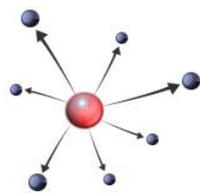

Guideline Supplementary Paper

New Zealand Autism Spectrum Disorder Guideline's supplementary paper on the effectiveness of sexuality education for young people on the autism spectrum.



INSiGHT
Research Ltd

Independent Network of Specialists in Guidelines & Health Technology

With the support of the New Zealand Autism Spectrum Disorder Guideline's Living Guideline Group

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The work was researched and written by INSIGHT Research Ltd employees or contractors. Appraisal of the evidence, formulation of recommendations and reporting are independent of the Ministries of Health and Education.

Statement of intent

INSIGHT Research produces evidence-based best practice guidelines, health technology assessments and literature reviews to help health care practitioners, educators, policy-makers and consumers make decisions about health care in specific circumstances. The evidence is developed from systematic reviews of international literature and placed within the New Zealand context.

Guidelines, including supplementary papers, are not intended to replace a health practitioner's judgement in each individual case.

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About the evidence review

Purpose

The first edition of the New Zealand Autism Spectrum Disorder Guideline (referred to henceforth as the “guideline”) was published in April 2008 [1]. As part of their commitment to the implementation of the guideline, New Zealand’s Ministry of Health and Ministry of Education agreed to establish a “Living Guideline process” in 2009. This process ensures that the guideline is regularly updated and refined to reflect new evidence and changing user needs.

Updates to the guideline are required when the guideline’s recommendations are no longer valid in view of research evidence that has emerged since the guideline’s literature searches were conducted. A multidisciplinary advisory panel called the Living Guideline Group (LGG) are responsible for prioritising what topics should be updated. For each topic, a literature review is undertaken by INSIGHT Research which includes a critical synthesis of research published since the original guideline’s searches were completed in 2004. The LGG consider the completed literature review, and report on any implications for guideline recommendations.

The topic updates are produced in the form of Supplementary Papers. These include a systematic literature review on the topic being updated, and revised and new recommendations developed by the LGG after considering this review. Supplementary Papers have been produced annually since 2009 [2-9].

The current Supplementary Paper updates the guideline with respect to the effectiveness of sexuality education programmes for adolescents and young adults on the autism spectrum.

The entire living guideline process is co-funded by the New Zealand Ministry of Health and Ministry of Education.

Scope of the evidence review

The current review aims to update evidence published from 2004 onwards relating to sexuality education for young people on the autism spectrum. The LGG identified this topic as an area worthy of updating and one which could lead to revised or additional recommendations in the guideline [10].

Specifically, the review relates to the effectiveness of interventions aimed at providing education, training, and/or support relevant to sexual development, sexual health, and sexuality for adolescents and young adults on the autism spectrum. Sexuality includes sexual understanding and sociosexual knowledge, sexual identity and orientation, sexual

expression, desire, and behaviour. Interventions were those which target adolescents and young adults on the autism spectrum either directly or indirectly through their family members, carers, clinicians, educators, and service providers.

Excluded from critical appraisal were interventions related to sexual abuse, and sexual behaviour as side effects of medication.

This document should be read in the context of the guideline's 2nd edition [10]. There are common elements of sexual education and social skills training and the supplementary paper on the latter topic completed in 2015 [7] will complement the current paper.

Definitions

The current report relates to sexuality. Sexuality is “a central aspect of being human throughout life (which) encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction. Sexuality is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviours, practices, roles and relationships. While sexuality can include all of these dimensions, not all of them are always experienced or expressed. Sexuality is influenced by the interaction of biological, psychological, social, economic, political, cultural, legal, historical, religious and spiritual factors” [11].

Autism Spectrum Disorder (ASD) is a condition that affects communication, social interaction and adaptive behaviour functioning. In the current edition of the diagnostic manual of mental disorders, the DSM-5 [12], four pervasive developmental disorder subcategories specified in the manual's predecessor, the DSM-IV [13], are now subsumed into one broad category of autism spectrum disorder. These subtypes are autistic disorder, Asperger's disorder (Asperger syndrome), childhood disintegrative disorder (CDD), and pervasive developmental disorder not otherwise specified (PDD-NOS). The name pervasive developmental disorder (PDD) has now been changed to Autism Spectrum Disorder (ASD). The diverse range of disability and intellectual function expressed by people across the autism spectrum requires that a wide range of services and approaches be employed to reflect the heterogeneity of the condition.

It is recognised that people on the autism spectrum have the right to self-refer and be referred to as they choose. The term ASD is still used widely internationally and the guideline's first edition [1] was prescient in recognising the movement toward considering autism as a spectrum condition. However, increasingly people in the autism community prefer to use identity-first language to refer to themselves as being autistic, autists or Aspies. This recognises autism as a central part of their identity, rather than being a person “with autism”. Others prefer to describe themselves as being on the spectrum, or as having autism or Asperger's. ASD is also sometimes defined as autism spectrum *difference* rather than *disorder*. In the UK, the term Autism Spectrum Condition (ASC) is sometimes used instead of ASD. The term “person on the autism spectrum” is used in this supplementary report to mean someone understood to have met criteria for the

diagnosis of ASD. However for clarity and consistency with the first edition of the guideline [1], the acronym ASD is sometimes used when referring to a formal diagnosis, particularly when used as a selection criteria in cited research studies.

It is understood that the term “high functioning” to describe more cognitively and verbally able groups of people on the autism spectrum is considered unhelpful and divisive by many on the autism spectrum. In this report, the term “high functioning” is only used when quoting specific inclusion criteria for appraised studies. In such studies, the term refers to people with higher cognitive ability either as established by intelligence tests (generally indicated by full IQ scores of 70 or above), or through the diagnosis of “high-functioning autism” or Asperger syndrome (under DSM-IV criteria) [13]. It is acknowledged that these distinctions may no longer be used clinically in light of the removal of Asperger syndrome as a separate diagnostic classification in DSM-5 [12].

