ or refuse to answer any questions, and you are free to withdraw from the focus group at any time without effect or consequences. A consent form accompanies this information sheet. If you agree to participate please read and sign the form. You can bring the signed form with you to the focus group meeting, and copies will also be available at the meeting if you prefer.

Recognition of Contribution / Time / Travel costs

If you would like to participate, in recognition of your contribution and participation time, you will be provided with a $50.00 Coles/Myer voucher for each focus group meeting. This voucher will be provided to you face-to-face on completion of the focus group meeting.

How will I receive feedback?

On project completion, outcomes of the project will be given to all participants via email.

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 in South Australia (Project number 7517). For queries regarding the ethics approval of this project please contact the Executive Officer of the Committee via telephone on +61 8 8201 3116 or email human.researchethics@flinders.edu.au

Appendix Six: Example Letter of Introduction

Flinders
UNIVERSITY

13 October 2019

LETTER OF INTRODUCTION

(for parents / guardians of secondary school children)

Dear Parent/Guardian

I hold the position of Associate Professor in Education at Flinders University. This letter is to introduce Vanessa Alexander who is a Doctor of Education student in the School of Education at Flinders University. She will produce her student card, which carries a photograph, as proof of identity.
She is undertaking research leading to the production of a thesis or other publications on the subject of representation and portrayal of autism in education.

She would like to invite you to assist in this project by consenting to your child completing a semi-structured interview which covers certain aspects of this topic. No more than 60 minutes on one occasion would be required. You are welcome to be present during the interview.

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. Your child is, of course, free to discontinue participation at any time or to decline to answer particular questions. Vanessa intends on making an audio recording of the audio and she will seek your consent as the parent/guardian, as well as the consent from your child on the attached consent form. Further details are in the attached Information Sheet.

Any enquiries you may have concerning this project should be directed to me at the address given above or by telephone on 8201 5376, by fax on 8201 3184 or by email kerry.bissaker@flinders.edu.au

Thank you for your attention and assistance.

Yours sincerely

Dr Kerry Bissaker

Associate Professor of Education

School of Education

Flinders University

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee in South Australia (Project number 7517).
For queries regarding the ethics approval of this project, or to discuss any concerns or complaints, please contact the Executive Officer of the committee via telephone on +61 8 8201 3116 or email human.researchethics@flinders.edu.au

Appendix Seven: Example of Consent Form

Flinders
UNIVERSITY

PARENTAL CONSENT FORM
FOR CHILD PARTICIPATION IN RESEARCH
(by interview)

A critical discourse analysis of the dominant representations of autism in education.

I ....

being over the age of 18 years, hereby consent to participate as requested in the semi-structured interview 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 child's 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:
    - My child may not directly benefit from taking part in this research
    - My child is free to withdraw from the project at any time and is free to decline to answer particular questions
    - While the information gained in this study will be published as explained, my child will not be identified, and individual information will remain confidential
    - My child may ask that the recording/observation be stopped at any time, and he/she may withdraw at any time from the session or the research without disadvantage

6. I understand that only the researchers on this project will have access to my child's research data and raw results; unless I explicitly provide consent for it to be shared with other parties. If the need to seek your consent to share your child's research data with other parties does arise, I will be contacted by the researchers via email.

Parent / Guardian 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: Vanessa Alexander

Researcher's signature…………………. Date…………………………………...

NB: Two signed copies should be obtained (one for researcher; one for parent / guardian).

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee in South Australia (Project number 7517). For queries regarding the ethics approval of this project please contact the Executive Officer of the Committee via telephone on +61 8 8201 3116 or email human.researchethics@flinders.edu.au

Appendix Eight: Research Questions

Educator questions:

1. When I say the word ‘autism’ what is the first feeling, memory or image that comes to mind?
2. Take some time to look at the Photolanguage cards. Please choose one or more image that you feel represents an aspect of autism and describe why it does.
3. What do you believe has influenced your understanding of autism?
4. What are your sources of information about autism?
5. What experiences have shaped your practices with people on the autism spectrum?
6. Have you seen anything recently in the media about autism, if yes what was it?

