

# Sexual Health Literacy of Autistic Young Women: A Qualitative Systematic Review

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# Declaration of Original Nature of Work

I certify that this dissertation:

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

31 August 2019

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Date

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## Table of Contents

|  |            |
|--|------------|
| <b>Declaration of Original Nature of Work .....</b>        | <b>ii</b>  |
| <b>Acknowledgements .....</b>                              | <b>iii</b> |
| <b>List of Tables .....</b>                                | <b>vi</b>  |
| <b>List of Figures.....</b>                                | <b>vi</b>  |
| <b>Abstract.....</b>                                       | <b>vii</b> |
| <b>Chapter 1: Introduction .....</b>                       | <b>1</b>   |
| Purpose of the Review .....                                | 1          |
| <b>Chapter 2: Background.....</b>                          | <b>3</b>   |
| Autism.....  | 3          |
| Sexual Health Literacy .....                               | 4          |
| Sexual Identity .....                                      | 6          |
| Sexuality Education, Diverse Populations, and Autism ..... | 7          |
| Research Question .....                                    | 10         |
| <b>Chapter 3: Methods and Methodology .....</b>            | <b>13</b>  |
| Methodology .....  | 13         |
| Methods.....   | 14         |
| <b>Chapter 4: Results.....</b>                             | <b>22</b>  |
| Search Results .....                                       | 22         |
| Overview of Included Studies.....                          | 25         |
| Methodological Quality .....                               | 29         |
| Characteristics of Included Studies.....                   | 30         |
| Findings of the Review .....                               | 35         |
| <b>Chapter 5: Discussion .....</b>                         | <b>45</b>  |
| Overview of Findings .....                                 | 45         |
| Summary .....  | 52         |
| Strengths and Limitations .....                            | 53         |

|   |           |
|---|-----------|
| Implications for Practice .....                               | 54        |
| Future Directions .....                                       | 55        |
| Conclusion .....  | 56        |
| <b>References .....</b>                                       | <b>57</b> |
| <b>Appendix A: CASP Checklist .....</b>                       | <b>75</b> |
| <b>Appendix B: JBI Qualitative Data Extraction Tool .....</b> | <b>81</b> |
| <b>Appendix C: Table of Excluded Studies .....</b>            | <b>82</b> |

## List of Tables

|   |    |
|---|----|
| Table 1 <i>Inclusion criteria</i> .....                                   | 16 |
| Table 2 <i>Exclusion criteria</i> .....                                   | 16 |
| Table 3 <i>Search terms used in database searches</i> .....               | 17 |
| Table 4 <i>Articles used for ancestry searches</i> .....                  | 18 |
| Table 5 <i>Journal database search terms</i> .....                        | 19 |
| Table 6 <i>Search results by method</i> .....                             | 22 |
| Table 7 <i>Critical Appraisal of included studies</i> .....               | 30 |
| Table 8 <i>Characteristics of included studies</i> .....                  | 31 |
| Table 9 <i>Summary of individual study participant demographics</i> ..... | 35 |

## List of Figures

|   |    |
|---|----|
| <i>Figure 1</i> Joanna Briggs Institute: Approach to data synthesis. ....                                   | 21 |
| <i>Figure 2</i> Preferred reporting items for systematic reviews and meta-analyses (PRISMA) flow chart..... | 24 |
| <i>Figure 3</i> Critical appraisal questions .....  | 30 |
| <i>Figure 4</i> Meta-aggregative synthesis of initial findings .....  | 37 |

# **Abstract**

## **Background**

It is thought that autistic young women have lower sexual health literacy than their non-autistic peers due to differences in learning and participation styles and needs.

## **Objective**

This purpose of this systematic review is to examine the qualitative literature to explore current knowledge of the sexual health literacy of autistic young women with a view to informing future practice in sexual health education and provision.

## **Design**

A meta-aggregative approach was used. Studies were included if attributable data relating to sexual health, sexual identity, sexual knowledge, or the acquisition of sex education was able to be extracted for autistic women aged 16–25 years from studies published from January 2000–March 2019.

## **Results**

Four studies were included for the review. Thirteen findings were extracted and synthesised into six categories and then into two synthesised findings. The synthesised findings addressed factors such as gender and sexuality identity, sex education, and social communication.

## **Conclusion**

There are significant gaps in the understanding of how autistic young women acquire sexual health literacy. For this population to be informed about sex, sexual identity, and sexual health, evidence-based information and resources need to be made available in a method and format that makes sense to them.

# Chapter 1: Introduction

This section will introduce the topic of the systematic review and provide a brief summary of the focus and scope of the review.

## Purpose of the Review

Autistic adults who do not have a co-existing cognitive impairment display differences or face challenges in areas of social communication, such as following conversational rules and social mores, and building and maintaining relationships (American Psychiatric Association, 2013b). It has been well documented that the experience of autism for females is different to that of males (Bush, 2018; Kock, Strydom, O’Brady, & Tantam, 2019). It is also known that the experience of sexuality and sexual health differs for autistic individuals from non-autistic individuals (Bush, 2018; Parchomiuk, 2018), as well as for autistic males and females (Pecora, Mesibov, & Stokes, 2016) There is an existing body of research on the sexuality of autistic men and women—which often relies heavily on input from family members or carers (Barnett & Maticka-Tyndale, 2015)—as well a small but growing number of reports on the sexuality of autistic women (e.g., Bush, 2019; Kock et al., 2019). There is, however, a lack of synthesised evidence and evidence-based guidelines regarding the sexual health status and sexual health literacy of young autistic women and very little that directly explores the experiences of autistic women between the ages of 16–25 years in their own words and from their own point of view on the formation of their sexual identity and acquisition of sexual health literacy.

The author of this review has an extensive career background in the disability field and has worked for an autism peak agency as well as a sexual health organisation. She is also the parent of two autistic teenage daughters who both identify as sexuality diverse. As such,

the concurrence of sexuality, sexual health, and autism was a common theme on both a personal and professional level. However, when searching for evidence-based information or guidelines to provide to her daughters, other autistic young women and their families and carers, as well as teachers and other support staff on matters of sexuality and sexual health, the author observed that such information in an appropriately accessible format was scarce, which contributed the choice of topic for the review.

The purpose of this work is to examine the existing qualitative literature to explore current knowledge of the sexual health literacy of autistic young women with a view to informing future practice in sexual health education and provision.

Following this introduction, Chapter 2 will present background information and current knowledge of the review topic. Methodology and rationalisation for the methodology chosen will be discussed in Chapter 3 and methods used for this review will be presented. Chapter 4 will detail the results of the systematic review as well as meta-aggregative findings. Finally, in Chapter 5, the findings will be discussed and implications for practice and recommendations for future research will be presented.

## **Chapter 2: Background**

This chapter will provide background information to the topic of the systematic review. Current knowledge of the factors informing this review will be discussed and consolidated. The research question and aim of the paper will be presented.

### **Autism**

Autism Spectrum Disorder (ASD), or autism, is a lifelong, neurodevelopmental disorder that is often diagnosed around the ages of 4–5 years (Zwaigenbaum & Penner, 2018), however may not become evident until a later age, particularly for females (Bargiela, Steward, & Mandy, 2016). People who have a diagnosis of autism typically have difficulties in social communication and interaction, and restricted, repetitive interests and patterns of behaviour (American Psychiatric Association, 2013b). These effects are experienced differently and to varying degrees by every person and every autistic person has strengths and challenges (Amaze, 2019). While autistic individuals differ from their non-autistic peers in learning styles and needs, a diagnosis of autism does not necessarily co-exist with an intellectual impairment (American Psychiatric Association, 2013b).

The topic of appropriate terminology in the autism community is ever evolving and much debated. People who have a diagnosis of autism or identify as autistic are currently reported as preferring to be referred to as an autistic person, rather than a ‘person with autism’ or ‘on the spectrum’ (Amaze, 2019). It is not the intention of this work to define or debate autism terminology, so for the purposes of this paper and following the lead of Kenny et al. (2016) as well as peak autism bodies (Amaze, 2019; The National Autistic Society, 2018) the term ‘autistic’ will be used.

The stated diagnostic ratio of boys to girls in autism varies according to source, geographic location, age at diagnosis, and presence of intellectual impairment (Elsabbagh et al., 2012; Fulton, Paynter, & Trembath, 2017; Loomes, Hull, & Mandy, 2017). However, it is clear that females, especially those who do not have a co-existing intellectual impairment, are frequently mis- or under-diagnosed, or diagnosed later in life (Fulton et al., 2017; Haney, 2016; Milner, McIntosh, Colvert, & Happé, 2019; Ratto et al., 2018). This difference in diagnosis rates according to gender is the subject of several studies, with research stating the ratio of diagnosis in boys to girls as approximately 3:1 (Elsabbagh et al., 2012; Zwaigenbaum et al., 2012). It is known that autistic females typically present differently to autistic males in that they experience more sensory sensitivities and appear more interested in and able to initiate friendships and conversation (Harrop et al., 2018; Kock et al., 2019; Lai, Lombardo, Auyeung, Chakrabarti, & Baron-Cohen, 2015; Lai et al., 2011; Milner et al., 2019) and it is thought that autistic females with higher cognitive abilities are less likely to be diagnosed (Ratto et al., 2018). It has also been stated that the gender disparity in diagnosis results in less research being conducted with autistic females (Fulton et al., 2017; Milner et al., 2019; Ratto et al., 2018). As clinical practice is informed by research this, in turn, leads to females on the spectrum receiving less support (Fulton et al., 2017; Milner et al., 2019; Ratto et al., 2018).

In summary, autistic females, especially those without cognitive impairment, are often mis- or underdiagnosed. Less research is conducted with this group, which consequently impacts clinical practice. Therefore, the type and amount of support received by autistic females is negatively affected.

## **Sexual Health Literacy**

Sexual health is defined by the World Health Organization (WHO) as "... a state of physical, emotional, mental and social well-being in relation to sexuality" (World Health

Organization [WHO], 2019, para. 4). Individual sexual health is affected by a number of factors, such as education, socio-economic status, access to health services and, for many, the skill and confidence of the health care provider (McCabe & Holmes, 2014; Whitfield, Jomeen, Hayter, & Gardiner, 2013).

The term ‘sexual health literacy’ stems from the concept of health literacy (Lytton, 2013). Health literacy, in simplest terms, is the ability to navigate the health care system and take care of oneself (Lytton, 2013). With this in mind, sexual health literacy can be described as the understanding of information about sex, sexual health, and sexuality — including one’s own sexual identity, and the ability to make sex- and sexuality-related decisions based on that knowledge (Graf & Patrick, 2015; Rohleder & Flowers, 2018). The health system is complex and can be difficult to navigate for the general population (Lytton, 2013) and it is known that only 40% of Australian adults have health literacy at a level that enables them to make informed choices about their health (Australian Commission on Safety and Quality in Health care (ACSQHC), 2014). For those who have additional challenges, such as low functional literacy, cognitive disability, or autism, or who care for or support someone who has additional impairments, the obstacles to the acquisition of a functional level of health literacy that incorporates and supports those support needs can be insurmountable (Lytton, 2013). Without the fundamental skills needed to attain basic health literacy, sexual health literacy cannot be achieved.

To summarise, sexual health literacy encompasses the ability to care for oneself in matters of sex, sexuality, and sexual health. It denotes an understanding of, and ability to recognise and act upon knowledge and make appropriate and healthy decisions regarding sex, sexuality, and sexual health.

## **Sexual Identity**

Sexual identity develops at different rates and in different ways according to various factors, such as gender, education, ethnicity, and social strata or experience (Richters, Altman, et al., 2014; A. M. Smith, Rissel, Richters, Grulich, & de Visser, 2003). As young people move through adolescence, they often seek information about sex from informal sources, such as peers and family, rather than formal sex education programs they are offered at school (Whitfield et al., 2013). Such informal information becomes increasingly focussed on gender and sexuality norms. Romantic and sexual relationships become a focal point of social experiences, the participation in and observance of further adding to the young person's store of knowledge of what is considered acceptable and normal. (Bleakley, Khurana, Hennessy, & Ellithorpe, 2018).