Target audience

The systematic review that forms the bulk of this report aims primarily to provide an updated synthesis of research evidence on a specific topic for consideration by the Living Guideline Group. As such it is written in an academic style and is not intended for the general reader.

However, the technical report informs the Living Guideline Group in revising and developing new Recommendations and Good Practice Points to update the New Zealand Autism Spectrum Disorder Guideline. These outputs (summarised on page xi, and detailed in Section 3 of this paper) are intended for a broader audience, including the providers of professional health, education and support services for New Zealanders on the autism spectrum, as well for people on the autism spectrum themselves, their families, and whānau.

Treaty of Waitangi

INSIGHT Research acknowledges the importance of the Treaty of Waitangi to Aotearoa/New Zealand, and considers the Treaty principles of partnership, participation and protection as central to improving Māori health and education.

INSIGHT Research’s commitment to improving Māori health outcomes means we attempt to identify points in the guideline or evidence review process where Māori health must be considered and addressed. In addition, it is expected that Māori health is considered at all points in the guideline or evidence review in a less explicit manner.

Recommendation development process

The research topic was identified and prioritised by the LGG. A literature review updating the published evidence was conducted by INSIGHT Research and disseminated to the LGG as pre-reading for a one day, face-to-face meeting on 23 November 2017.

At the meeting, the currency of the guideline was discussed in view of the updated evidence. Existing Recommendations/Good Practice Points were revised and new ones developed based on the considered evidence. Those changed are described, accompanied by the LGG's rationale and additional notes, in **Section 3** of this paper.

INSIGHT Research follows specific structured processes for evidence synthesis. Full methodological details and a list of Living Guideline Group members is provided in **Appendix 1**. **Appendix 2** presents a Glossary of key epidemiological and topic-specific terms, abbreviations and acronyms. **Appendix 3** presents evidence tables of included studies for the current review update.

Summary: New recommendations and good practice points

Summary Table I: New recommendations relevant to sexuality and autism

Reference	New recommendation	Grade
3.2.2.6a	Tailored sexuality education, particularly when delivered individually and intensively, should be considered for young people on the autism spectrum.	B

Note: Grades indicate the strength of the supporting evidence rather than the importance of the evidence. Grade A indicates good evidence, B is fair evidence, C is international expert consensus, and I is insufficient, poor quality, or conflicting evidence. See Table A1.2 in Appendix 1 for details.

Summary Table II: New good practice points relevant to sexuality and autism

Reference	New Good Practice Points	Grade
3.2.2.8/6.24b	All people supporting young people and adults on the autism spectrum should be sensitive to gender and sexual diversity.	✓
3.2.2.9	Sexuality education programmes in New Zealand need to be responsive to the cultural and linguistic diversity of their participants.	✓
3.2.2.9a	New Zealand research is needed to develop and evaluate sexuality education programmes for young people on the autism spectrum.	✓
3.2.2.9b	Decisions about participating in sexuality education should be guided by whether a person on the autism spectrum values it, and whether they are expected to benefit from it.	✓

Note: Where a consensus-based recommendation is based on the experience of members of the Living Guideline Group, or feedback from consultation within New Zealand, it is referred to as a good practice point.

1 Introduction

1.1 Background

Sexuality

Most sexual activity is not directly associated with reproduction and is relevant throughout a person's lifespan. The World Health Organisation (WHO) recognizes the desire of individuals and couples of all sexual orientations and any background to have fulfilling and pleasurable sexual relationships [14]. Further:

“Sexuality is a central aspect of being human throughout life (which) encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction. Sexuality is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviours, practices, roles and relationships.” [11].

While all of these dimensions represent sexuality, not all of them are necessarily experienced or expressed in an individual. Sexuality is not a fixed concept. The expression of sexuality can vary as a function of the interaction of various social, biological, psychological, economic, political, cultural, legal, historical, religious and spiritual factors [11].

The concept of psychosexual functioning is useful in distinguishing and encompassing three broad areas of sexuality: sexual behaviours (behaviour and experiences), sexual selfhood (affecting the internal functioning of people), and sexual socialisation [15].

Sexual development for people on the autism spectrum

Adolescents all experience physical, hormonal, and emotional changes associated with puberty and their emerging sexuality [16]. This may be accompanied by developing interests and information-seeking around their gender identity, sexual expression, body image, relationships, and sexual pleasure.

Young people on the autism spectrum are no different to their typically developing peers in needing to navigate the bodily, mental, emotional and social changes associated with puberty. However this was not always accepted, with early studies [17, 18] suggesting that people on the autism spectrum were not interested in intimate relationships, and promoting misconceptions that individuals on the autism spectrum do not have “normal” sexual thoughts, feelings and desires, are sexually immature, or are asexual [19, 20]. In the last several years there has been a growing research interest in sexuality in autism that refutes these outmoded views. Whilst there is some evidence to suggest that people on the autism spectrum may have delayed onset of emotional changes and sexual urges associated with puberty [21, 22], it is understood that people on the autism spectrum

demonstrate the full range of sexual interests, needs and engagement as their typically developing peers [23].

The growing literature has also documented how gender dysphoria - where a person's biological sex and perceived gender do not match - and autism frequently co-occur [24, 25]. Recent guidelines recommend that teenagers seeking treatment at gender clinics be screened for autism, and that those on the autism spectrum be assessed for gender concerns [26]. However there are limitations to the literature and conceptual challenges in how gender identity is best understood which make the interpretation of these associations challenging [27].

Several studies have suggested that young people on the autism spectrum have less sexual knowledge and skills compared with their typically developing peers [23, 28-30]. Seeking out sexual information can be challenging for people on the autism spectrum [21]. They may have fewer social sources to draw from [23], and there may be a lack of access to sexuality information from a peer group and the media when compared with typically developing peers [30]. A lack of both knowledge and skills can hamper efforts by people on the autism spectrum in expressing their sexuality and developing intimate relationships in a safe and healthy way [31]. For those who are sexually active, a lack of accessible sexual information can raise health risks including sexually transmitted infections (STIs), reproductive tract infections (RTIs), unintended pregnancy, and sexual dysfunction [14]

Whilst some studies have found people on the autism spectrum to have less psychosexual knowledge than neurotypical controls [32, 33], other studies have found that sexual knowledge in cognitively able individuals on the autism spectrum are comparable with typically developing ones [33]. Differences may relate to how psychosexual knowledge is operationalised, ranging from basic vocabulary, broad psychosexual knowledge, judgements of parents and carer informants, to complex understanding of sexual physiology and behaviour [34].