Student questions

1. When I say the word “autism”, what comes into your mind?
2. Take some time to look at the Photolanguage cards. Please choose one or more image that you feel represents an aspect of autism and describe why it does.
3. Is there anything that you’ve seen recently on TV or social media about autism?
4. What do you think having an autism diagnosis means at school?
5. When you are at school, how do you think the other kids understand you?

Appendix Nine: Phase One: Familiarising oneself with the data. Notes from interviews and focus groups

Teacher 1- Martha

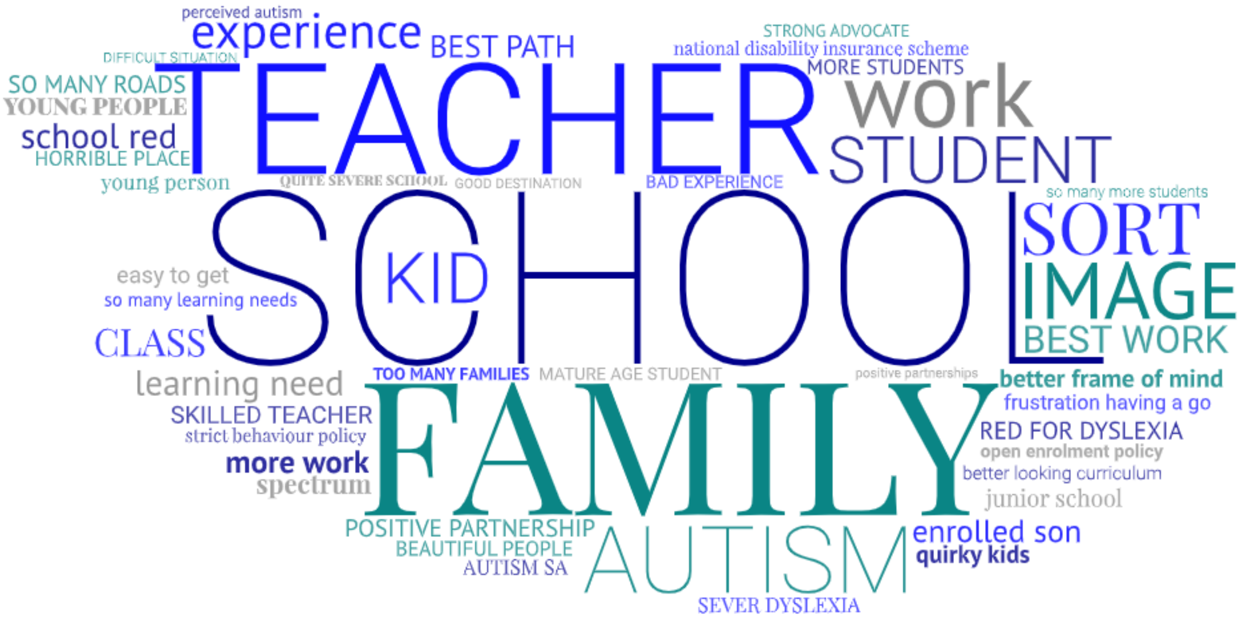
My first interview went well a big focus for Martha was around relationships and getting to know individual students she used a term ‘grinning and bearing it” and also things like “trial and error” so I think for her feeling prepared when she was a new teacher and even along the way was a challenge she talked a lot about training attending professional development sessions as a teacher learning new things along the way and also in her role supporting other teachers referenced a lot of different professionals and websites that she uses she didn't talk specifically about research as such but it was more focused on different ways of learning our information I think in terms of the research she talked a lot about autism from a medical perspective and tended to use language that tended to be othering to young people on the spectrum.