The concept of sexual identity has been the subject of many reports, yet not all offer a straightforward definition. It has been described in many ways; from basic, self-designation to describe sexual orientation (Katz-Wise, 2015), to more complex approaches that encompass the multidimensional, with reference to personality theory (Horley & Clarke, 2016). Sexual identity has been described as a social construct (Harrison & Cooley, 2016) and as a self-applied label born of various life experiences (Horley & Clarke, 2016) that can be subject to fluidity over the lifetime (Richters, Altman, et al., 2014; A. M. Smith et al., 2003). While sexual orientation is described as an innate sexual preference for, or attraction to individuals of one or both sexes (Dewinter, De Graaf, & Begeer, 2017; Russell, Thompson, & Harris, 2011) the notion of sexual identity as a label of one's own making relies on the individual having the ability to comprehend and define sexuality, both their own and in relation to that of others (Dewinter et al., 2017; Russell et al., 2011). While many factors affect this ability, not least being the societal and cultural attitudes directly surrounding the individual (Tissot, 2009), access to accurate and accessible information as a

basis for personal identification and description is crucial (Curtiss & Ebata, 2016; Parchomiuk, 2018; Pecora et al., 2016).

A 2013 study found that approximately 9% of men and 19% of women aged 16–69 years reported feelings of non-heterosexual attraction (Richters, Altman, et al., 2014). However, while same-sex attraction and gender and sexuality diversity are generally more accepted now than in the recent and distant past (Richters, Altman, et al., 2014), the subject of autistic people and sexuality is a subject of some discussion and increasing research (Dewinter et al., 2017; Dewinter, Vermeiren, Vanwesenbeeck, & Van Nieuwenhuizen, 2016; George & Stokes, 2018c). While 11% of the wider Australian population are reported as being of diverse sexualities and/or genders (Australian Human Rights Commission, 2014), it has been reported that those autistic individuals are more likely to be gender and sexuality diverse than their non-autistic peers (George & Stokes, 2018b, 2018c). It has been stated that autistic young women, in particular, are significantly more likely to be bisexual or same-sex attracted than their neurotypical peers (Dewinter et al., 2017; George & Stokes, 2018c).

In summary, the identification and acknowledgement of personal sexual identity requires the individual to have the ability to consolidate, comprehend, and define formal and informal information (Parchomiuk, 2018). Accessing such information, which must be accurate, easily understood, and related to the individual's pertinent needs is an ability that may be affected by the differing learning styles of autistic individuals (Curtiss & Ebata, 2016; Dewinter et al., 2017).

## **Sexuality Education, Diverse Populations, and Autism**

During adolescence, most young people will be offered sex education at school and relationships and sexuality education is included in the Australian school curriculum (Collier-Harris & Goldman, 2017). It has been stated, however, that the sexuality education offered in

schools is often inconsistent and vague in content and delivery (Ezer, Jones, Fisher, & Power, 2018). In addition, there are a variety of factors that affect assimilation of sexual knowledge. Not least of these being the fact that each young person will interpret the information offered or being taught differently (Farrelly, O'Brien, & Prain, 2007), as well as the manner in which the education is framed (Coll, O'Sullivan, & Enright, 2018), and how issues of diverse sexualities and gender are addressed (Shannon & Smith, 2015). While sexuality education is ostensibly part of the Australian school curriculum, studies into the experiences of lesbian, gay, bisexual, transgender, intersex, and queer (LGBTIQ) youth reported that they had received minimal sexuality education (Robinson, Bansel, Denson, Ovenden, & Davies, 2013), or that they struggled to engage with the education that was offered in school (Ullman, 2015). Young people reported that the education they did receive was overwhelmingly heteronormative and focussed on reproduction (or the avoidance thereof) and heterosexual safe sex, which they felt was irrelevant (Robinson et al., 2013; Ullman, 2015). It was found that young LGBTIQ people would benefit from sexuality education that acknowledged a diverse audience and included information about non-heterosexual safe sex, as well as respectful relationships (Robinson et al., 2013). Instead, LGBTIQ young people gained much of their sexual knowledge through peer interactions and informal networks (Byron & Hunt, 2017; Robinson et al., 2013).

Similarly, it is thought that autistic young people are not afforded the same sexuality education opportunities as their typically developing peers due to difficulty learning in mainstream classroom settings (Hancock, Stokes, & Mesibov, 2017; Åsberg, Zander, Zander, & Dahlgren Sandberg, 2012) and/or the inability to effectively participate in the relevant peer interactions (Barnett & Maticka-Tyndale, 2015; Hancock et al., 2017; Head, McGillivray, & Stokes, 2014). In addition to the literature addressing the sexuality education needs of young people who fall outside the heterosexual norm (e.g., Jones & Hillier, 2012), there is some

work addressing the needs of those who have below-average IQ (Schaafsma, Kok, Stoffelen, & Curfs, 2015). Recent work addresses an autistic population that has a co-occurring intellectual disability (Sala, Hooley, Attwood, Mesibov, & Stokes, 2019) and there is an emerging body of literature addressing the specific needs of autistic young people (e.g., Ballan & Freyer, 2017; Bush, 2018; Visser et al., 2017). While it is known that autistic females have quite distinct learning needs (Bölte, Duketis, Poustka, & Holtmann, 2011; Ratto et al., 2018), there are few studies addressing the particular needs of autistic young women in sexuality education.

It is known that perception of the information that is received in adolescence affects its application throughout life and provides the adult with the skills and tools required to make healthy decisions (Holland-Hall & Quint, 2017; Simpson et al., 2017). When the information offered is not able to be processed or applied due to social and learning difficulties, autistic individuals, young women in particular, may find themselves at a distinct disadvantage (Hancock et al., 2017; Hannah & Stagg, 2016).

### **Summary.**

In order to achieve a level of sexual health literacy that enables the individual to make informed decisions that impact on their sexual health, autistic individuals need to be able to access information and education relating to sex, sexuality, and sexual health. It is known that autistic females in particular have distinct learning styles (Bölte et al., 2011; Ratto et al., 2018), and that the same population is more likely to be gender and sexuality diverse than their non-autistic peers (Dewinter et al., 2017; George & Stokes, 2018c). It is also known that young people who are gender and/or sexuality diverse often find it difficult to engage in general mainstream classroom sex education offerings (Robinson et al., 2013; Ullman, 2015).

These factors together point toward the probability that young autistic women are likely to have difficulty acquiring and applying sexual health literacy in their daily lives.

## **Research Question**

While there is an evolving body of research focused on the sexuality of autistic people (e.g., Brooks, 2018; George & Stokes, 2018b; George & Stokes, 2018c), there is a lack of synthesised evidence that concentrates specifically on the sexuality and sexual lives of autistic young women and a similar amount of evidence-based guidelines to be found that address the sexual health literacy of the same population. Much of the current literature on autistic females is focused on paediatric populations (Baldwin & Costley, 2016) or reports data provided by parents or carers (Bush, 2016; Landon, 2016). Thus, the complexities and subtleties of the challenges autistic young women face in achieving sexual health literacy are not well defined. It may be that autistic girls and young women have lower sexual health literacy than their non-autistic peers due to differences in learning and participation styles and needs.

### **Aim of the review.**

The aim of this paper is to systematically review the qualitative literature and identify factors that affect the attainment of sexual health literacy in autistic young women who do not have an intellectual impairment. Autistic females, especially those who do not have a co-existing intellectual impairment, have typically been under-reported or under-diagnosed due to differences in clinical presentation (Halladay et al., 2015; Hiller, Young, & Weber, 2014). Therefore, it was expected that there would be a dearth of studies that focussed specifically on autistic girls and young women, especially those without intellectual impairment. However, while awareness of the sexuality support needs of those with intellectual disability

has increased, the needs of those who are autistic are quite different (Gougeon, 2010; Hancock et al., 2017). Similarly, the experiences in relation to sexual health literacy of autistic young women who do not have an intellectual impairment are likely to be significantly different to those who do have a co-existing intellectual impairment, or require higher levels of support due to the functional impact of their autism (Byers, Nichols, & Voyer, 2013). Consequently, only those studies that pertain directly to autism or provide clear distinction of results for autistic females and clearly state the functional impact or level of autism will be considered.

### **Focus of the review.**

The review will consolidate existing qualitative literature addressing the sexual health literacy of autistic young women aged 16–25 years who do not have a co-existing intellectual impairment. The lower age of 16 years was chosen as it is known that 50% of the Australian population have their first sexual experience between the ages of 16–18 years (Richters, de Visser, Rissel, & Grulich, 2014). It is also, in the state in which this paper was prepared, the legal age at which a person may legally have sex as long as one partner is not in a position where they have care or supervision of the other (Victoria Legal Aid, 2018). Papers published from January 2000–March 2019 were considered for inclusion. This time span allowed for the broadest possible span of current articles, and also allowed for articles informed by the publication of the Diagnostic and Statistical Manual of Mental Disorders, fourth edition, text revision (DSM IV-TR; American Psychiatric Association, 2000) to be considered. The DSM IV-TR included four disorders: autistic disorder; Asperger's disorder; childhood disintegrative disorder; and pervasive developmental disorder – not otherwise specified (PDD-NOS), which, using the diagnostic criteria of the fifth edition of the DSM, DSM-5, would all meet the criteria for a diagnosis of ASD (American Psychiatric Association,

2013a). For the purposes of this review, the diagnosis and method of diagnosis met the inclusion criteria of the study in question, i.e., self-diagnosed or diagnosed using a recognised diagnostic tool.

**Research question.**

Current knowledge of sexual health literacy for autistic young women will be explored via the following question:

*What are the experiences of autistic young women in the acquisition of sexual health knowledge?*

This chapter has provided an introduction and background to the topic of the systematic review. Current knowledge of the factors informing this review have been presented and consolidated, thus introducing the review question and the aim and focus of the review. The following chapter will present the methodology and methods of the review.

## Chapter 3: Methods and Methodology

This section of the systematic review details the methods used to conduct the review. A rationalisation of the choice of qualitative methodology is presented, along with inclusion and exclusion criteria, search strategy details, and screening and selection process. Details of critical appraisal method, data extraction, and method of data synthesis are also detailed.

The protocol used for this systematic review of the qualitative literature was peer-reviewed and was developed using the guidelines set out by (Boland, Cherry, & Dickson, 2017). Details of the protocol were registered on PROSPERO on February 13, 2019 and can be accessed at [www.crd.york.ac.uk/PROSPERO/display\\_record.asp?ID=CRD42019109278](http://www.crd.york.ac.uk/PROSPERO/display_record.asp?ID=CRD42019109278)

### Methodology

Qualitative research is known to be useful in exploring and developing a detailed, holistic understanding of a known human or cultural phenomenon (Creswell, 2014; Lockwood, Munn, & Porritt, 2015). In health research, qualitative methods are useful in identifying discrepancies in health systems and highlighting the processes that effectively exclude certain members of the population from accessing appropriate health services (Sinding, 2010; Singh & Bunyak, 2019). By exploring in-depth perspectives from a person-centred viewpoint and ascertaining barriers to and enablers of effective interventions, qualitative research can lead to a greater depth of understanding, which in turn leads to improved service provision (Aromataris & Munn, 2017; Lavis, 2009; Singh & Bunyak, 2019). A systematic review of the qualitative literature using the process of meta-aggregation, as this review does, consolidates themes identified by researchers and presents them as a meta-aggregated whole (Aromataris & Munn, 2017; Lockwood et al., 2015). This assists with a clear and broad understanding of the experiences of the population under

review, allows for gaps in the literature to be identified, and supports identification of barriers and alternate views (Boland et al., 2017; Lavis, 2009; Seers, 2014). The process of meta-aggregation also allows for the development of synthesised findings, from which recommendations for future practice and research can be extrapolated (Lockwood et al., 2015).

Research into sexuality and sexual health is a complex and sensitive area, and is also a comparatively recent field (Epstein & Mamo, 2017). In addition, autistic young women are a group that is relatively recently recognised, poorly understood, and currently under-researched (Kanfiszer, Davies, & Collins, 2017; Milner et al., 2019). In order to truly understand and meet the needs of autistic young women in relation to sexual health literacy, first-hand reports are vital and are likely to capture nuances that might otherwise not appear through a quantitative study (Singh & Bunyak, 2019). Furthermore, it has been suggested that autistic participants in sexuality-related research may find a qualitative approach more fitting, in that a qualitative approach allows for a broader range of responses and allows participants the opportunity to freely express feelings and opinions on sexuality-related matters (George & Stokes, 2018c). It is for this reason that a qualitative method was chosen for this systematic review of the existing literature.