Social norms are not always clear, explicit, or consistent, and they rely on the ability for a person to pick up on subtle, often non-verbal, cues and nuances. Understanding of these can be particularly challenging for people on the autism spectrum [35] given the social and communication difficulties that characterise autism [12]. Many social rules, such as those around personal hygiene, may be considered arbitrary and unnecessary without an understanding of the behaviours in a social context.

Expressions of sexuality also draw meaning from their social context, and what is acceptable in private may be deemed inappropriate or even deviant in public. Some of the challenges some people on the autism spectrum face relate to a lack of understanding of social norms around privacy, modesty, personal space, boundaries, and touching [29]. Examples of types of problematic sexual behaviour identified in the literature include compulsive masturbation; public masturbation; inappropriate romantic gestures, arousal, or touching; exhibitionism; and paraphilia [36].

As social communication skills play an important role in forming and maintaining friendships and intimate relationships, people on the autism spectrum can be at a

disadvantage. They may employ naive but inappropriate strategies for seeking relationships, such as stalking, giving unwanted romantic attention, and non-consensual physical contact [23, 30]. Such behaviour can contribute to social isolation and loneliness.

Sensory preferences commonly expressed by people on the autism spectrum can sometimes lead to unusual and socially inappropriate behaviours with unintended sexual connotations. For example, touching a person's legs or pantyhose, smelling or stroking hair, or licking a person's face [29]. These behaviours can be misunderstood as being intentionally offensive or even sexually deviant. The propensity for repetitive and stereotyped behaviour and hypo- and hyper-sensitivities may contribute to higher risks for developing sexual preoccupations, or paraphilias such as fetishism, exhibitionism, voyeurism, frotteurism, sexual assault, and paedophilia [16, 37, 38].

The higher rates of problem sexual behaviours in people on the autism spectrum have been suggested as being related to a host of factors. These include limited or reduced social skills, empathy, emotion recognition, knowledge, social awareness, and inhibitions, as well as preoccupations, sensory preferences, and persistent repetitive behaviours [28-30, 34]. A lack of sensitivity to, or understanding of, the unintentionality of potentially offensive expressions of sexual behaviour (such as unwanted touching, public masturbation) can lead to crisis responses by school personnel, bus drivers, health providers, and police [29]. These can lead to harsh penalties such as school exclusion or being charged as sex offenders within the criminal justice system. In court, people on the autism spectrum (as potential victims of sexual abuse or as offenders) can be particularly vulnerable to misunderstanding when they lack the language or concepts needed to describe sexual events when giving evidence or being cross-examined (Sally Kedge, Talking Trouble Aotearoa, *personal communication*, 31 March 2018).

Difficulties in interpreting the approaches, intentions and behaviour of others can make identifying "red flags" of dangerous situations difficult for a person on the autism spectrum [29]. Negotiating sexual consent can also be problematic. These communication challenges, particularly where intellectual impairment is present, can increase a person on the autism spectrum's vulnerability to exploitation, victimisation, and abuse ranging from being teased, taken advantage of, and bullied to actually becoming victims of physical and sexual assault [32]. A community-based sample of children on the autism spectrum in the US reported a prevalence of 12.2% of sexual abuse. Those who experienced physical and sexual victimisation were also more likely to demonstrate abusive sexual behaviour towards others [39].

According to the New Zealand Office of the Children's Commission, there is an emerging trend in increased access to online pornography by children and young people and the potential for associated risky behaviour. People on the autism spectrum can be particularly vulnerable to coercion, abuse and inappropriate behaviour through the internet. Parents of young people on the autism spectrum need effective and specialised information on discussing internet safety, harms of pornography, what is real and fantasy, and what comprises positive healthy sexual relationships (Dr Kathleen Logan, *personal communication*, 28 February, 2018).

Sexuality education for young people on the autism spectrum

Sexual education and sexual health is a standard inclusion in *The New Zealand Curriculum* and must be part of teaching programmes at both primary and secondary school levels [40]. However there is evidence to suggest that generic sexuality education may not be meeting the needs of people on the autism spectrum. Self-report data from one study on sexuality education of adolescents found that those with “high functioning autism” (HFA) have lower levels of sexual knowledge than their typically developing peers [41].

Given the particular challenges experienced by people on the autism spectrum in learning about their sexuality, there has been a demand for the development of programmes, training and services that support and educate young people on the autism spectrum in this area. The emerging literature highlights the importance of having high quality, appropriate sexuality education to promote healthy sexual development and reduce the risk of problem behaviours, exploitation and abuse [23, 29, 30, 42]. Common areas to cover include informing adolescents (or assisting parents, caregivers, educators and other professionals in teaching them) about their body’s physical changes, personal hygiene, the differentiation between public and private behaviour, respecting personal boundaries, developing relationships, sexual behaviours with and without partners, obtaining explicit consent, and preventing exploitation and abuse [15, 29].

Typical sexuality education approaches may be less suited to people on the autism spectrum for a range of reasons. For example, the use of euphemisms and innuendo (e.g., “going all the way”) can be confusing for people on the autism spectrum given common difficulties in understanding pragmatic language [16]. It has been suggested that appropriate social expectations need to be taught, with programmes aiming to provide explicit explanation of often implicit rules [15]. Drawing on behaviourist principles of social learning theory [43], sexuality education courses commonly proposed in the literature include opportunities for observational learning and practical experience (e.g., behavioural modeling, practicing conversational skills, role playing) with positive reinforcement and conditioning [15, 44]. Other suggested strategies include:

- employing simple, precise and direct instruction [16, 44];
- use of visual supports such as pictures and written words [44];
- offering multiple reinforcers [16];
- and repeated presentation of material [16].