Martha Word Cloud:

Teacher 2 - Sylvia

This interview was very emotional Sylvia cried in a couple of parts she was particularly emotional about adolescence and facing depression during the interview Sylvia disclosed that she has a child with learning difficulties and that when she was studying as a mature age student she was motivated by the experience she's that she's had as a Mum and watching the challenges that her child had experience so to me that really highlights some of the motivation around how personal experiences can then affect the way that you as a professional work with other people's families so she was very emotional about the journey of families that it's a lot there can be many challenges. As a professional Sylvia works in a prestigious private school and hearing a lot about the work that she's done in promoting inclusive practices the importance of positive experiences for students with disabilities so all children can benefit from being together she had lots of ideas around breaking down barriers and some of the things that influences other teachers' conceptions about autism and she didn't refer to the media very much explicitly apart from Facebook.

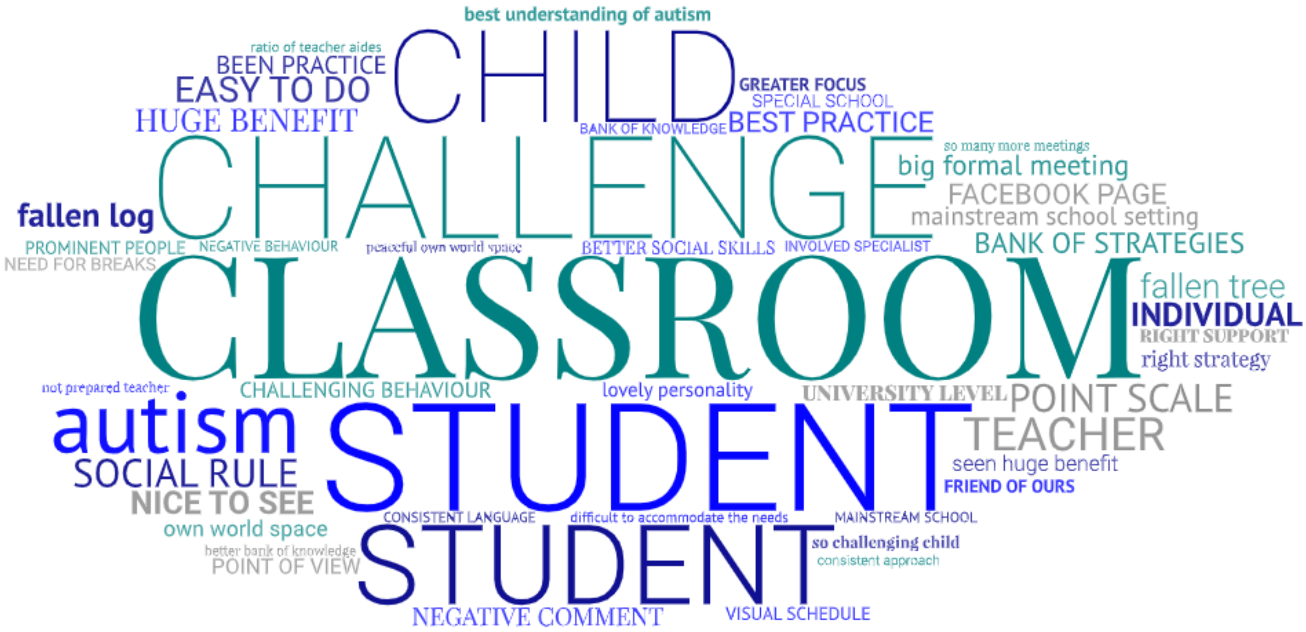
Sylvia Word Cloud:



Teacher 3- Jane

This interview was difficult at times trying to fully understand what the participant meant she gave some examples that related more to programs such as 'Way to A" or using visuals. During the interview she referred to children a lot said that that was her main experience so she always thinks of children when she thinks about the word autism. Some of the examples she shared challenged me by the way that she responded punitively to behavior. She talked about all the teachers at her school thinking that autism equates to challenging behavior and that made me feel sad. This teacher talked a lot about strategies so her approach seemed more focused on outside help e.g., meetings with psychologists. There was less about relationships with the actual student. I found that interesting from the perspective of what she does in her work in terms of media she referenced social media in particular and learning from families posting various things on Facebook. She admitted that sometimes what parents post is quite negative about schools but that can be helpful to look at what hasn't been working so you can try and change your practice to support parents that may be going through a similar experience at school.