## **Methods**

### **Inclusion and exclusion criteria.**

#### ***Population of interest.***

The population of interest was autistic females aged 16–25 years who had a diagnosis of autism, ASD, or Asperger’s syndrome and who did not have a co-existing intellectual impairment. The method of diagnosis met the inclusion criteria of the study in which they were participating, i.e., self-diagnosed or diagnosed using a recognised diagnostic tool.

### ***Phenomena of interest.***

The purpose of this paper was to review the current qualitative literature on the acquisition of sexual health literacy of autistic young women. Therefore, studies were included if they had a clear focus on sexual health, acquisition of sexual knowledge, navigation of sexual health provision, formation of sexual identity, sexual experiences, or sexuality. Studies that focused exclusively on friendship, or romantic attraction or interests were not considered.

### ***Context.***

No limitations on the geographic location of study participants were set for this review. Studies were required to be written in English or have an available verified translation. Where study participants were sourced from was also not a consideration, though it is known that many autism studies investigate participants sourced from clinics or practices that specialise in autism (Bargiela et al., 2016). This has the potential of excluding many women who do not fit the ‘usual’ autism diagnostic criteria and have therefore remained undiagnosed until late adolescence or adulthood (Giarelli et al., 2010).

### ***Types of studies.***

Studies considered for inclusion in the review were those which used a qualitative methodology, or a mixed methods approach with qualitative results clearly distinguishable. Both peer-reviewed work and grey literature were considered for inclusion. In order to have the greatest possible pool of potential appropriate studies, papers published from January 2000–March 2019 were considered for potential inclusion. Inclusion and exclusion criteria are detailed in Tables 1 and 2.

Table 1 *Inclusion criteria*

| <b>Inclusion criteria</b>  |
|--|
| Female participants: aged 16–25 years  |
| The study focus was autistic females, or results for autistic female participants were clearly distinguishable |
| Participants had a diagnosis of autism, ASD or Asperger’s syndrome   |
| It was clearly stated that eligible participants did not have a co-existing intellectual impairment.           |
| Study was conducted from January 2000–March 2019   |

Table 2 *Exclusion criteria*

| <b>Exclusion criteria</b>  |
|--|
| Results for females were not clearly distinguishable from those for males or could not be extracted from a broader age group |
| Participants were parents/carers of autistic young women   |
| Systematic reviews, single case studies, editorials  |
| Quantitative methodologies   |
| Study was not in English or did not have a verified translation  |

**Search strategy.**

The literature search was performed during the period March 2018–January 2019. Comprehensive database searches were conducted on October 27, 2018. The search was prepared by the author and reviewed by an information scientist, who was consulted for advice on structuring the search for individual databases. Databases searched included: Proquest (Medicine and Health, and Education databases), Medline, PsycINFO, CINAHL,

SCOPUS, and Expanded Academic ASAP. Different combinations of search terms appropriate to each database were used. Search terms used are listed in Table 3.

Table 3 *Search terms used in database searches*

| Search topic           | Search terms  |
|------------------------|---|
| Autism                 | Autis* OR 'Autism Spectrum Disorder' OR ASD OR Asperger* OR High functioning autis* OR HFA<br><br>AND |
| Autism – female        | Girl* OR Wom*n OR female<br><br>AND   |
| Sexual health literacy | Sexual health literacy OR 'Health literacy' OR Sexual health OR Sexuality OR Sex*                     |

As the topic of sexual health literacy encompasses several aspects and can be viewed from a variety of perspectives, and in order to search as comprehensively as possible, additional searches were performed. In addition to the database searches previously described, ancestry searches were performed of the reference lists and bibliographies of all papers included from the systematic search, as well as selected other articles. Articles used for ancestry searches can be viewed in Table 4. (Conn et al., 2003). Articles were selected for ancestry searches based on specificity of topic relating to the research question. The archives of specific journals relating to sexuality and autism were also searched on March 8 and 9 2019. Journals and search terms used are listed in Table 5.

Table 4 *Articles used for ancestry searches*

| Author/Year                              | Details   |
|--|---|
| (Barnett & Maticka-Tyndale, 2015)        | Qualitative exploration of sexual experiences among adults on the Autism Spectrum: Implications for sex education. <i>Perspectives on Sexual and Reproductive Health</i> , 47(4), 171–179.  |
| (Bush, 2018)                             | Dimensions of sexuality among young women, with and without autism, with predominantly sexual minority identities. <i>Sexuality and Disability</i> , 1–18.  |
| (Cridland, Jones, Caputi, & Magee, 2014) | Being a girl in a boys’ world: Investigating the experiences of girls with autism spectrum disorders during adolescence. <i>Journal of Autism and Developmental Disorders</i> , 44, 1261–1274.  |
| (George, 2016)                           | <i>Sexual orientation and gender-identity in high functioning individuals with autism spectrum disorder.</i> (Doctor of Philosophy). Deakin University, Melbourne. Retrieved from <a href="http://dro.deakin.edu.au/view/DU:30089386">http://dro.deakin.edu.au/view/DU:30089386</a>   |
| (Gougeon, 2010)                          | Sexuality and autism: A critical review of selected literature using a social-relational model of disability. <i>American Journal of Sexuality Education</i> , 5(4), 328–361.   |
| (Hannah & Stagg, 2016)                   | Experiences of Sex Education and Sexual Awareness in Young Adults with Autism Spectrum Disorder. <i>Journal of Autism and Developmental Disorders</i> , 46(12), 3678–3687.  |
| (Kock et al., 2019)                      | Autistic women’s experience of intimate relationships: the impact of an adult diagnosis. <i>Advances in Autism</i> , 5(1), 38–49.   |
| (Landon, 2016)                           | <i>Romantic relationships: An exploration of the lived experiences of young women who identify a diagnosis of autism spectrum disorder.</i> (Professional Doctorate in Educational and Child Psychology). University of East London, London. Retrieved from <a href="https://search.proquest.com/docview/1896110260?accountid=10910">https://search.proquest.com/docview/1896110260?accountid=10910</a> |
| (Mackenzie & Watts, 2013)                | Sexual health, neurodiversity and capacity to consent to sex. <i>Tizard Learning Disability Review</i> , 18(2), 88–98.  |
| (Mehzabin & Stokes, 2011)                | Self-assessed sexuality in young adults with High Functioning Autism. <i>Research in Autism Spectrum Disorders</i> , 5(1), 614–621.   |
| (Strang et al., 2018)                    | “They thought it was an obsession”: Trajectories and perspectives of autistic transgender and gender-diverse adolescents. <i>Journal of Autism and Developmental Disorders</i> , 1–17.  |
| (Tint, Weiss, & Lunsky, 2017)            | Identifying the clinical needs and patterns of health service use of adolescent girls and women with autism spectrum disorder. <i>Autism Research</i> , 10(9), 1558–1566.   |

Table 5 *Journal database search terms*

| <b>Journal</b>                                 | <b>Search term</b> |
|--|--------------------|
| Sexuality and Disability                       | Autis*             |
| American Journal of Sexuality Education        |                    |
| Sex Education                                  |                    |
| Perspectives on Sexual and Reproductive Health |                    |
| Autism   | Sexual*            |
| Autism Research                                |                    |
| Advances in autism                             |                    |
| Research in Autism Spectrum Disorders          | Sexuality          |
|  | Sexual             |

### **Screening and selection.**

On completion of searches, results were exported to a systematic review management program (Covidence, Veritas Health Innovation, 2019). Two reviewers initially pre-tested a small sample of abstracts against inclusion criteria, then independently reviewed abstracts (or titles if abstract was unavailable) against the inclusion criteria. A third reviewer was available in the event of disagreement but was not required. Articles selected for potential inclusion were assessed using full text against the inclusion criteria.

### **Critical appraisal.**

Appraisal of quality of identified papers was conducted independently by two reviewers using a Critical Appraisal Skills Programme (CASP) qualitative checklist (Critical Appraisal Skills Programme [CASP], 2018). A copy of the checklist is included in Appendix A. Full text of articles chosen for potential inclusion were assessed for quality by two reviewers. A third reviewer was available in the event of disagreement but was not required. Six studies were assessed and two were excluded on the basis of the data relevant to the population included in this systematic review not being extractable.

### **Data extraction.**

Following quality assessment and using the standardised Joanna Briggs Institute Qualitative Assessment and Review Instrument (QARI) data extraction tool (Aromataris & Munn, 2017) the following data was extracted from each of the studies that met eligibility criteria for inclusion in the systematic review: author, year, journal, geographical location, study setting, approach, participants, data analysis approach, and author conclusions. Themes and verbatim statements or illustrations that supported the themes were also extracted. A copy of the data extraction tool used is provided in Appendix B.

### **Method of synthesis.**

It is the intent of this systematic review to inform future practice by synthesising current knowledge, rather than re-interpreting existing data. Thus, a meta-aggregation approach (Aromataris & Munn, 2017) was used in the synthesis of the data in this systematic review. Meta-aggregation summarises but does not re-interpret data that has been presented in the studies included in the synthesis (Hannes & Pearson, 2012). It is useful in synthesising qualitative research in that the context and meaning of the original research is easily maintained (Hannes & Pearson, 2012; Lockwood et al., 2015). Findings from included papers were aggregated using a three-step process as per the Joanna Briggs Institute methodology (Figure 1; Aromataris & Munn, 2017) and categorised according to theme in order to synthesise the data into a single set of findings.

### **Joanna Briggs Institute: Approach to data synthesis**

- 1 Extraction of all findings from all included papers with an accompanying illustration and establishing a level of credibility for each finding
- 2 Developing categories for findings that are sufficiently similar, with at least 2 findings per category
- 3 Developing one or more synthesized findings of at least 2 categories.

Adapted from Aromantis and Munn, 2017  
<https://wiki.joannabriggs.org/display/MANUAL/2.7.6.4+Data+synthesis>

*Figure 1* Joanna Briggs Institute: Approach to data synthesis.

This chapter has presented the methodology and methods used to conduct the systematic review of existing literature. The next chapter will report the results of the review, including the process of study selection and inclusion, assessment of methodological quality, and characteristics of the included studies, data extraction, and meta-synthesis.

## Chapter 4: Results

This section of the systematic review describes the results of study selection and inclusion, and assessment of methodological quality. An overview of included studies is provided, and characteristics are described. Findings are presented and meta-aggregative results are reported.

### Search Results

#### Study inclusion.

Searches of bibliographic databases returned 423 results, searches of selected journal databases returned two new results, and ancestry searches of selected journal reference lists returned nine results. In total, 434 titles and abstracts were returned by searches. Search results by method are shown in Table 6.

Table 6 *Search results by method*

| Search                                 | Results    |
|--|------------|
| Database                               | 423        |
| Hand search of journal database        | 2          |
| Ancestry search of 12 journal articles | 9          |
| <b>Total</b>                           | <b>434</b> |

A total of 434 citations were exported to Covidence (Veritas Health Innovation, 2019), where 135 duplicates were identified (manually and by the Covidence duplication tool) and removed. The remaining 299 titles and abstracts were screened for eligibility against the inclusion criteria (see Table 1).

A number of studies were excluded at this stage as it was apparent that the focus of the study was the gender differences in autism presentation and diagnosis, rather than sexuality or sexual health (n=52). Other studies excluded at this stage were those that did not report male and female results separately and/or those where the focus was on autistic people with co-occurring intellectual impairment (n=34). There was a group of studies excluded at this stage as the focus of the study was parent/carer report, rather than autistic young women themselves (n=11). This screening process excluded 276 citations, leaving 23 for full-text screening. Full-text screening excluded 17 studies. Four studies of the 17 excluded at full-text screening stage were excluded on the basis of wrong study design (quantitative), and four of the 17 excluded studies were of qualitative or mixed-method design, but quotes were not able to be attributed to specific participants, which did not allow for data extraction for this review. Nine of the 17 excluded studies were eliminated on the basis of different population under study: seven were parent interview; one involved a professional population; and one study had a participant population which was under 16 years of age.

Six studies were included for critical appraisal. Two studies were excluded at this stage on the basis of data relevant to the population included in this systematic review not being extractable. Four studies were found to fulfil inclusion criteria and were determined as eligible for inclusion in the review. Refer to Appendix C for a table of excluded studies and the reasons for exclusion. The results of the study selection process are illustrated in Figure 2.