It is also recommended that content matches the person on the autism spectrum’s interest and engagement [16] and takes into account their communication level, social skills, cognitive ability, conceptual ability, and other aspects of their functioning [44].

When considering “problem sexual behaviours” for adolescents on the autism spectrum, individualised approaches may be required. Qualitative review of case illustrate a range of behavioural techniques used for intervening on specific problem sexual behaviour including social stories, applied behavioural analysis, visualisation, explicit teaching, and

rewarding [34]. However before intervening, it is important to interpret any “problem behaviour” within the context of typical teen development. As Banerjee and colleagues observe [44]:

The impulsiveness, aggressiveness, confusion, and defiance that often accompany the biological and physical changes occurring in adolescents with autism are often not so different from those same behaviours occurring during normal adolescent development.

Furthermore, in considering what a “problem” behaviour is, it is important to consider for whom the behaviour is a problem. It may be that the problem can be at least in some way addressed by increasing understanding of the individual on the autism spectrum’s behaviour by those around them.

The current review update

An initial broad scoping search on sexual behaviour identified a very diverse range of potential topics, including physical changes associated with puberty, body awareness, sexual attraction, sexual health, sexuality and gender identity, romantic relationships, inappropriate touching, sexual abuse, and increased sexual behaviour as a side effect of medication, among others. These areas represent a very diffuse range of potential topics relating to different age groups, different issues to address, and different intervention modalities.

Originally, sexuality and sexuality education was excluded as a specific topic in the guideline [10] “because of resourcing and time constraints” (pg. 283). Nevertheless, the current guideline does cover some topics that are relevant to the broad topic of sexuality. There is an extended section (2.1.e, pg. 65¹) on intimate relationships, inclusive of marriage, life partnerships and homosexual relationships. Service supports and advice are discussed in this context. Also, under Section 5.3.a (People with ASD as victims of crimes, pg. 182), education on sexual and community safety and abuse is discussed in detail, leading to three Recommendations (5.3.3, 5.3.4, 5.3.5).

Given the areas already covered in the guideline [10], and the need to identify a less diffuse topic, the current review focuses on the effectiveness of interventions aimed at providing education, training and/or support relevant to sexuality for young people on the autism spectrum (either directly, or through their family members, carers, clinicians, educators, and service providers).

1.2 Recommendations relating to sexuality in the guideline

¹ All references to page numbers within guideline refer to the 2nd edition (August, 2016) [10].

Whilst sexuality and sexuality education were not explicitly reviewed for the original guideline [10] due to time and resourcing constraints, Recommendations and Good Practice Points (GPPs) did arise relevant to the topic in several places.

Table 1.1: Good Practice Point relevant to sexuality in the guideline

Reference	GPP	
GPP 1.2.14	Assessment should consider the influence of diversity such as sense of self, ethnicity, culture, gender, sexuality, religion, socio-economic status, and geographic factors.	✓

Table 1.2: Recommendations relevant to sexuality in the guideline

Reference	Recommendation	Grade
2.3.9	Research should be undertaken to identify the needs of people with ASD with regard to constipation, allergies, medication reactions, menstruation and exercise	C
2.3.12	The effectiveness of health-promotion campaigns with people with ASD should be investigated. Health-promotion campaigns should ensure that people with ASD are included as a specific target group.	C

Note: Grades indicate the strength of the supporting evidence rather than the importance of the evidence. Grade A indicates good evidence, B is fair evidence, C is international expert consensus, and I is insufficient, poor quality, or conflicting evidence. See Table A1.2 in Appendix 1 for details.

A new Good Practice Point (see **Table 1.1**) was added to the guideline [10] by the LGG in the update on the impact of the DSM-5 [6] on the guideline. The GPP noted the importance of considering a client's sexuality during assessment procedures.

A brief section on 'Other health issues' (pg. 73) noted the lack of reliable research on menstruation (among other issues), as specified in Recommendation 2.3.9 (see **Table 1.2**).

In Section 2.3.e of the guideline (on Health promotion), the lack of research relating to the effectiveness of health-promotion campaigns targeting people on the autism spectrum with respect to sexual health and safety (among other health issues) is discussed, and associated with Recommendation 2.3.12 (see **Table 1.2**).

The evidence relating to sexuality and autism in the first edition of the guideline [1], as well as that considered in updates incorporated into the guideline's 2nd edition [10], form part of the evidence base considered by the LGG alongside the current review update (see **Section 3**).

1.3 Objectives of the current review update

The objectives of this review update were to:

- Systematically identify, select, and narratively synthesise research evidence published since January 2004 which evaluate the effectiveness of educational programmes, training and supports relating to sexuality for assisting adolescents and young adults on the autism spectrum.
- Consider this evidence as it supplements the guideline [10] in order to inform the LGG's revision of existing recommendations/Good Practice Points and/or development of new ones.

2 Systematic review of sexuality education for young people on the autism spectrum

This chapter describes the findings of a systematic review relating to sexuality education for adolescents and young adults on the autism spectrum.

2.1 Scope and methods

Full details of review methods including search strategies, appraisal of study quality and data extraction are presented in **Appendix 1**.

Research question

The review update's primary research question is: "how effective are educational programmes, training and supports relating to sexuality for adolescents and young adults on the autism spectrum?"

Identification and selection of studies for inclusion

Search strategies were limited to English language publications from January 1 2004 to ensure capture of articles published since the search was conducted for the original guideline [1]. Studies already appraised in the guideline's first or second edition [1,10] relevant to the topic were excluded from the current review regardless of date of publication.

Nine bibliographic, health technology assessment, and guideline databases were included in the systematic search (see **Appendix 1** for further details). The search was conducted on 17/18 July 2017 and updated on 15 August 2017. Following removal of duplicates, 73 potentially relevant articles were identified.

Selection criteria for included and excluded studies are described in **Table 2.1**. Selection criteria were applied to titles and abstracts to identify articles for retrieval, and then to retrieved full text articles, to identify included studies.

Bibliographies of retrieved publications and recent narrative reviews were examined to identify any additional eligible studies. It should be noted that narrative reviews retrieved for this purpose or to provide background material were not critically appraised for inclusion in the review.