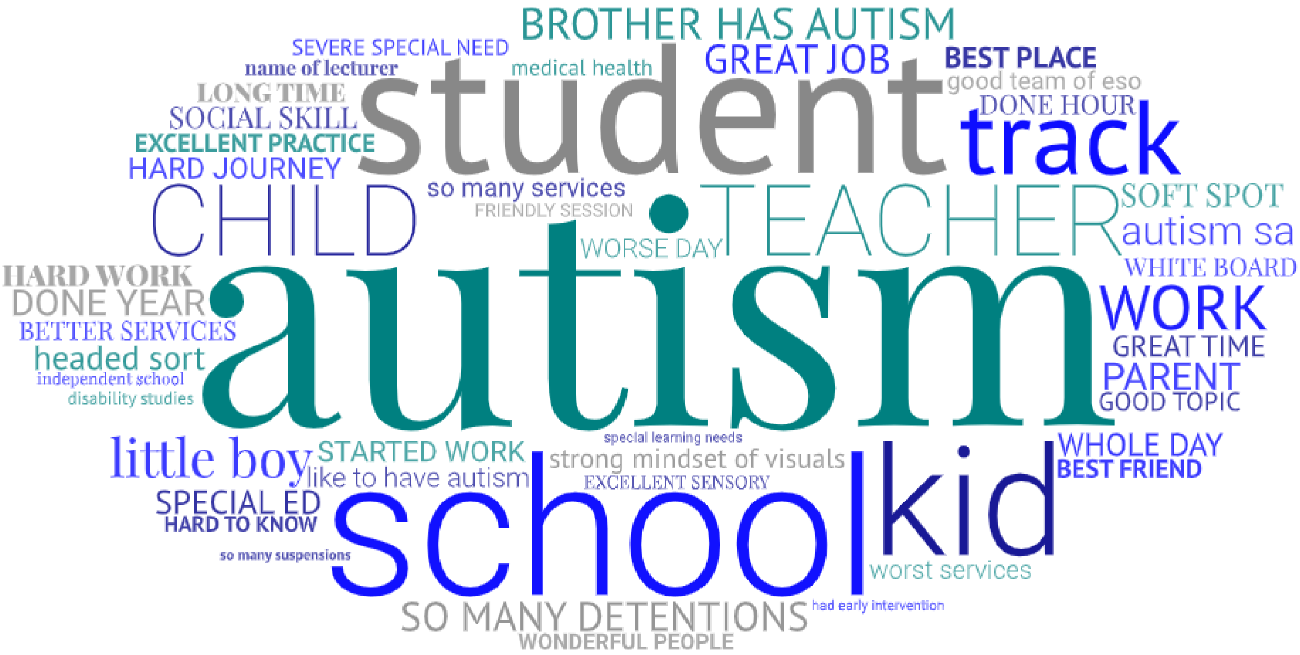
Jane Word Cloud:



Teacher 4 - Mary

Mary talked a lot about the NDIS and that parents don't want to write or report things that are negative about their child, but if you don't put things in a particular way then you won't get funding. She used the example to think of your child having their worst day- what do you see- what would that look like? I understand that as a process but to me there's a tension there. I know in my own work we talk about a strength based approach to language and I like that as an idea but that doesn't then get the help that families or schools made and again I think that that's sad Mary also talked a lot about the importance of teacher assistants in the school role and working as a team to have a shared language and to have consistency of approaches she identified a number of misconceptions that she felt colleagues at school had about autism and were being influenced by shows like the good doctor