## PRISMA 2009 Flow Diagram

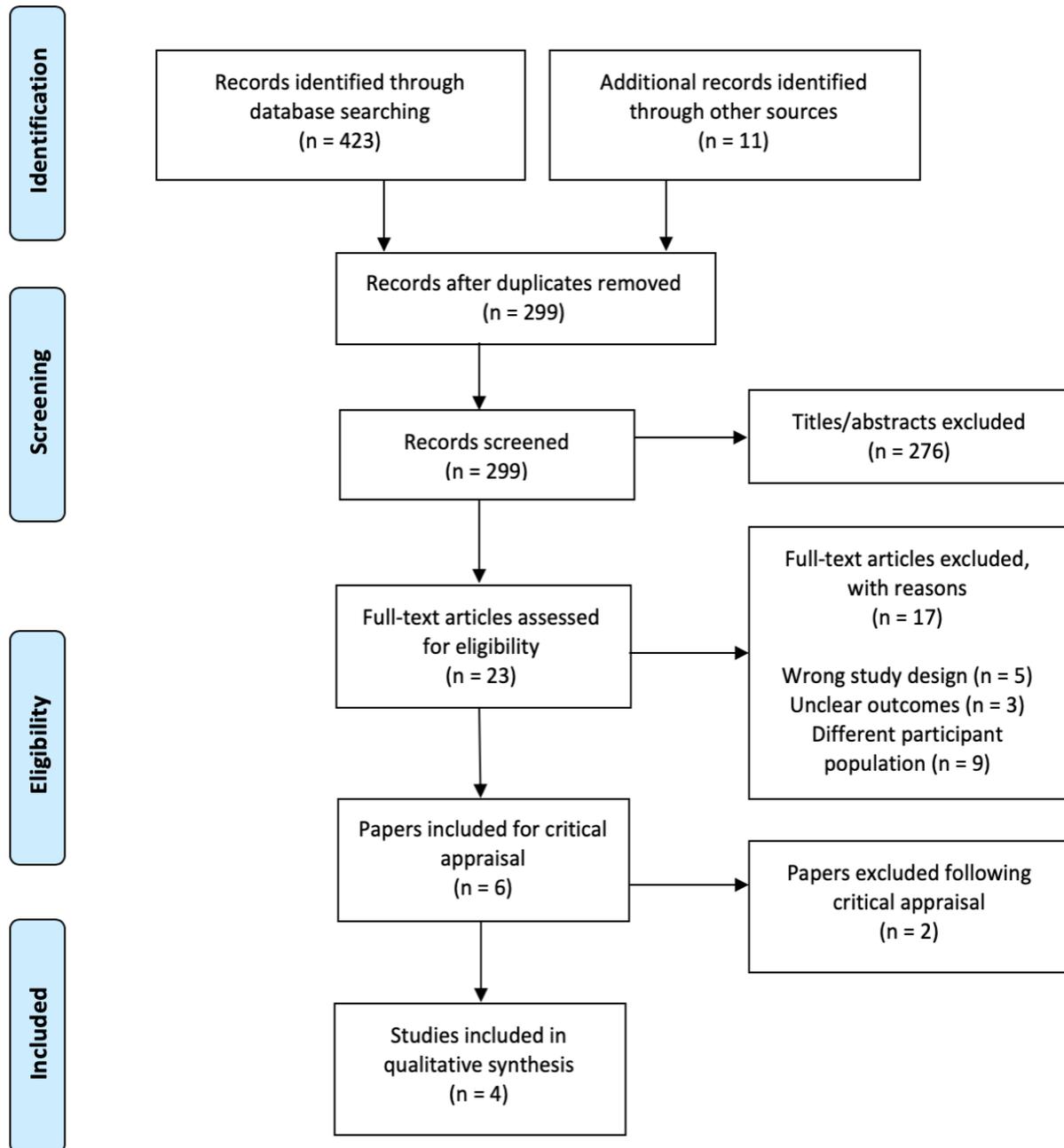


Figure 2 Preferred reporting items for systematic reviews and meta-analyses (PRISMA) flow chart

(Moher, Liberati, Tetzlaff, & Altman, 2010)

## Overview of Included Studies

This section presents an overview of the four studies included in the review. Study details, design, criteria for autism diagnosis, participant population, including age, gender, and sexuality identity of participants, and key findings will be presented.

None of the studies included for the review had a population exclusive to the review criteria and it is apparent that this population has not been considered as distinct group. The lowest minimum age across the included studies was 18 years and the oldest study participant was 62 years. Gender identity was discussed by two of the included studies: the Barnett and Maticka-Tyndale (2015) study had five participants who identified as genderqueer or androgynous, but none of those five were within the age range for the purposes of this review. The Landon (2016) study stated that “all participants identified as being young women” (p. 40) but then discussed one participant who described herself as gender non-binary. This participant did fit all other criteria for this review and was voluntarily participating in a study of autistic young women, so was included.

**Barnett and Maticka-Tyndale (2015).** *Qualitative exploration of sexual experiences among adults on the autism spectrum.*

The Barnett and Maticka-Tyndale (2015) study was a thematic analysis of internet-facilitated interviews with autistic adults (n=24). The age range of participants was 18–61 years. Study criteria for autism diagnosis was self-identification on the autism spectrum. Thirteen participants identified as female, six as male, and five as genderqueer or androgynous. The sexual identity of participants was discussed, with eleven participants identified as heterosexual and three adding identification as bi-curious, asexual, and sapiosexual (described by the authors as ‘primary attraction to intelligence’). Six participants

identified as asexual, four as bisexual-queer, and three participants identified as lesbian or gay. Data from one participant of the study, a 23-year-old female who used the pseudonym 'Billy Joel', were eligible for this review.

Key findings of the study were that participants were less likely than the non-autistic population to be heterosexual or gender-conforming and were more likely to have had their first sexual or romantic experience later than the general population. The most common concerns cited by participants were managing sensory dysregulation in the context of partnered sex and beginning and maintaining relationships. Recommendations made by the authors included targeted sex education that normalises sexuality and gender differences for autistic individuals, and future research on the impact of sensory sensitivities on sexual health.

**Hannah and Stagg (2016).** *Experiences of sex education and sexual awareness in young adults with autism spectrum disorder.*

The Hannah and Stagg (2016) study was a study of 40 individuals aged 18–25 years. Twenty participants (12 males and 8 females) were autistic and 20 (7 males and 13 females) were not. Study criteria for autism diagnosis was clinical diagnosis of autism, but verification of such was not mentioned. The study design was mixed methods, with the aim of exploring the perceptions of autistic adults regarding sex, relationships, and sex education compared to their non-autistic peers. The sexuality identity of participants was not discussed. The qualitative portion of the study was examined for the purposes of this review, and involved semi-structured, face-to-face interviews with two males and two females from the autistic participants of the quantitative study, and two males and two females from the non-autistic participants of the quantitative study. Data from two autistic female participants, 'F1' and 'F2', who participated in the qualitative study were eligible for this review.

Key findings of the study were that mainstream sex and relationship education did not meet the needs of the autistic participants and, due to difficulties participating in peer groups and forming friendships, they were not able to benefit from knowledge gained through peer interactions. It was also found that autistic participants exhibited a higher level of vulnerability to sexual exploitation and victimisation than their non-autistic peers. Recommendations focussed on the need for sex education to be tailored specifically for autistic individuals, taking into account concerns such as lack of social and peer support, and difficulties interpreting the actions and intentions of others.

**Kock et al. (2019).** *Autistic women's experience of intimate relationships: The impact of an adult diagnosis.*

Kock et al. (2019) conducted semi-structured, face-to-face interviews with eight autistic female participants to examine the experience of intimate relationships of women who had been diagnosed with autism as adults, with diagnosis according to DSM-IV or DSM-5 in the previous five years as a study criterion. Diagnosis was verified where possible. Participants of the study were aged 20–40 years, with data from one participant, 'P4', who was aged 24 years, eligible for this review. The sexuality of the participants was described, with three participants identified as heterosexual, three as bisexual, one as bisexual and demisexual (described as attraction where an emotional bond exists; Demisexuality Resource Center, 2015), and one participant identified as asexual.

Key findings of the study were a need for autism-specific post-diagnosis support and counselling, with a focus on beginning and maintaining intimate relationships, for autistic women diagnosed in adulthood. It was also found that autistic women have a need for support in managing sexual interactions, including protective behaviours, managing sensory challenges, and communication within relationships. Recommendations for future research

included research on the sexual identities of autistic people, including those from different cultural groups.

**Landon (2016).** *Romantic relationships: An exploration of the lived experiences of young women who identify a diagnosis of autism spectrum disorder.*

The Landon (2016) paper was from a Doctoral thesis which had the aim of exploring the lived experiences of autistic women in romantic relationships. The study took the form of semi-structured, face-to-face interviews with six autistic women aged 19–29 years. Data from three of these participants, ‘Claire’, aged 22 years, ‘Ellie’, aged 19 years, and ‘Fiona’, aged 19 years, were eligible to be included in this review. Study criteria for autism diagnosis required self-identification as autistic and did not require a formal diagnosis.

The participants’ sexuality and gender identity were not discussed in detail, apart from when it arose as part of the individual interviews. With regard to gender identification, one participant described herself as gender non-binary and four other participants were reported as identifying as ‘non-stereotypical feminine’. When discussing sexuality, three participants described themselves as bisexual or pansexual, while all but one reported previous same-sex sexual experiences. Two participants were reported as asexual and one had never had sex and was not interested in ever doing so.

Key themes that emerged from the study were sexual vulnerabilities, abuse in relationships, confusion around gender and sexuality identity, and a lack of understanding of consent in sexual matters. Recommendations for practice and future research included the need to support autistic young women to understand the concept of gender identity, specific, targeted sex education including the concept of consent.

## Methodological Quality

The four studies that met the inclusion and exclusion criteria were assessed for quality using the CASP Qualitative Checklist (Critical Appraisal Skills Programme [CASP], 2018). The checklist can be viewed in Appendix A. The quality of the included studies was moderately high, with one study (Landon, 2016) scoring a ‘yes’ (i.e., positive) answer for 9 out of a possible 9 quality measures. One study scored 8 (Kock et al., 2019) and the remaining two (Barnett & Maticka-Tyndale, 2015; Hannah & Stagg, 2016) scored 7 out of 9.

Two of the four studies (Barnett & Maticka-Tyndale, 2015; Hannah & Stagg, 2016) were rated as ‘can’t tell’ for Question 4, which related to study participant recruitment strategy, and whether the strategy used was appropriate to the aims of the research. In these studies, recruitment strategy or the limitations thereof (e.g., internet) was not described or discussed in detail. Three of the four studies appraised were rated as ‘no’ for Question 6 (Barnett & Maticka-Tyndale, 2015; Hannah & Stagg, 2016; Kock et al., 2019), which asked “Has the relationship between researcher and participants been adequately considered?”. Two of these three studies involved face-to-face interviews (Hannah & Stagg, 2016; Kock et al., 2019) and one was an internet-facilitated chat format (Barnett & Maticka-Tyndale, 2015). One of the studies had an autistic young woman as “community advisor” (Barnett & Maticka-Tyndale, 2015), but none of the three studies in question examined or considered potentially confounding factors of the researcher/participant relationship. All studies included recommendations for future research. Full details of critical appraisal questions are shown in Figure 3. Table 7 presents results of the critical appraisal.

### Critical Appraisal Questions

- 1 Was there a clear statement of the aims of the research?
- 2 Is a qualitative methodology appropriate?
- 3 Was the research design appropriate to address the aims of the research?
- 4 Was the recruitment strategy appropriate to the aims of the research?
- 5 Was the data collected in a way that addressed the research issue?
- 6 Has the relationship between researcher and participants been adequately considered?
- 7 Have ethical issues been taken into consideration?
- 8 Was the data analysis sufficiently rigorous?
- 9 Is there a clear statement of findings?