Hand searching of journals and contacting of authors for unpublished research was not undertaken.

Table 2.1: Inclusion and exclusion criteria for selection of studies

Characteristic	Inclusion criteria
Publication type	Studies published 1 January 2004 or later.
Participant characteristics	People aged 12-44 years (or of a sub-sample reported separately) diagnosed with Autism Spectrum Disorder (ASD) as classified by or consistent with DSM-IV-TR [13] or DSM-5 [12].
Study Design	Randomised controlled trials, pseudo-experimental designs, single case experimental designs, case series, with at least one repeated (at both pre- and post-intervention) relevant outcome measure. Secondary studies (systematic reviews and/or meta-analyses) published in or since 2012 that had a clear and relevant review question, used at least one electronic bibliographic database, included at least one study eligible for the current review.
Sample size	More than 5 participants receiving the intervention being investigated.
Intervention	Sexuality education (i.e., curriculum, training, strategies and/or support) relevant to sexuality, sexual development, and sexual health delivered either individually or in groups.
Comparator	For experimental studies, the comparison/control group could be no intervention, wait-list control, or receiving usual care.
Outcome	Primary outcomes were published measures completed pre- and post-intervention by self-report, informant-report and/or clinician/assessor-relating to the following domains: <ul style="list-style-type: none"> • Problem sexual behaviour (including behaviour deemed contextually inappropriate) • Sexual knowledge • Social responsiveness/functioning • Quality of life Other secondary measures (where a primary outcome was also reported) included <ul style="list-style-type: none"> • Satisfaction with programme • Confidence and readiness for delivering programme
Characteristic	Exclusion criteria
Publication type	Non-systematic reviews, correspondence, editorials, commentaries, expert opinion articles, articles published in abstract form, conference proceedings, poster presentations, dissertation abstracts, books, news reports, trade magazines, policy and guidance, animal studies, single case studies, and non-empirical research were excluded, except where retrieved as providing background material. Unpublished data
Attrition	Studies with >50% attrition from either arm of a trial (unless adequate statistical methodology has been applied to account for missing data).
Language	Non-English language articles

Table 2.1: Inclusion and exclusion criteria for selection of studies (continued)

Scope	Studies that did not provide separate analyses/syntheses of results relevant to the scope of the review (e.g., with respect to age group and diagnosis). Studies cited in the guideline [1,10]
Study Design	Case series or cross-sectional studies with post-intervention only assessment

Publication type

Included were studies published in the language English between 1 January 2004 – 15 August 2017 inclusive, including primary (original) research published as full original reports and secondary research (systematic reviews and meta-analyses).

Participants

The study population were people aged 12-44 years (or for samples with a mean age within this range) diagnosed with Autism Spectrum Disorder (ASD) as classified by or consistent with DSM-IV [13] or DSM-5 [12]. Studies of broader populations were included where results were reported separately for the eligible group.

Studies were also included where participants were adults who potentially provide education, training or supports relevant to sexuality for people on the autism spectrum (e.g., family/whānau, carers, clinicians, educators, service providers).

Sample size

Eligible studies had more than 5 participants receiving the intervention being investigated.

Intervention

Included studies evaluated interventions (i.e., curriculum, training, strategies and/or support) relevant to sexuality, sexual development, and sexual health. Sexuality included sexual understanding, sociosexual knowledge, sexual identity and orientation, and sexual expression, desire, and behaviour. Interventions were typically given over a number of sessions over several weeks.

Any modality of intervention delivery was included (i.e., individually-delivered sessions, group-based interventions, or a combination of both).

Comparator

For experimental studies, the comparison/control group could be no intervention, wait-list control, or receiving usual care.

Outcomes

Outcomes measured quantitatively or qualitatively were included. Key outcomes of interest as dependent variables related to the following domains:

- Problem sexual behaviour (including behaviour deemed contextually inappropriate)
- Sexual knowledge
- Social responsiveness/functioning
- Quality of life

Process outcomes of interest included:

- Satisfaction with programme
- Confidence and readiness for delivering programme

Moderators of effectiveness of interventions identified through multivariate statistical analyses was also of interest.

Study designs

The goal was to identify evidence at higher levels of the evidence hierarchy (for example, controlled experimental studies) and only in their absence, include lower order evidence (see **Appendix 1** for further details).

The review considered randomised controlled trials (RCTs), pseudo-experimental designs, single arm study designs, and case series where they reported at least one repeated measure of an relevant outcome assessed at both pre- and post-intervention. Cross-sectional studies or case series with post-intervention only assessment were therefore excluded. Longer-term follow-up of outcomes and measurement of maintenance of treatment effects were of interest where reported.

In addition, recently published (in or since 2012) secondary studies (systematic reviews and/or meta-analyses) were eligible for appraisal where they had a clear and relevant review question, reported on the eligible study population (solely or separately as a synthesised sub-group), and used at least one electronic bibliographic database.

Exclusions

Research papers were **excluded** if they:

- were published prior to 2004 (however earlier primary studies may be reported in included systematic reviews);

- were non-systematic reviews, letters, editorials, expert opinion articles, commentaries, news reports, trade magazines, case reports, book chapters, articles published only in abstract form, conference proceedings, poster presentations, correspondence, news items, dissertation abstracts, unpublished work, and non-empirical research were excluded, except where retrieved as providing background material;
- were not published in the English language;
- reported on samples of five or fewer participants in either arm of the study (intervention or comparator);
- were not deemed appropriate to the research question or nature of review, including:
 - biological studies (genetics, vaccines, neurophysiology, neuro-imaging, medical and dietary interventions, in vitro studies, animal studies);
 - prevalence studies;
 - studies describing service provision (without explicit evaluation of the intervention);
 - studies describing development of an intervention, outcome measure or diagnostic test (without explicit evaluation of the intervention);
 - studies of sexual abuse of people on the autism spectrum; and
 - studies relating to sexual behaviour that has occurred as a side effect of medications.