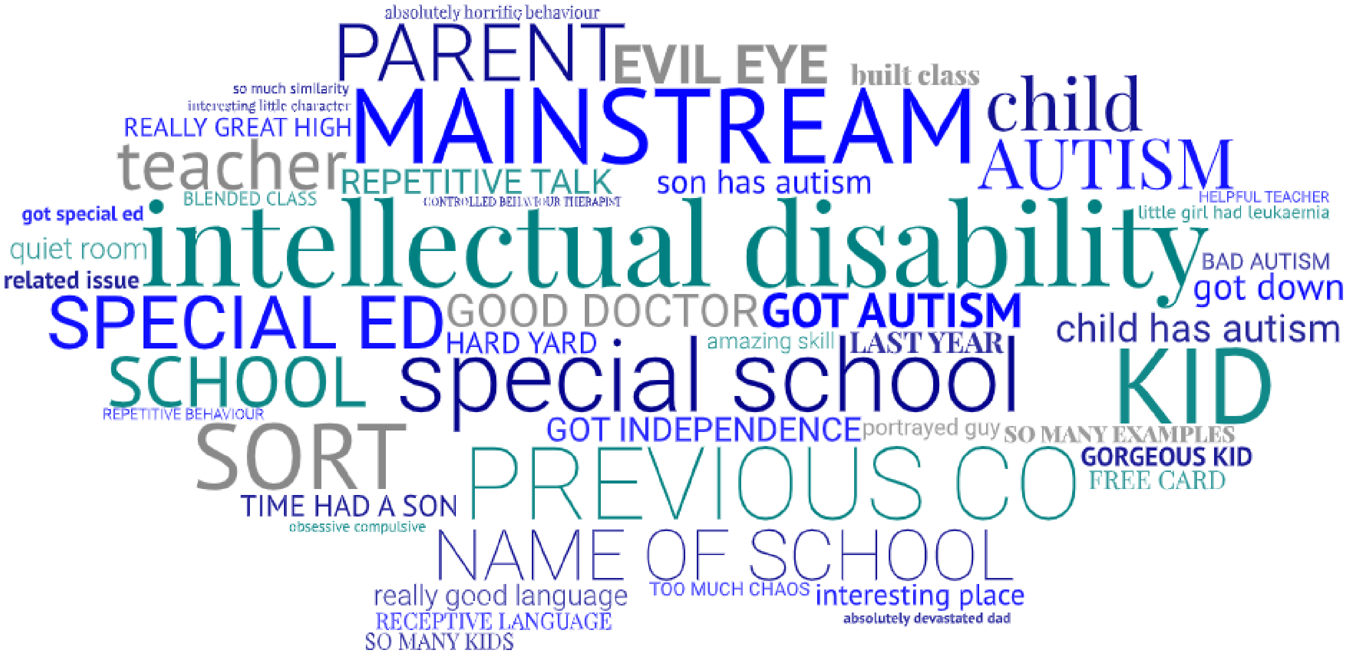
Mary Word Cloud:



Teacher 5- Tina

I found parts of this interview difficult Tina talked about the poster child for autism kids that tick every box she talked about nonverbal children knowing more than what they let on there was a feeling at times that some kids that she taught who are autistic using it to get out of work. Tina talked a lot about parents and having quite a few challenges it sounds like with parent expectations I noticed that she actually talked a lot about expectations as being something that needed to be raised for students with disabilities generally but particularly kids on the spectrum she gave a really lovely example of being proven wrong. At times I felt like she came from an ‘expert model’ that she knew everything she needed to know about autism but gave one example where a young student who was nonverbal started to communicate through an augmentative communication device and shared some insights that she had no idea about. That was a really powerful word example that she shared she also talked about a colleague who was a parent of a young man on the spectrum and working so closely with her over the years and sharing some of those personal stories was a way for her to learn about the day-to-day impacts and I guess strengths and challenges over time. This teacher works in a high needs school with lots of challenges and I think experiences those daily. Tina talked about a few conspiracy theories around autism and the epidemic language that she used she talked a lot about not being prepared as an undergraduate teacher that she had really strong views about teacher education needing more focus on disabilities generally. She felt if teachers knew more about autism that would help them just generally in their classrooms