Figure 3 Critical appraisal questions

(Critical Appraisal Skills Programme [CASP], 2018)

Table 7 Critical Appraisal of included studies

| Study                             | Q1 | Q2 | Q3 | Q4 | Q5 | Q6 | Q7 | Q8 | Q9 |
|-----------------------------------|----|----|----|----|----|----|----|----|----|
| (Barnett & Maticka-Tyndale, 2015) | Y  | Y  | Y  | CT | Y  | N  | Y  | Y  | Y  |
| (Hannah & Stagg, 2016)            | Y  | Y  | Y  | CT | Y  | N  | Y  | Y  | Y  |
| (Kock et al., 2019)               | Y  | Y  | Y  | Y  | Y  | N  | Y  | Y  | Y  |
| (Landon, 2016)                    | Y  | Y  | Y  | Y  | Y  | Y  | Y  | Y  | Y  |

Y = Yes, N = No, CT = Can't tell (see Appendix 1 for details of questions)

## Characteristics of Included Studies

Characteristics of included studies are summarised in Table 8. A detailed description of the setting, participant population, and diagnosis method of each of the studies included in this review, as well as a summary of participant demographics follows.

Table 8 *Characteristics of included studies*

| Study                             | Methodology                       | Method   | Phenomena of interest   | Geographical/ Setting  | Participants   | Data analysis     | Conclusion   |
|-----------------------------------|-----------------------------------|--|---|--|--|-------------------|--|
| (Barnett & Maticka-Tyndale, 2015) | Phenomenology                     | Semi-structured, internet facilitated interviews | How autistic individuals describe their own sexuality and sexual experiences. Examine implications of those descriptions for the delivery of sex education  | U.S.<br><br>Online (email, chat, streaming audio, e.g., Skype) | N = 24<br>(13 F, 6 M, 5 Genderqueer or androgynous)<br><br>Ages 18–61 years<br>Person on autism spectrum, aged 18 years or older, ability to communicate orally or through writing.<br><br>Eligible for this review: N=2 | Thematic analysis | Participants’ concerns regarding courtship and sensory difficulties in the context of partnered sexuality were exacerbated by inadequate and inappropriate sex education experiences |
| (Hannah & Stagg, 2016)            | Mixed method – inductive approach | Semi-structured interview                        | What perceptions do young people with ASD have surrounding their experiences of sex, relationships and sex education?<br>How have these experiences made them feel?<br>How do these experiences and perceptions compare to typically developing young adults? | U.K.<br><br>Private room at library or ASD social club         | Qualitative portion: N=8 (4 M, 4 F)<br>Ages 18–25 years<br>No intellectual disability.<br><br>Eligible for this review: N=4  | Thematic analysis | Findings suggest that young people with ASD have specific needs and requirements from sex education that are separate from those of typically developing young people                |

|                     |   |                           |   |  |   |  |  |
|---------------------|---|---------------------------|---|--|---|--|--|
| (Kock et al., 2019) | Phenomenology                                     | Semi-structured interview | Explore the experience of intimate relationships of women who have been diagnosed with autism in adulthood  | U.K.<br><br>Various: participants' homes, university meeting rooms | N=8 F<br>Age 20–40 years<br><br>Eligible for this review: N=1 | Interpretive phenomenological analysis | The findings indicate a need to support women with ASD in how to manage their sexual interactions  |
| (Landon, 2016)      | Social constructivist epistemological perspective | Multiple case study       | How the participants make sense of and understand their own experiences of romantic relationships, in the dual contexts of being a young woman and being on the autism spectrum | U.K.<br><br>Quiet room of participant choice                       | N=6 F<br>Age 19–29 years<br><br>Eligible for this review: N=3 | Interpretive phenomenological analysis | Young autistic women may be vulnerable to relationship abuse or exploitation.<br>... educational psychologists will have a role in helping support young women to reach (desired) outcomes |

Note: While data from ten study participants were eligible for inclusion in this review, attributable data were only able to be extracted for seven.

### **Setting.**

Four studies met the inclusion criteria. Geographical setting was the United Kingdom (U.K.) for three studies (Hannah & Stagg, 2016; Kock et al., 2019; Landon, 2016) and United States (U.S.) for one (Barnett & Maticka-Tyndale, 2015). The setting for the Barnett and Maticka-Tyndale study was the internet format of the participant's choice (email, internet chat, or streaming audio, e.g., Skype), however an inclusion criterion was U.S. citizenship. The studies by Hannah and Stagg, Kock et al., and Landon all employed a face-to-face interview format: in a private room at a library or autism social club (Hannah & Stagg); various locations including private home or university meeting room (Kock et al.); or an unspecified quiet room of the participant's choice (Landon).

### **Participant population.**

Two studies (Kock et al., 2019; Landon, 2016) had a specifically female participant population and one had a population of both male and female participants (Hannah & Stagg, 2016). The Barnett and Maticka-Tyndale (2015) study included male and female participants but acknowledged participants' possible differences in gender identification. Age range for the studies varied, however only data for female participants aged 16–25 years was extracted for this review, with data from a total of seven participants being eligible.

### **Autism diagnosis.**

As shown in the *Overview of Included Studies*, criteria for autism diagnosis status varied in each study. Barnett and Maticka-Tyndale (2015) required that the participants be self-identified as on the autism spectrum. Diagnosis or verification of such was not discussed further, beyond a comment with regard to the participants' self-identification as autistic individuals as a positive contribution to the nuance and detail of qualitative research. The

Hannah and Stagg (2016) study included both non-autistic and autistic participants and referred to the latter as having a clinical diagnosis of Autism Spectrum Disorder but did not elaborate on how or whether this was verified. Kock et al. (2019) required that participants had received a diagnosis in accordance with the DSM-IV or DSM-5 within the previous 5 years. Diagnosis was verified where possible, according to source of diagnosis. The author stated that diagnoses that originated from practitioners of the U.K. National Autistic Service (NAS) were not able to be verified, and thus relied on participant confirmation. Similar to the Barnett and Maticka-Tyndale study, the Landon (2016) study did not require evidence of a formal autism diagnosis and relied on the report of participants. It was stated that the author felt that such a requirement would negatively affect the researcher's rapport with participants, although one of the semi-structured interview questions was about diagnosis: what diagnosis the study participant identified with and how they realised they were autistic. The fact that autistic females often do not receive diagnoses until adulthood was cited as a reason for waiving the requirement for a formal diagnosis (Attwood, 2007); it was stated that as participants in this study were young adults, it was probable they would not have a formal diagnosis of autism.

Participant demographics are summarised in Table 9.

Table 9 *Summary of individual study participant demographics*

| <b>Study</b>                      | <b>Participant</b> | <b>Age</b> | <b>Sexuality</b>     | <b>Gender identity</b> | <b>Diagnosis method</b> |
|-----------------------------------|--------------------|------------|----------------------|------------------------|-------------------------|
| (Barnett & Maticka-Tyndale, 2015) | Billy Joel         | 23         | Asexual              | Female                 | Self-identified         |
| (Hannah & Stagg, 2016)            | F1                 | *NS        | *NS                  | Female                 | Clinical diagnosis      |
| (Hannah & Stagg, 2016)            | F2                 | *NS        | *NS                  | Female                 | Clinical diagnosis      |
| (Kock et al., 2019)               | P4                 | 24         | Bisexual             | Female                 | Clinical diagnosis      |
| (Landon, 2016)                    | Claire             | 22         | Pansexual            | Non-binary             | Self-identified         |
| (Landon, 2016)                    | Ellie              | 19         | Bisexual             | Female                 | Clinical diagnosis      |
| (Landon, 2016)                    | Fiona              | 19         | Bisexual;<br>Asexual | Female                 | Clinical diagnosis      |

\*NS = Not Stated. Study was restricted to participants aged 18–25 years.

## **Findings of the Review**

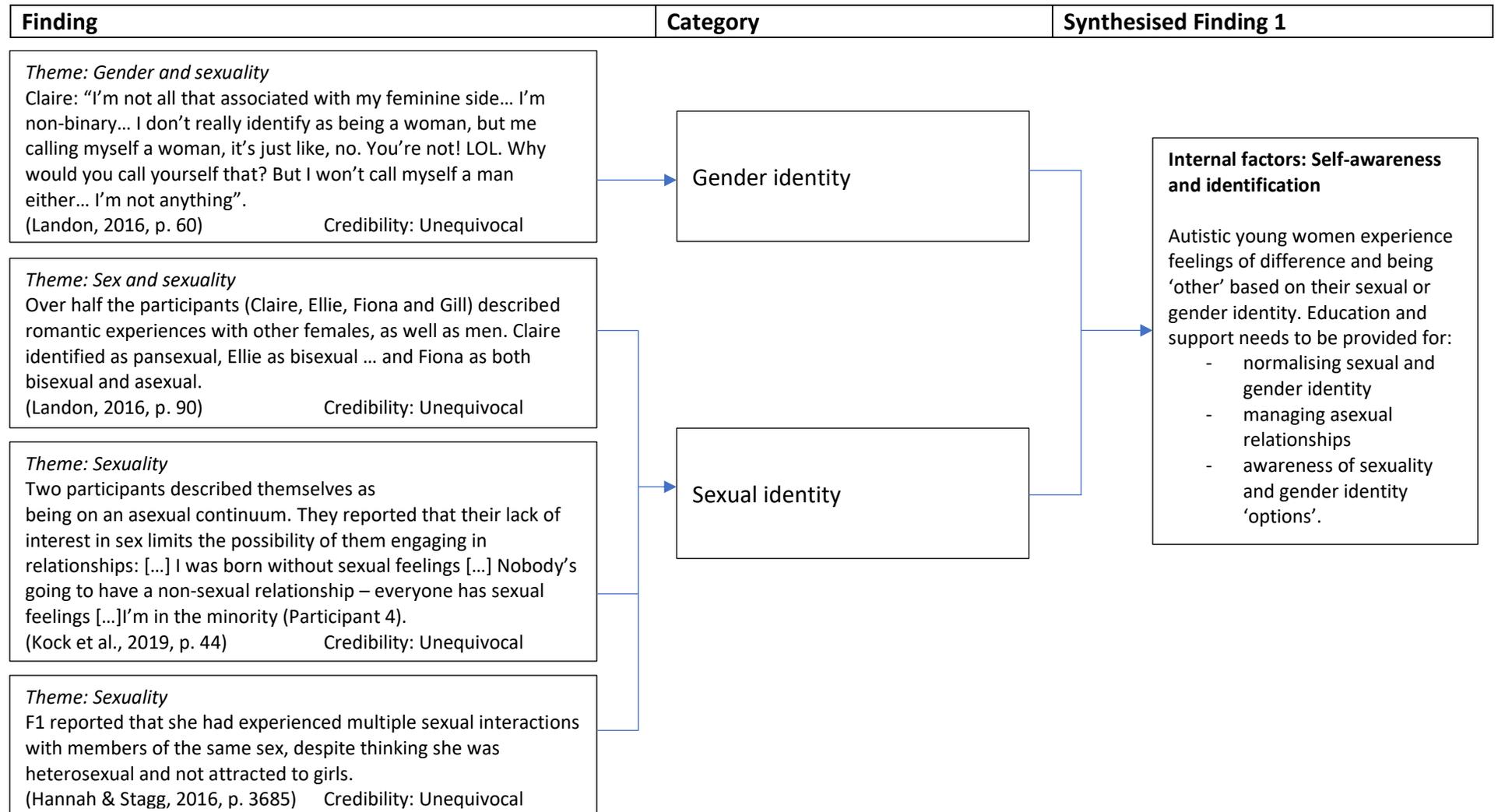
Thirteen findings that illustrated the experiences of autistic women in matters of sexuality and sexual health were extracted from the four studies included in the review. The findings were assessed for similarity of theme or content and grouped accordingly into categories. A credibility level according to the Joanna Briggs Institute Reviewers Manual (Aromataris & Munn, 2017) was assigned to each finding to illustrate that the finding was:

- Unequivocal: relates to evidence beyond reasonable doubt which may include findings that are matter of fact, directly reported/observed and not open to challenge; or
- Credible: albeit interpretations, plausible in light of data and theoretical framework. They can be logically inferred from the data. Because the findings are interpretive they can be challenged (Aromataris & Munn, 2017).

Six theme categories were established, from which two synthesised findings were identified, based on similarity in meaning: *Internal Factors: Self-awareness and identification*, which relates to the study participants' gender and sexuality self-awareness and identification, and *External Factors: Education and social communication*, which relates to factors around sex education and social communication. The first synthesised finding, *Internal Factors: Self-awareness and identification* was comprised of two theme categories, which were supported by four findings. The second synthesis, *External Factors: Education and social communication*, contained four theme categories from nine findings. Some findings were peripherally linked to the subject at hand, but due to the paucity of studies eligible for inclusion in the review, it was necessary to include all related material.