Critical appraisal of included studies

Included primary studies were broadly assigned “levels of evidence” which correspond to an evidence hierarchy [45]. This hierarchy (see **Appendix 1, Table A1.1**) ranks the quality of research designs which are broadly associated with particular methodological strengths and limitations so as to rank them in terms of quality, from the most robust level of I (for systematic reviews of level II studies) to IV (before-and-after studies with repeated measures assessed at baseline and post-intervention for the treatment group). Systematic reviews of lower order evidence rank at the same level as that order of evidence.

Each study may be designed and/or conducted with particular strengths and weaknesses which can be assessed using critical appraisal tools. In this review, included studies were formally appraised using the SIGN quality checklists from the Scottish Intercollegiate Guidelines Network [46] as appropriate to study design, including those for systematic reviews and randomised controlled trials. No checklist is available for cross-sectional or case series studies (level IV). The quality and resistance to risk of bias of an individual study was scored as either ++ (high quality), + (acceptable), or – (low quality), and included in the Evidence Tables for included studies (**Appendix 3**).

Full details of review methods including search strategies, appraisal of study quality and data extraction are presented in **Appendix 1**.

2.2 Body of evidence

Included studies

Twelve studies met selection criteria and were eligible for inclusion in the review; 5 secondary studies (i.e., systematic reviews, clinical guidelines), and 7 primary studies.

Summary characteristics for each study are presented in Evidence Tables (see **Appendix 3**). These report the country the study was conducted in, study design, evidence level (as defined in **Appendix 1, Table A1.1**), study aim, participant characteristics, and a summary of the study's methods, results, authors' conclusions, and reviewer's conclusions, source of funding, and SIGN study quality rating.

Throughout the tables and text, studies are ordered according to the following hierarchy: study type (systematic reviews, followed by primary studies), year of publication (oldest first), and first author's surname (alphabetical order).

Systematic reviews

Five recently published secondary studies on the review topic were identified [31, 36, 47-49]. Three were clinical practice guidelines, and two were systematic reviews.

All three guidelines were based on high quality systematic reviews. Two of the guidelines were from the UK's National Institute for Health and Clinical Excellence (NICE): one relating to adults on the autism spectrum [47] and the other to young people aged under 19 years [48]. A third guideline was published in Scotland by the Scottish Intercollegiate Guidelines Network (SIGN) [49]. A lower quality systematic review from the UK [36] and high quality one from Australia [31] were also appraised.

All secondary reviews considered aspects of sexuality in people on the autism spectrum. Aspects highlighted in the reviews included: the importance of, and needs for, information relating to sexuality; higher rates of gender dysphoria for the autism community; risks of abuse and problem sexual behaviour; sex differences in knowledge and behaviour; and the need for sexuality education for people on the spectrum and their parents/carers. Effectiveness of sexuality education interventions was not specifically investigated in the secondary reviews, and they are therefore best considered as background for the purposes of the current review.

Primary studies

Seven primary studies were appraised [15, 16, 19, 29, 38, 44, 50]. Of these, four were conducted in the US [16, 19, 29, 50], two in The Netherlands [15, 38], and one in India [44]. One study was a randomised controlled trial [38]. The other six were "before-and-after" case-series studies; that is, with repeated measures assessed both before ("baseline") and after ("follow-up") the intervention.

Five of the seven primary studies [15, 16, 38, 44, 50] reported directly on people on the autism spectrum. For these, sample sizes ranged from 6 to 189 people (M=55.6). Whilst

sex and mean age was not reported for the Indian study [44], all five targeted adolescents with ages ranging from 9 to 20 years. Where reported, mean age ranged from 13 to 16 years. With the exception of one small study of 6 male teens [16], samples approximated the 4:1 male to female ratio that is commonly seen in studies of ASD prevalence [51].

The other two primary studies aimed to intervene indirectly through people associated with individuals on the autism spectrum. One study targeted 10 parents of adolescents on the autism spectrum (5 girls, 5 boys, aged 10-14) [29]. Another evaluated an intervention with 43 professionals working with individuals on the autism spectrum [19].

Interventions for the seven primary studies all consisted of sexuality education; however, the format and intensity varied widely. Five of the studies evaluated an educational intervention aimed at adolescents on the autism spectrum; three provided this individually [15, 38, 44], and two were delivered to groups [16, 50]. The other two primary studies considered group-delivered interventions for professionals who may work with people on the autism spectrum [19] and parents of adolescents on the autism spectrum [29].

At the least intensive end of the range were group-based interventions. These included a 4.5 hour *Healthy Relationships and Autism* curriculum given in six 45-minute sessions [16]. The two studies evaluating interventions indirectly targeting people on the autism spectrum were also group-based: the intervention targeting professionals involved an all-day (7-hour) workshop [19], and the parent-intervention consisted of 8 hours of education given in 1-hour sessions [29]. Parents and adolescent groups were simultaneously given 12 hours of sexuality education in six 2-hour sessions [50]. Slightly more intense were 13.5 hours (18 45-minute sessions) of the Tackling Teenage Training (TTT) intervention provided individually to adolescents on the autism spectrum in a randomised controlled trial [38]. The pilot study of this intervention gave 18 hours of the TTT intervention in weekly, individual sessions [15]. Finally, the most intense intervention evaluated was set in India and involved forty 30-60 minute individual sessions (20-40 hours of intervention), along with the mother attending [44].

A large range of outcomes were investigated. Most were developed by the researchers and tailored specifically for the intervention being evaluated and program goals. Outcomes assessed (and re-assessed in the repeated measures design) of the primary studies included four studies measuring psychosexual knowledge (of information taught within the curriculum) [15, 16, 38, 50], including a parent-reported measure of their teens' insight into interpersonal boundaries [38]. Other outcomes included parents' comfort in discussing sexuality with their teen [29], and professionals' perceived readiness to provide sexuality education to individuals on the autism spectrum [19]. Satisfaction with online content provided post intervention was measured in one study [19].