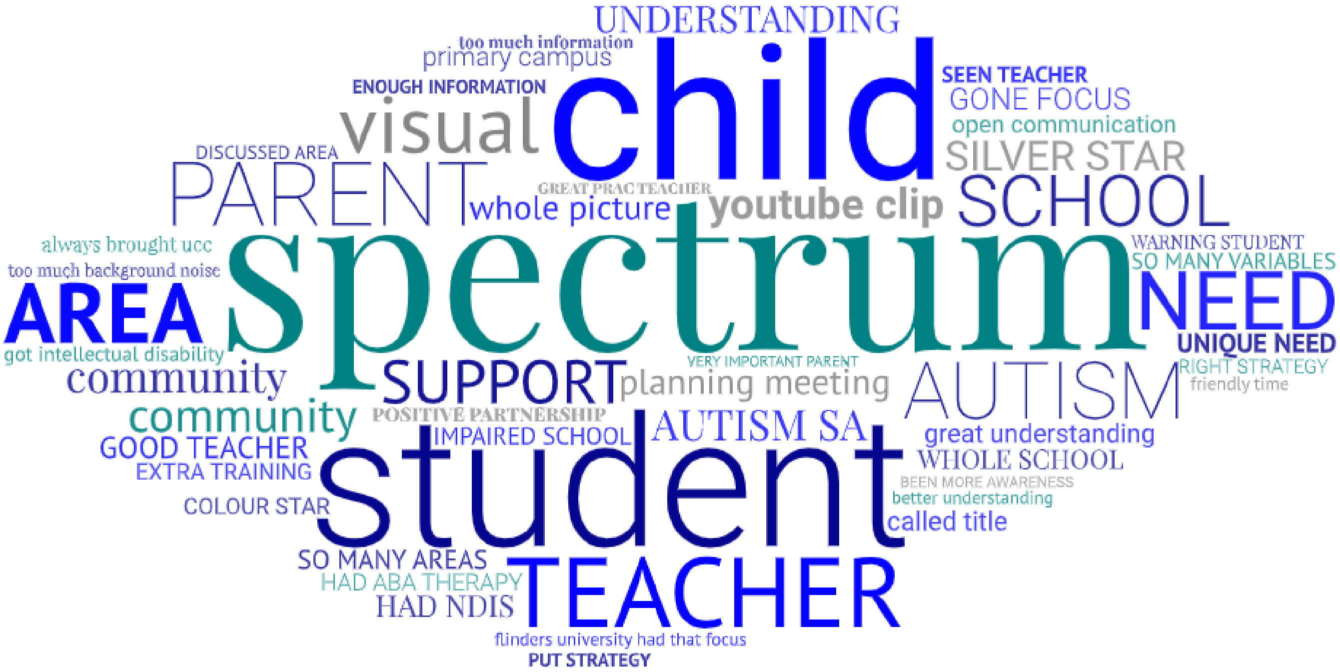
Tina Word Cloud:



Teacher 6- Rose

Rose provided really thoughtful responses in the interview she was very aware of the sensory challenges. For autistic students she talked about the complexity of trying to listen to information or instructions from a teacher and possible distractions that could be linked to an air conditioner or other elements that impact the student. It wasn't until later in the interview that she disclosed that she is apparent or a school aged autistic child so I wondered whether some of her responses and awareness comes from that lived experience of being a parent as well as a teacher. Rose highlighted the need for undergraduate teachers to be better informed about disabilities and autism I feel like that is a theme that's come out already around teacher preparedness. She made an interesting comment about half the things that you learn at uni you never use in practice. Rose highlighted social media as being a source of information for teachers as they are time poor and so having access to quick snippets of information as being useful. Rose was the first teacher to reference journal articles and research as a source of information as well as the anecdote points