The narrative describes the categories that form the synthesised findings and provides a descriptive summary of the review. Figure 4 provides a visual representation of initial findings, credibility level, theme categories, and synthesised findings.

Figure 4 Meta-aggregative synthesis of initial findings



| Finding | Category | Synthesised Finding 2 |
|---------|----------|-----------------------|
|---------|----------|-----------------------|

*Theme: Negative experiences*  
 F1 described how another female had purposely intoxicated her with alcohol with the intent of having sex with her. Another occasion was described by F1 whereby she was influenced and encouraged by others to perform sexual acts with a female. F1 did not appear to be aware that these incidences could be perceived as someone taking advantage of her or abuse. (Hannah & Stagg, 2016, p. 3686) Credibility: Unequivocal

*Theme: Understanding others*  
 F2 expressed that she felt herself and others with autism needed help understanding other’s intentions and identifying “the right sort of partner”. (Hannah & Stagg, 2016, p. 3686) Credibility: Unequivocal

*Theme: Shared strategies for success*  
 The intentional, open and explicit communication required to plan sex or maintain flexibility with regard to competing needs was the central strategy that emerged. This strategy, which we call “literal declaration,” was discussed by every participant, and is characterized by direct, explicit disclosure. (Barnett & Maticka-Tyndale, 2015, p. 176) Credibility: Unequivocal

*Theme: Experience of relationships as an autistic person*  
 All eight participants spoke about a wide range of difficulties which they experienced in their intimate relationships. (Kock et al., 2019, p. 44) Credibility: Credible

*Theme: Methods of understanding relationships*  
 Twice when asked how she knew someone liked her, Claire used sex as evidence: “He continued being all flirty and everything and like end up having sex.... The morning after he was like, ‘...I still don’t want to be with you.’ What’s that supposed to mean?” (Landon, 2016, p. 61) Credibility: Unequivocal

Sexual vulnerabilities

Communication within or perceptions of sex and sexual relationships

**External factors: Education and social communication**

Autistic young women need clear, specific education about

- Sex and sexuality
- Protective behaviours
- Communication in relationships
- Rights and responsibilities in relationships
- Managing expectations around sexual encounters and in relationships

| Finding | Category | Synthesis |
|---------|----------|-----------|
|---------|----------|-----------|

*Theme: Inadequate sex education*  
 Billy Joel, a 23-year-old asexual woman, had this to say:  
 “I understand how crucial it was to learn at school even though it was boring, because I didn’t get any of it at home. At the same time, I feel like it was learning about something not real. There was no conceptualization for what sex really is, and as an adult (well, a college student), it took people literally telling me that it was fun, enjoyable, and felt good for me to get why people engage in those behaviors.”  
 (Barnett & Maticka-Tyndale, 2015, p.175)  
 Credibility: Unequivocal

*Theme: Dissatisfaction with sex education in school*  
 “I feel like I’ve been given the tools, but I just didn’t use them because they weren’t clear enough”.  
 (Hannah & Stagg, 2016, p. 3682) Credibility: Unequivocal

*Theme: Abuse and manipulation of romantic interest*  
 Ellie described several crushes in terms of what they could offer her. When describing her first sexual experience, she said:  
 “I wanted to lose my virginity, he offered and just got it done and over with... I didn’t feel any attachment”.  
 (Landon, 2016, p. 71) Credibility: Credible

*Theme: Sex and sexuality*  
 Fiona: “He thought that I was weird for not wanting to have sex with him. Although I am weird I don’t think I am weird for that reason”.  
 (Landon, 2016, p. 91) Credibility: Unequivocal

Inadequate sex education

Attitudes toward sex and sexuality



### **Synthesised Finding 1: Internal Factors: Self-awareness and identification.**

Data from three studies (Hannah & Stagg, 2016; Kock et al., 2019; Landon, 2016) were extracted to form the two categories that formed this synthesised finding. The initial findings related to issues of gender identity, and sexuality and sexual identity.

Categories were: *Gender Identity*, and *Sexual Identity*.

#### ***Category: Gender identity.***

Finding: *Gender and Sexuality*.

Data from one study participant reported feelings of ambivalence toward gender labels and expressed a feeling of a lack of gender identity (Landon, 2016). There were no other findings that related directly to gender; thus, this finding formed the category *Gender Identity*.

#### ***Category: Sexual identity.***

Findings: *Sex and Sexuality* and *Sexuality*.

The category *Sexual Identity* comprised three findings associated with perception of sexual identity. Data from study participants reported feelings of asexuality or confusion around sexual identity. One finding with the theme of *Sexuality* reported data from a study participant who felt that as an asexual person, she was in the minority and that she believed that she was not going to be able to find a partner who would participate in a non-sexual relationship (Kock et al., 2019). Another finding, also with the theme *Sexuality*, reported data from a study participant who identified as heterosexual but had sexual relationships with other females (Hannah & Stagg, 2016). A third finding, under the theme *Sex and Sexuality* contained data that discussed the fact that study participants had relationships with women as well as men (Landon, 2016). This was not reported as being necessarily problematic, and it

was also reported that the relevant study participants all described a sexuality other than heterosexual.

***Synthesis.***

Data across the two categories (*Gender Identity* and *Sexual Identity*) included in Synthesised Finding 1 reported study participants as feeling outside the sexual and/or sexuality 'norm'. The reports and statements stemmed from internal beliefs and identification; thus, the two categories were included in the synthesised finding *Internal Factors: Self-awareness and identification.*

**Synthesised Finding 2: External factors: Education and social communication.**

Data was extracted from all four studies included in the review to form this synthesised finding. Extracted data related to how study participants described their perceptions of sex and sexual relationships, how they communicated within or perceived sexual encounters, the level of sex education provided and how it was understood or used, and attitudes toward sex and sexuality. Nine findings were grouped into four theme categories: *Sexual Vulnerabilities; Communication Within Sexual Relationships; Inadequate Sex Education; and Attitudes Toward Sex and Sexuality.*

***Category: Sexual vulnerabilities.***

***Finding: Sexual Vulnerabilities.***

Data from the finding with the theme *Negative Experiences* reported that one study participant was deliberately given alcohol by another female with the intent of having sex with her (Hannah & Stagg, 2016). The same finding also contained a report that the same study participant had been encouraged by others to perform sexual acts, but the young

woman was not aware that the other person was taking advantage of her, or that both of these acts could be perceived as abusive. This finding was the only explicit statement by a study participant of possible vulnerability to abuse, thus it formed the category *Sexual Vulnerabilities*.

***Category: Communication within or perceptions of sex and sexual relationships.***

Findings: *Understanding Others*; *Shared Strategies for Success*; *Experience of Relationships as an Autistic Person*; and *Methods of Understanding Relationships*.

Data was extracted from four findings related to communication difficulties within sexual relationships and were grouped in the category *Communication Within or Perceptions of Sex and Sexual Relationships*. The finding *Understanding Others* contained data from one study participant that showed an explicit statement that she needed help understanding the intentions of others (Hannah & Stagg, 2016). This statement was made in the context of intimate relationships as well as sexual safety and so was included in this category. Data from another finding, *Methods of Understanding Relationships* described a situation where the study participant was not able to interpret the actions of a sexual partner and, after having sex, was confused as to whether he liked her (Landon, 2016). The finding *Shared Strategies for Success* reported data showing that autistic women found that explicit, open communication was essential to manage competing needs in a relationship and was a strategy that study participants had independently developed and reported (Barnett & Maticka-Tyndale, 2015). Another finding, *Experience of Relationships as an Autistic Person* contained data from study participants experiencing a wide range of difficulties in relationships (Kock et al., 2019).

***Category: Inadequate sex education.***

Findings: *Inadequate Sex Education*; and *Dissatisfaction with Sex Education in School*.

These two findings clearly reported data showing that the sex education that had been provided at school was insufficient and inadequate; this formed the category of *Inadequate Sex Education*. Data from one study participant contained the statement that she had been given the education, but it was not clear enough for her to be able to use it (Hannah & Stagg, 2016). This formed the finding *Dissatisfaction with Sex Education in School*. Data from the finding *Inadequate Sex Education* contained a statement that the study participant felt she was given the education, but due to the abstract nature of that education, was not aware that sex could be enjoyable. Data from the same participant reported that she did not receive sex education in her home setting (Barnett & Maticka-Tyndale, 2015).

***Category: Attitudes toward sex and sexuality.***

Findings: *Abuse and Manipulation of Romantic Interest*; and *Sex and Sexuality*.

The third category included in Synthesised Finding 2 was *Attitudes Toward Sexuality*. This category was comprised of two findings: *Abuse and Manipulation of Romantic Interest*, and *Sex and Sexuality*, wherein data from study participants reported a lack of empathy toward or understanding of their partner's feelings or views and exemplified a lack of understanding of intimate relationships. The finding with the theme *Abuse and Manipulation of Romantic Interest* reported data from a study participant who described her first sexual experience in terms of what the experience offered her. She stated that she felt no attachment to her sexual partner, intimating that he was a means to an end, which was the loss of her virginity (Landon, 2016). The second finding, *Sex and Sexuality* reported data as a statement from an autistic woman who stated that that her partner found her 'weird' because she didn't

want to have sex with him. She stated that she felt that she was indeed weird, but not for the reason given (Landon, 2016).

### ***Synthesis.***

Participants across the four categories included in Synthesised Finding 2 (*Sexual Vulnerabilities; Communication Within Sexual Relationships; Inadequate Sex Education; and Attitudes Toward Sex and Sexuality*) contained data that reported situations or behaviours that were exhibited where basic school sex education, as well as more specific support and education around communication in social situations were a factor. This type of support comes from external sources; thus, these findings and categories were included in the synthesised finding *External factors: Education and social communication*.

This chapter has demonstrated the results of the review and provided an overview of the studies. Characteristics of the studies were also presented. The findings, categories, and the meta-aggregated synthesis were demonstrated. The following chapter will discuss an overview of the findings and implications thereof, strengths and limitations will be explored, and considerations for future research and practice will be presented.

## **Chapter 5: Discussion**

This review synthesised current qualitative research on the lived experience of sexual health literacy of autistic young women and presented a meta-aggregative synthesis of findings and key issues. The following chapter is a discussion of the implications of the findings of the review. Strengths and limitations will be explored and considerations for future research and practice will be presented.

### **Overview of Findings**

The aim of this review was to explore the experiences of autistic young women in the acquisition of sexual health literacy via a systematic review of the qualitative literature. It was anticipated that there would be few studies and a thorough search of the literature proved this expectation to be accurate. The lack of qualitative research addressing the sexual health literacy of autistic young women aged 16–25 years highlights the importance of considering the current interventions being practiced and reviewing the support being offered to autistic women in matters of sexual health and sex education.

The findings of the review were incorporated into two synthesised findings. The findings confirmed that autistic young women find the acquisition of sexual health literacy to be challenging due to a combination of internal factors, such as self-awareness and self-identification, and external factors such as education and social communication. These points will be discussed with reference to issues such as identity and belonging, sexual and emotional safety, social communication and its impact on sexual vulnerability, sexuality education, and sexual health.

## **Internal factors: Self-awareness and identification.**

### ***Identity and belonging.***

The systematic review identified a number of challenges that autistic young women reported in the area of sexuality and sexual health. Throughout the review, data from study participants on the topic of diverse sexual and gender identity identified that the study participants felt in the minority and experienced a feeling of a lack of belonging (Kock et al., 2019). Data also showed that study participants experienced difficulties reflecting upon and being aware of their sexuality (Hannah & Stagg, 2016) and that autistic individuals experienced their sexuality and gender diversity as being outside what the individual perceived to be 'normal' (Barnett & Maticka-Tyndale, 2015). Landon (2016) stated that participants had aspirations of relationships where the façade of 'normal' could be set aside and a sense of acceptance and belonging achieved.