With respect to behavioural outcomes, independent observation was not included in any study. Instead, three studies relied on self-ratings [19, 38, 44]. The RCT of the Tackling Teenage Training programme [38] measured adolescents' self-rated social functioning, and romantic relationship skills. Problem/inappropriate behaviour was measured in two studies [38, 44]. The evaluation of a workshop for professionals asked about their

knowledge seeking, collaborating, readiness to educate, utilisation of curriculum, advocacy, and provision of sexuality education [19].

2.3 Narrative appraisal of studies

A narrative review of included studies is provided in this section. Evidence Tables reporting on the 11 included studies are presented in **Appendix 3**.

Secondary studies

Five secondary studies were identified which were broadly relevant to sexuality: two systematic reviews and three guidelines (see **Table A3.2**).

National Institute for Health and Clinical Excellence (2012) [47]

The UK's National Institute for Health and Clinical Excellence (NICE) produced a guideline in 2012 on the recognition, referral, diagnosis and management of adults on the autism spectrum [47]. The guideline was informed by systematic reviews using comprehensive search, appraisal and synthesis methods (SIGN rating: ++, indicating high quality). Studies evaluating sexuality education were not identified, however sexuality arose as an important factor in several areas of the guideline. Following a thematic analysis of qualitative studies describing the experiences of having autism, the theme of relationships was identified, where it was observed that "*intimate relationships were desired, however misinterpretation of social cues could sometimes lead to vulnerable situations or inappropriate sexual advances*". In addition, two papers suggestive of higher rates of gender dysphoria in people on the autism spectrum were appraised [52, 53]. The following new Recommendation was developed:

"All staff working with adults with autism should be sensitive to issues of sexuality, including asexuality and the need to develop personal and sexual relationships. In particular, be aware that problems in social interaction and communication may lead to the person with autism misunderstanding another person's behaviour or to their possible exploitation by others."

National Institute for Health and Clinical Excellence (2013) [48]

Another guideline from NICE in the UK in 2013 [48] considered the management and support of children and young people (aged under 19 years) on the autism spectrum. Again, sexuality education was not evaluated specifically, however sexuality was considered in reviewing experience, organisation and delivery of care. The high quality (SIGN rating: ++) review employed a very broad search strategy and systematic data extraction, appraisal, and synthesis methods. Emergent themes were identified and validated in focus groups by young people on the autism spectrum. Specifically, unmet needs were identified for parent training in ways to approach the child or young person's sexuality [29], with 57% of 149 parents surveyed in one study requesting more

information on relationships and sexuality education [54]. Further, the following clinical practice recommendation was developed by the Guideline Development Group:

“When the needs of families and carers have been identified, discuss help available locally and, taking into account their preferences, offer information, advice, training and support, especially if they:

- need help with the personal, social or emotional care of the child or young person, including age-related needs such as self-care, relationships or sexuality*
- are involved in the delivery of an intervention for the child or young person in collaboration with health and social care professionals.”*

Beddows & Brookes (2016) [36]

Again in the UK, a systematic review considered research relating to inappropriate sexual behaviour in adolescents on the autism spectrum. The review, of low quality (SIGN rating: -), used a limited search of databases but was open to a broad range of publication types. It provided no information on selection criteria, or appraisal methods. Of 42 studies “appraised”, 7 were presented in a table with methodological critique, and findings were summarised narratively. Five publications (including one pamphlet) were referred to with respect to education interventions. From these, the authors conclude that education should be individualised, and accessible; that adolescents on the spectrum are less likely to access sexuality information from their peers; and that applied behavioural analysis can be effective for replacing original inappropriate behaviour with new behaviour. The authors recommended individualised, repetitive, and accessible sexuality education for adolescents on the autism spectrum that included the following topics: friendship development, theory of mind, social rules, social norms, interpretation of senses, formal sexuality education, and parent education. Limitations of the evidence base acknowledged included that most studies appraised had small sample sizes, tended to rely on data from parent-informants, and tended to focus on “high functioning” people on the autism spectrum.

Pecora et al (2016) [31]

A recent systematic review from Australian researchers aimed (within a broader review) to investigate sexuality in individuals with high functioning autism (HFA) compared with typically developing individuals. The methods were rated as being of high quality (SIGN rating: +), accessing a reasonably broad range of databases and reference checking to identify peer-reviewed journal articles, books, and theses published to April 2016. Results were summarised in detailed evidence tables. Use of quality checklists was not reported. Studies of participants on the autism spectrum aged over 10 years and without intellectual disability were considered. In total, 27 observational and cross-sectional studies met selection criteria for qualitative synthesis, and a random-effects meta-analysis pooled data from 9 eligible studies with separate small meta-analyses reported for those studies investigating the same dependent variables. Key findings included that females with HFA exhibited higher levels of sexual understanding compared with males

with HFA, and were subject to more adverse sexual experiences than both males with HFA and neurotypical peers. By comparison, males with HFA reported greater desire for, and engagement in both solitary and dyadic sexual content than females with HFA.

Scottish Intercollegiate Guidelines Network, 2016 [49]

Most recently, a clinical guideline has been produced in Scotland on assessment, diagnosis and interventions for autism [49]. Updating a previous guideline, the high-quality review (SIGN rating: ++) employed a broad search strategy, two reviewers, and appraisal checklists to review research relating to the identification of signs and symptoms of autism. One study was identified [55] relevant to sexuality which suggested a significantly higher prevalence of “autistic symptoms” in 92 participants of a gender clinic compared to the general population. This study led to the following recommendation: “Healthcare professionals should be aware of the indicators for an ASD in adults presenting with other conditions”.

2.3.2 Primary studies

Seven primary studies were identified which evaluated the effectiveness of sexuality education programmes, curriculum, strategies or supports (see **Table A3.1**).

Study characteristics and results (comparisons between pre- and post-intervention, significant and non-significant), for the included primary studies are summarised in **Table 2.2**, organised by year of publication (oldest first), and alphabetically by first author.