Rose Word Cloud:

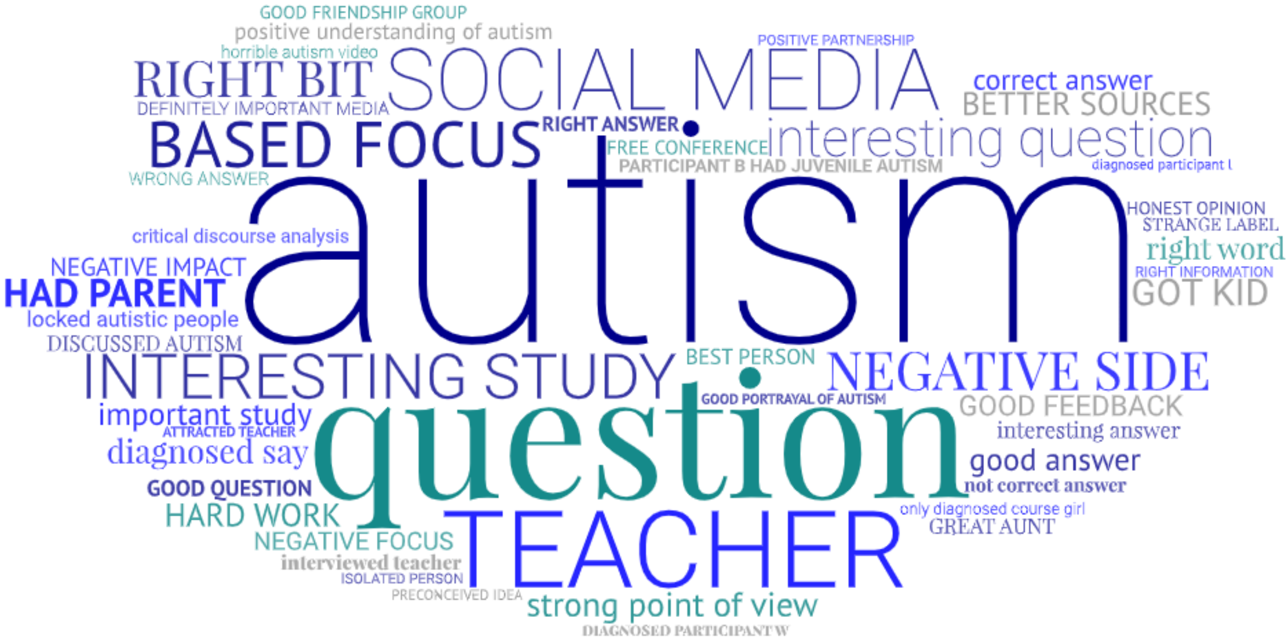


Focus Group 1st Meeting

The purpose of the first meeting was to present the questions I planned to ask autistic High School students. I wanted to do the first session around language and also the photo elicitation. I have already presented the ideas to autistic adults as part of the Autism CRC Research Academy but have fine tuned since then, so this is the next step.

I really enjoyed the focus group interview I was a bit nervous before hand. I have been putting a lot of pressure on myself that this is an area I worked in for a long time I should know what I'm doing. Then started worrying what if the focus group participants didn't like what I had to say or my suggestions for my research I also was just struggling generally with co-production because it was my thesis I wondered how could I do things that were still demonstrating that they were my ideas and was my work. I was worried that if some of my ideas weren't accepted or they didn't like them that that would be influencing my research but I think the more over saying this now is a note it's making sense to me that that actually is part of the process the boy engaging with autistic people getting that feedback that is part of co-production in terms of the interview I got one curveball was in relation to whether I was going to interview peers and I guess the short answer is no that's not part of what my plan is I was focused specifically on interviewing the school aged kids the focus group interviews are in addition to interviewing autistic adolescents but I'm glad I'm doing two actual interviews so it's the referencing too focus group is twofold following on from this interview I feel really excited when I showed the black and white photos I got some really interesting responses. I don't think they loved the images that much but I think they could see the point in them one of the adults said they found the black and white the image is depressing because there's no color in them so they felt lifeless. One of the adults said that they felt the black and white looked like it was old or out of fashion