It has been stated that autistic individuals are more subject to feelings of loneliness than their non-autistic peers (Whitehouse, Durkin, Jaquet, & Ziatas, 2009) and that autistic people are known to experience poorer mental health than their non-autistic counterparts (George & Stokes, 2018a). Sexuality and gender diverse young people are more likely to experience exclusion and bullying than non gender- and sexuality-diverse young people (Jones & Hillier, 2013; E. Smith et al., 2014) and autistic people, especially females, are known to have a greater incidence of non-heterosexual sexual identities than their non-autistic peers (Barnett & Maticka-Tyndale, 2015; Dewinter et al., 2017; George & Stokes, 2018c). While there is a body of research on the sexuality of autistic individuals, less attention has been paid to the specific needs of autistic young women in the realm of sexuality and intimate relationships. However, autistic females are known to have greater difficulty in socialising and have more difficulty managing and maintaining social situations as they move through adolescence and adulthood (Cridland et al., 2014; Mademtzi, Singh,

Shic, & Koenig, 2018). It is likely, therefore, that gender and/or sexuality diverse autistic females will experience exclusion or possibly bullying at some stage as an adolescent or young adult. Such bullying and exclusion, when experienced as homophobia, can have a significant negative effect on the schooling experience and mental health status of the person affected (Robinson et al., 2013; Ullman, 2015).

When all of these factors are considered together, data from the included studies shows that the young autistic women who were participants in the studies reported feeling a lack of belonging and confusion with regard to sexuality and/or gender identity. Autistic young women need support to recognise and identify their own gender and sexuality identities. In order to do this, they require information in a format they find accessible that assists them to feel part of a wider community.

### *Sexual and emotional safety.*

It has been reported, and it is shown by others reviewed herein (Barnett & Maticka-Tyndale, 2015; Hannah & Stagg, 2016; Kock et al., 2019; Landon, 2016), that autistic individuals are less aware of their sexuality than non-autistic peers (Bush, 2018; Hannah & Stagg, 2016). It is also clear that autistic young women who do not recognise their diverse sexuality are potentially at risk: If most school-based sex education is heteronormative (Robinson et al., 2013), and these young women do not identify as sexuality diverse, this potentially has implications for their sexual safety.

Recommendations have been made for the design of specific education programs to support autistic individuals to recognise and become more conscious of their sexuality, whether it be diverse or otherwise (Bush, 2018; Hannah & Stagg, 2016; MacKenzie, 2018) and it has been found that autistic women would benefit from support in the development of a positive sexual identity (Byers, Nichols, Voyer, & Reilly, 2013). (Barnett & Maticka-

Tyndale, 2015) recommended the development of interventions that seek to normalise the sexual and gender identity of autistic individuals. Such interventions may well be original but could also be adapted from existing interventions. It would make sense that the population for whom these interventions are intended should play a key role in the development and/or adaptation of these materials. The interventions should not necessarily seek to apply ‘labels’ to sexual identities but should support young autistic women to recognise and identify their sexuality needs in terms of mental and emotional health, as well as practical sexual health and safety measures.

**External factors: Education and social communication.**

*Social communication and sexual vulnerability.*

The second synthesised finding was drawn from factors relating to education and social communication. The categories included in this synthesis all pointed towards factors that indicated that autistic young women would benefit from education relating to sex and sexuality matters, as well as support in social communication. Social communication is communication that is required for social purposes (American Psychiatric Association, 2013b). Following conversational rules, understanding inferences, and interpreting non-verbal communication are all aspects of social communication and are aspects of communication with which many autistic individuals have difficulties (American Psychiatric Association, 2013b). It has been suggested that deficits in social communication not only affect the ability to build and maintain friendships and relationships and the ability to initiate sexual encounters, but may contribute to an increase in sexual vulnerability (Kock et al., 2019). The Hannah and Stagg (2016), Kock et al., and Landon (2016) studies, supported by Cridland et al. (2014), Pecora et al. (2016) and others, have all recognised and discussed the probability that young autistic women were more likely to be vulnerable to abuse or

exploitation both in and out of relationships due to difficulties in interpreting the intentions of others, especially with regard to verbal and non-verbal communication.

The interpretation and usage of social communication was also reported as a factor that led to challenges in communicating within and managing relationships: dealing with spontaneity, unclear or absent 'rules' (Kock et al., 2019); misinterpreting situations, potentially leading to behaviours such as stalking (Hannah & Stagg, 2016); and difficulty understanding the other person's point of view (Landon, 2016). Barnett and Maticka-Tyndale (2015) reported on a strategy named as "literal declaration" (p. 176), which participants of that study had developed in order to manage communication and planning around sexual situations. Sperry and Mesibov (2005) discussed the necessity for open, literal communication in order to begin or maintain successful relationships, intimate or otherwise. However, autistic individuals frequently lack the skills or knowledge required to either implement such strategies appropriately, or to interpret situations and provide the appropriate required response (Landon, 2016; Mehzabin & Stokes, 2011; Stokes, Newton, & Kaur, 2007).

Challenges in assertiveness and decision making with regard to sexual experiences were also addressed in the studies included in the review, including the ability of autistic young women to know when and how to make their wishes clearly known, or how to say 'no' in sexual situations (Hannah & Stagg, 2016; Landon, 2016). The ability to be assertive and to provide consent in sexual situations is an important aspect of sexual wellbeing, though there is currently no available research specifically addressing the assertiveness and ability of autistic women to give consent in sexual or intimate relationship situations and little on sexual decision-making of autistic individuals (Mackenzie & Watts, 2013, 2015). It has been found that autistic individuals are less likely to display assertiveness in general (Bejerot & Eriksson, 2014), but those autistic individuals who were in a relationship reported higher

levels of assertiveness in sexual situations than those who were not currently partnered (Byers, Nichols, Voyer, et al., 2013). However, it was not made clear whether such assertiveness extended to sexual situations outside the relationship or if it continued once the relationship ended. Transferability of learned assertiveness skills to other relationships or situations, sexual and otherwise, would be advantageous to all autistic individuals.

Specific support in social communication, especially with a focus on sexual encounters and managing relationships, including assertiveness in relationships and the giving and receiving of consent, from professionals trained in such (e.g., speech pathologists) would be of great benefit to many autistic young women.

### ***Sexuality education.***

Data from participants across all studies included in this review identified a lack of education, not only about the mechanics of sex itself, but about communication within sexual situations and intimate relationships. Sexual health, such as STI prevention, was not mentioned. Indeed, the overriding concern of most study participants appeared to be managing and enjoying sexual interactions, and partnership or relationships. While this is an entirely valid and important aspect of adult life and should certainly be encouraged and celebrated, being physically and emotionally safe while doing so is also of significant importance.

Data extracted from the Barnett and Maticka-Tyndale (2015) and Hannah and Stagg (2016) studies showed that participants were provided with sex education, but that they were unable to apply it to themselves or their own situations, due to an inability on the study participant's behalf to apply the knowledge offered to her own specific situation (Barnett & Maticka-Tyndale, 2015), or the materials not being clear or specific enough for the study participant to apply in any practical sense (Hannah & Stagg, 2016). Sex education for autistic

individuals has been investigated and discussed by several authors (e.g., Barnett & Maticka-Tyndale, 2015; Curtiss & Ebata, 2016; Hannah & Stagg, 2016; Pask, Hughes, & Sutton, 2016) and the need for such specialised education has been mentioned in several studies (e.g., Beddows & Brooks, 2016; Brown-Lavoie, Viecili, & Weiss, 2014; Dewinter et al., 2017). However, poor acquisition of sex education by autistic individuals has been recognised and discussed by few authors (Corona, Fox, Christodulu, & Worlock, 2015). It has been recognised that as autistic girls age, they find friendships and peer groups more difficult to build and maintain, hence they lack the sex-related information and discussion they would otherwise be privy to as part of an adolescent friendship or peer group (Curtiss & Ebata, 2016; Mademtzi et al., 2018). Nonetheless, despite recognition of the unique experiences of and need for research about autistic females, especially in matters relating to sex and sexuality, specific research addressing the particular needs of autistic females in sex education is scarce (Bargiela et al., 2016; Bush, 2018; Kock et al., 2019).

There are some studies that address the sex education needs of autistic individuals, but do not discuss gender differences (e.g., Corona et al., 2015; Curtiss & Ebata, 2016; Lehan Mackin, Loew, Gonzalez, Tykol, & Christensen, 2016) and less that examine the needs of adolescent autistic males (e.g., Pask et al., 2016). A comparison and examination of the differing and specific needs of autistic males and females, as well as autistic individuals who are gender diverse would be of benefit with regard to the development of specific interventions for all autistic individuals, and also interventions that meet the differing needs of each group.

### ***Sexual Health.***

While various aspects of sexuality, sexual vulnerabilities, relationships, and sexual and gender identity were discussed in each of the studies included in the review (Barnett &

Maticka-Tyndale, 2015; Hannah & Stagg, 2016; Kock et al., 2019; Landon, 2016), no reference was made in any of the studies to sexual health or sexually transmissible disease prevention, nor to contraception. Data extracted from studies included in the review identified barriers to sexual knowledge and difficulty absorbing and implementing sex education. Evidence from those studies showed that the sex education that the participants were exposed to was not meeting the needs of this population.

It has been stated that definitions of safe sex are generally heteronormative and do not translate well for those who do not identify as heterosexual (Grant & Nash, 2018). It is also known that many women who identify as lesbian, bisexual, or queer are likely to have had unprotected heterosexual sex (Grant & Nash, 2018; Mooney-Somers, Deacon, Klinner, Richters, & Parkhill, 2017). In addition, it has been found that the rate of STIs is similar in heterosexual and non-heterosexual women, and women who identify as non-heterosexual are less likely to have had a cervical screening test or an STI test (Mooney-Somers et al., 2017). While this data does not specifically address the autistic community, it is fair to hypothesise that non-heterosexual autistic women would experience the twofold difficulty of attempting to acquire sexual knowledge from an autistic point of view, as well as from a non-heterosexual point of view and would therefore exhibit the same or greater tendencies toward poor sexual health knowledge.

Development of specific or adaptation of existing sexual health resources for autistic women of all sexuality and gender identities would contribute to their improved sexual health.

## **Summary**

The results of this systematic review have highlighted the lack of qualitative research into the challenges young autistic women encounter in the acquisition of sexual health

literacy. The synthesised results showed a combination of internal factors, such as self-awareness and self-identification and external factors such as education and social communication contribute to autistic young women encountering difficulties in areas such as identity and belonging, sexual and emotional safety, social communication and its impact on sexual vulnerability, sexuality education, and sexual health. The lack of qualitative research in this area highlights the importance of reviewing the current interventions being practiced and the support being offered to autistic women in matters of sex education and sexual health.

## **Strengths and Limitations**

The strength of this review lies in the fact that this is largely unexplored territory. Reviewing the first-person accounts of autistic young women has shown that sexual health literacy as an overarching concept is a difficult status to attain for the target population. However, the review was not without its challenges and limitations. It was made clear that there is a paucity of dedicated qualitative research in this area, not least shown by the fact that none of the articles included had a population or topic exclusive to this review; it is apparent that this population has rarely been considered as distinct group in relation to the subject matter. Two of the included articles pertained mainly to sex education (Barnett & Maticka-Tyndale, 2015; Hannah & Stagg, 2016), and two were focussed on intimate or romantic relationships (Kock et al., 2019; Landon, 2016). As such, each of the articles used different measures for extracting data and reporting themes, which made comparison difficult. Each of the studies also had differing criteria for autism diagnosis, ranging from verified clinical diagnosis to self-identification. This factor highlights a difficulty in researching this population, in that autistic women are often undiagnosed, misdiagnosed, or not diagnosed until adulthood (Milner et al., 2019; Ratto et al., 2018). While verified clinical

diagnoses would be the gold standard of research, until autistic females are not only diagnosed at a younger age but with more accuracy, some flexibility will be required.

Following on from matters of diagnosis, a further limitation of the study was the small sample sizes of the included studies. As none of the included studies addressed a population exclusive to this review, data was only extracted for eligible participants, thus further restricting the sample size of the review. While it is common for qualitative research to have small sample sizes (Milner et al., 2019), this is a factor that may limit the generalisability of the results of this review.

No Australian studies were eligible for the review though, as the included studies were located in either the U.K. or U.S. it is reasonable to expect that the results could be generalised to the Australian context. As studies that were not in English were not considered for inclusion, it is possible that such articles may have contributed to the review.

## **Implications for Practice**

This review has highlighted important factors with regard to the sexual health literacy of autistic young women. It has been made clear that there are significant gaps in the practice and understanding of how autistic young women acquire sexual health literacy. That is, how they acquire and apply sexual health knowledge, form sexual identity, initiate sexual encounters, and form and maintain relationships. With these gaps in knowledge, autistic young women are at risk of STIs, sexual abuse and violence both in and out of relationships, and potential feelings of loneliness or depression due to difficulties confirming and understanding sexual and/or gender identity.