Focus Group 1st Meeting: Word Cloud



Focus Group 2nd Meeting

I was blown away by the generosity of the focus group interview they shared so openly some really challenging stories from their time at school I always find stories like that hard to hear and after all these years whilst I'm not shocked it still just makes me think it should not be this hard I really could hear the impact that one person can have in a positive way the oldest participant who must be in their 70s now was talking about teachers that they can remember from where they're at primary school who had the most positive impact on their on their life that goes to show the importance of relationships getting to know kids individually and trusting them one of the things that was going through my mind was all four of the adult focus group participants have studied at university. I did ponder that in terms of the cross section of adults that I was talking with. The insights shared were very powerful.

Focus Group 2nd Meeting: Word Cloud

Student 1- Sarah

This was my first interview with an adolescent autistic student for my research there was some good learning for me around the way I ran the session when I asked them to choose a couple of images I could see that it was quite anxiety provoking for that student in the way that they kept wanting to check in with me am I doing this correctly there was this perfectionism streak that seemed to be there so I think the way that I'll phrase it next time might be different too try and reassure them that there is no right or wrong way to go about it that you're not being assessed by the images that you choose it's just a way of having a conversation about whether they evoke any emotions or different ways of thinking about autism that I'm interested in it felt for this student that they have struggled in the past around disclosing about autism and feeling I don't know if it was embarrassed or if there's shame associated with the diagnosis but when I talked about you know some people being very loud and proud about their diagnosis or you know I think I gave the example of you know wearing the T-shirt she struggled with that as an idea and said that she thought that sounded obnoxious to wear a T-shirt relating to I am autistic so she chose her words carefully and try to remain positive but I think is worried about the way that she gets judged by others or she perceives that she's being judged by peers it sounds like she's head quite a few ups and downs in school and has changed schools a couple of times throughout her schooling journey but it's a good place now

Sarah Word Cloud:

Student 2
Jim used a lot of analogies in his interview which was really interesting one of my favorites so far has been his idea that he's like an Apple iPhone and neurotypical people I like androids I've heard similar analogies I guess in the past like I'm a some people say that there are a Mac system rather than windows or a different way of processing so I guess it's along those same lines he also talked about if he's disclosing to his friends he might say something like you're an orange I'm an apple get over yourself type thing so but yes we're both fruit but we're very different fruit so lots to think about there in terms of school he talked quite a lot about challenges he'd had with teachers and it sounds like a bit of a power struggle around the rules and I can see that that would be challenging for teachers like he referred to me as a 'boomer' multiple times which was kind of funny and I said well technically I'm not a boomer! I could see the funny side of it but I can see how other people might not find comments like that funny or feel challenged. He showed me a YouTube clip and a 'tick- tok' where autism was being he used it as a derogatory term.

Jim Word Cloud:

Student 3- Bob

The interviewing of the next two students was done at the same time as they are fraternal twins. Bob gave some really great examples of just wanting people to trust him and to give him a go he didn't talk that much about the media or couldn't think about felt difficult to answer some of those questions around what he thinks other people think about autism

Bob Word Cloud:

Student 4- Wendy

The interview with Wendy was the most difficult in terms of trying to extend some of the responses from the participant some of the answers were only a couple of words so I was trying to provide other scaffolding to try and elicit more information they did OK with choosing the pictures but just gave very simple responses which is fine there is no right or wrong way

Wendy Word Cloud:

Appendix Ten: Coding and data poems