Further work is required to provide practitioners, including speech pathologists and teachers, as well as parents and carers with the practical information and ‘tools’ or resources required to support young autistic women in the acquisition of sexual health literacy. It is

important that all practitioners and supporters be made aware of the needs of this population, including their need for practical knowledge around safe sex practices, regardless of the gender identity of their partner.

Equally important is the provision of resources that young autistic women can access to support their own sexual health knowledge needs. Informative, accessible sexual health resources that provide practical information not only about sex and sexual health but about rights and responsibilities in sex and relationships, and that seek to normalise sexuality, diverse or otherwise, would assist autistic young women to feel they are part of a wider community and would contribute significantly to their emotional and physical health and safety.

## **Future Directions**

This paper has reported on the findings of four qualitative studies pertaining to the sexuality of young autistic women. Although there is some research regarding non-autistic adolescents and how they seek and understand sexual health information, this review has shown that the specific experiences of autistic females with regard to sexual health literacy, in both acquisition and application of knowledge, have not been qualitatively studied and clearly warrant further attention. In-depth, specific qualitative research would explore the individual experiences of autistic young women and inform the development of accessible, appropriate resources and strategies for that population, assist with a clearer understanding of how this population would best engage with the subject matter, and build general awareness of the needs of autistic women as well as inform the practice of health and allied health workers, teachers, and others who support them. It is also recommended that future research compares and examines the differing needs of autistic males and females in how they learn

best with regard to sex education, with specific attention paid to autistic individuals who are sexuality and gender diverse.

## **Conclusion**

To the best of the author's knowledge, this is the first systematic review of the qualitative literature on the sexual health literacy of autistic young women. The review showed that relevant research is sparse and what does exist was incidental to the actual focus of the studies in question. The results showed that young autistic women find mainstream classroom sex education difficult to absorb and process, however they are not receiving the supplemental sex education and knowledge via peer input that non-autistic young women generally access. As a result, formation of sexual identity, feelings of belonging with regard to gender identity, safe sexual practices—regardless of gender identity of sexual partner—and safety in relationships and sexual encounters are all areas in which autistic young women are potentially at risk. In order for autistic young women to be physically and emotionally safe and informed about sex, sexual identity, and sexual health, they require evidence-based information and resources to be made available in a method and format that makes sense to them, and which they find accessible.

While applicable qualitative research was in short supply and the author would have preferred a surfeit of rich data to review and analyse, for a systematic review to be more inclined toward identification of the need for future research, rather than in-depth recommendations for practice is not unknown (Petticrew, 2001). This review reflects the reality that the sexual health literacy of autistic young women is somewhat of an unknown quantity. The contribution of this review lies in highlighting this fact, as well as the implications for practice and recommendations for future research.

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# Appendix A: CASP Checklist



CASP Checklist: 10 questions to help you make sense of a **Qualitative** research

**How to use this appraisal tool:** Three broad issues need to be considered when appraising a qualitative study:

- ▶ Are the results of the study valid? (Section A)
- ▶ What are the results? (Section B)
- ▶ Will the results help (Section C)

The 10 questions on the following pages are designed to help you think about these issues systematically. The first two questions are screening questions and can be answered quickly. If the answer to both is “yes”, it is worth proceeding with the remaining questions. There is some degree of overlap between the questions, you are asked to record a “yes”, “no” or “can’t tell” to most of the questions. A number of italicised prompts are given after each question. These are designed to remind you why the question is important. Record your reasons for your answers in the spaces provided.

**About:** These checklists were designed to be used as educational pedagogic tools, as part of a workshop setting, therefore we do not suggest a scoring system. The core CASP checklists (randomised controlled trial & systematic review) were based on JAMA 'Users' guides to the medical literature 1994 (adapted from Guyatt GH, Sackett DL, and Cook DJ), and piloted with health care practitioners.

For each new checklist, a group of experts were assembled to develop and pilot the checklist and the workshop format with which it would be used. Over the years overall adjustments have been made to the format, but a recent survey of checklist users reiterated that the basic format continues to be useful and appropriate.

**Referencing:** we recommend using the Harvard style citation, i.e.: *Critical Appraisal Skills Programme (2018). CASP (insert name of checklist i.e. Qualitative) Checklist. [online] Available at: URL. Accessed: Date Accessed.*

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Paper for appraisal and reference: .....

Section A: Are the results valid?

1. Was there a clear statement of the aims of the research?

|            |                          |
|------------|--------------------------|
| Yes        | <input type="checkbox"/> |
| Can't Tell | <input type="checkbox"/> |
| No         | <input type="checkbox"/> |

- HINT: Consider
- what was the goal of the research
  - why it was thought important
  - its relevance

Comments:

2. Is a qualitative methodology appropriate?

|            |                          |
|------------|--------------------------|
| Yes        | <input type="checkbox"/> |
| Can't Tell | <input type="checkbox"/> |
| No         | <input type="checkbox"/> |

- HINT: Consider
- If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants
  - Is qualitative research the right methodology for addressing the research goal

Comments:

Is it worth continuing?

3. Was the research design appropriate to address the aims of the research?

|            |                          |
|------------|--------------------------|
| Yes        | <input type="checkbox"/> |
| Can't Tell | <input type="checkbox"/> |
| No         | <input type="checkbox"/> |

- HINT: Consider
- if the researcher has justified the research design (e.g. have they discussed how they decided which method to use)

Comments:

4. Was the recruitment strategy appropriate to the aims of the research?

|            |                          |
|------------|--------------------------|
| Yes        | <input type="checkbox"/> |
| Can't Tell | <input type="checkbox"/> |
| No         | <input type="checkbox"/> |

HINT: Consider

- If the researcher has explained how the participants were selected
- If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study
- If there are any discussions around recruitment (e.g. why some people chose not to take part)

Comments:

5. Was the data collected in a way that addressed the research issue?

|            |                          |
|------------|--------------------------|
| Yes        | <input type="checkbox"/> |
| Can't Tell | <input type="checkbox"/> |
| No         | <input type="checkbox"/> |

HINT: Consider

- If the setting for the data collection was justified
- If it is clear how data were collected (e.g. focus group, semi-structured interview etc.)
- If the researcher has justified the methods chosen
  - If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews are conducted, or did they use a topic guide)
  - If methods were modified during the study. If so, has the researcher explained how and why
  - If the form of data is clear (e.g. tape recordings, video material, notes etc.)
    - If the researcher has discussed saturation of data

Comments:

6. Has the relationship between researcher and participants been adequately considered?

|            |                          |
|------------|--------------------------|
| Yes        | <input type="checkbox"/> |
| Can't Tell | <input type="checkbox"/> |
| No         | <input type="checkbox"/> |

HINT: Consider

- If the researcher critically examined their own role, potential bias and influence during (a) formulation of the research questions (b) data collection, including sample recruitment and choice of location
- How the researcher responded to events during the study and whether they considered the implications of any changes in the research design

Comments:

Section B: What are the results?

7. Have ethical issues been taken into consideration?

|            |                          |
|------------|--------------------------|
| Yes        | <input type="checkbox"/> |
| Can't Tell | <input type="checkbox"/> |
| No         | <input type="checkbox"/> |

HINT: Consider

- If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained
  - If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or they have handled the effects of the study on the participants during and after the study)
- If approval has been sought from the ethics committee

Comments:

8. Was the data analysis sufficiently rigorous?

|            |                          |
|------------|--------------------------|
| Yes        | <input type="checkbox"/> |
| Can't Tell | <input type="checkbox"/> |
| No         | <input type="checkbox"/> |

HINT: Consider

- If there is an in-depth description of the analysis process
- If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data
- Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process
- If sufficient data are presented to support the findings
  - To what extent contradictory data are taken into account
- Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation

Comments:

9. Is there a clear statement of findings?

|            |                          |
|------------|--------------------------|
| Yes        | <input type="checkbox"/> |
| Can't Tell | <input type="checkbox"/> |
| No         | <input type="checkbox"/> |

HINT: Consider whether

- If the findings are explicit
- If there is adequate discussion of the evidence both for and against the researcher's arguments
- If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst)
- If the findings are discussed in relation to the original research question

Comments:

Section C: Will the results help locally?

10. How valuable is the research?

HINT: Consider

- If the researcher discusses the contribution the study makes to existing knowledge or understanding (e.g. do they consider the findings in relation to current practice or policy, or relevant research-based literature
- If they identify new areas where research is necessary
- If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used

Comments:

## **Appendix B: JBI Qualitative Data Extraction Tool**

JBI QARI Data Extraction Tool For Qualitative Research has been removed due to copyright restriction.

View the tool at:

<https://wiki.joannabriggs.org/display/MANUAL/Appendix+2.3%3A+JBI+Qualitative+data+extraction+tool>

## Appendix C: Table of Excluded Studies

| Reference                             | Study description  | Reason for exclusion  |
|---------------------------------------|--|---|
| (Ballan, 2012)                        | Semi-structured interviews with parents of autistic children to explore communication about sexuality                                      | Wrong population (parents/carers)   |
| (Ballan & Freyer, 2017)               | Discussion of issues in sexuality education for autistic adolescents and suggested interventions for mental health professionals           | Wrong population (professionals)  |
| (Bush, 2016)                          | Exploration of self-reported sexuality among autistic and non-autistic women   | Data relevant to the population included in this systematic review not able to be extracted |
| (Byers, Nichols, Voyer, et al., 2013) | Exploration of factors associated with sexual wellbeing of autistic adults   | Wrong study design (quantitative)   |
| (Corona et al., 2015)                 | Report on pilot and evaluation of sexuality and relationship education program with autistic adolescents and their parents                 | Wrong population (paediatric)   |
| (Cridland et al., 2014)               | Investigation of experiences of autistic adolescent girls via semi-structured interview with mothers and daughters                         | Unclear outcomes (no relevant data able to be extracted)                                    |
| (Dewinter et al., 2017)               | Comparison of sexual orientation and romantic relationship experience of autistic adolescents and adults with non-autistic peers           | Wrong study design (quantitative)   |
| (George, 2016)                        | Examination of sexual and gender diversity among autistic individuals  | Data relevant to the population included in this systematic review not able to be extracted |
| (Holmes, Himle, & Strassberg, 2016)   | Examination of relationship between autism, parental romantic expectations, and parental provision of sexuality and relationship education | Wrong population (parents/carers)   |
| (Lehan Mackin et al., 2016)           | Investigation of parent perceptions of sexual education needs of their autistic children and preferred method of delivery of interventions | Wrong population (parents/carers)   |
| (MacKenzie, 2018)                     | Discussion of stereotypes and prejudices faced by autistic people with regard to sex and sexuality   | Unclear outcomes (no relevant data able to be extracted)                                    |
| (Mademtzi et al., 2018)               | Investigation of parent perspective of challenges faced by autistic females  | Wrong population (parents/carers)   |

|   |   |   |
|---|---|---|
| (Mehzabin & Stokes, 2011)                   | Examination of self-assessed sexuality of autistic young adults   | Unclear outcomes (no relevant data able to be extracted)    |
| (Navot, Jorgenson, & Webb, 2017)            | Qualitative study investigating the relationship between mothers and their autistic daughters from the maternal perspective | Wrong population (parents/carers)                           |
| (Ohkubo, Inoue, & Watanabe, 2008)           | Investigation of parent need for sex education for their autistic children  | Wrong population (parents/carers)                           |
| (Pearlman-Avni, Cohen, & Eldan, 2017)       | Examination of the correlation between being in an intimate relationship and quality of life in autistic adults             | Wrong design (mixed methods; data not able to be extracted) |
| (Schöttle, Briken, Tüscher, & Turner, 2017) | Examination of the frequency of hypersexual and paraphilic behaviour in autistic individuals                                | Wrong design (quantitative)                                 |
| (Stokes & Kaur, 2005)                       | Investigation of parental views and concerns regarding the sexuality of their autistic child                                | Wrong population (parents/carers)                           |
| (Strang et al., 2018)                       | Investigation of the experiences of autistic transgender and gender diverse adolescents                                     | Unclear outcomes (no relevant data able to be extracted)    |