Nichols & Blakeley-Smith (2010) [29]

The earliest evaluation included in this review is an exploratory case series (evidence level IV) study from the US [29]. It involved two parts: first, focus groups were conducted with parents of adolescents on the autism spectrum about their perspectives, concerns and service needs, and second, data was used to develop a psychoeducational curriculum for parents which was trialed and evaluated. A self-selected sample of parents of 10 adolescents on the autism spectrum participated. Their children were 5 girls and 5 boys, 6 diagnosed with Asperger’s syndrome and 4 with autism. Parents were divided into two groups (of 5 each) and received 8 weekly 1-hour sessions. The curriculum included parent-sharing and support, goal setting, advice on communication, and didactic teaching of issues including privacy, hygiene, masturbation, affection, personal boundaries, attraction and dating, monitoring of progress, and abuse prevention.

Table 2.2: Characteristics and results of primary studies

Reference	Quality, country	Sample	Intervention delivery	Intensity	Significantly improved outcomes (<i>informant</i>)	No difference in outcomes (<i>informant</i>)
Nichols & Blakeley-Smith (2010) [29]	Evidence: IV (case series) Quality: NA US	N=10 parents of adolescents with ASD aged 10-14 years; all male.	Group	8 X 1-hour sessions =8 hours	- increased parents' confidence in discussing sexuality with parents in group (<i>self</i>) - increased parents' confidence in discussing sexuality with school staff (<i>self</i>)	- parents' confidence in discussing sexuality with child (<i>self</i>) - parents' confidence in discussing sexuality with rest of family (<i>self</i>) * - parents' confidence in discussing sexuality with physician (<i>self</i>)
Banerjee et al (2013) [44]	Evidence: IV (case series) Quality: NA India	N=45 adolescents with ASD; Age range= 9-20 years. Male & female (ratio not reported)	Individual	40 X 30-60 minute sessions =20-40 hours (variable)	- decreased adolescents' "odd sexual behaviour" (<i>clinician</i>) - decreased adolescents' problem/inappropriate behaviour (<i>clinician</i>)	
Dekker et al (2015) [15]	Evidence: IV (case series) Quality: NA The Netherlands	N=30 adolescents with ASD, high functioning; M age=15 years (range: 11-19); 77% male	Individual	18 X 1-hour sessions =18 hours	- increased psychosexual knowledge of adolescents (<i>self</i>)	
Corona et al (2016) [50]	Evidence: IV (case series) Quality: NA US	N=8 adolescents with ASD; M age=13 years (range: 12-16); 75% male	Group	6 X 2-hour sessions =12 hours	- decreased parents' concern (<i>self</i>) - increased number of topics discussed with adolescent (<i>self</i>)	- adolescents' psychosexual knowledge (<i>self</i>) - parents' comfort with discussing sexuality with child (<i>self</i>)

Table 2.2: Characteristics of primary studies (continued)

Reference	Quality, country	Sample	Intervention delivery	Intensity	Significantly improved outcomes (<i>informant</i>)	Not significantly improved outcomes (<i>informant</i>)
Curtiss & Ebata (2016) [19]	Evidence: IV (case series) Quality: NZ US	N=43 professionals working with people with ASD	Group	Single all-day workshop =7 hours	<ul style="list-style-type: none"> - increased professionals' reported knowledge seeking (<i>self</i>) - increased professionals' reported collaboration (<i>self</i>) - increased professionals' perceived readiness to provide sexuality education (<i>self</i>) 	<ul style="list-style-type: none"> - professionals' reported use of curriculum (<i>self</i>) - professionals' reported advocacy (<i>self</i>) - professionals' provision of sexuality education (<i>self</i>)
Pask et al (2016) [16]	Evidence: IV (case series) Quality: NZ US	N=6 adolescents with ASD (M age=16 years (range: 15-17 years); all male)	Group	6 X 45 minutes sessions =4.5 hours		<ul style="list-style-type: none"> - adolescents' psychosexual knowledge (<i>self</i>)
Visser et al (2017) [38]	Evidence: II (RCT) Quality: + The Netherlands	N=189 adolescents; M age=14 years (range: 12-18 years); 75% male. Treatment=95 Control=94	Individual	18 X 45 minute sessions =13.5 hours	<ul style="list-style-type: none"> - adolescents' increased psychosexual knowledge of (<i>self</i>) ** - increased adolescents' psychosexual knowledge (<i>parent</i>) - increased adolescents' insight into interpersonal boundaries (<i>parent</i>) 	<ul style="list-style-type: none"> - adolescents' social functioning (<i>self</i>) - adolescents' romantic relationship skills (<i>self</i>) - adolescents' problem/inappropriate sexual behaviour (<i>parent</i>) - adolescents' autism-related problem sexual behaviour (<i>self</i>) - adolescents' autism-related problem sexual behaviour (<i>parent</i>)

Key: + rated as good quality; * = trend towards significance; ** maintained 6 months post intervention; ASD=Autism Spectrum Disorder; M=mean; NA=Not Applicable; RCT=randomised controlled trial; US=United States of America. Note: See [Glossary](#) (Appendix 2) for full titles of assessment tools

In pre-test/post-test comparisons, parents reported having significantly higher confidence in discussing sexuality with the group and school staff, and a trend for higher confidence in talking to their family, but not for talking with their child on the autism spectrum, or physician. High initial comfort levels of parents may have led to a ceiling effect, reducing likelihood of significant increases post-test. Qualitative data was also gathered providing positive feedback about the usefulness of the courses for parents in terms of information and the support of other parents going through similar challenges. Any impact on parents' interactions with their child on the autism spectrum were not investigated in this modest pilot study.

Banerjee et al (2013) [44]

A sexuality and health education curriculum was developed and evaluated by researchers in India using a before-and-after case series study (evidence level IV) [44]. Study participants were 45 male and female adolescents aged 9-20 years recruited from special schools of Kolkata. Students with clinically ascertained diagnoses of ASD and of average physical health were included, and students who were uninterested or unmotivated excluded. Participants received 40 weekly 30-60 minute individual sessions of *Sex and Health Education* curriculum. The intervention was based on Indian cultural norms and included five domains: biology and personal appearance, privacy/modesty (about sexual expression), health/hygiene/ personal care, recognition of emotion, and social behaviour. Session times varied to reflect the individual needs and motivation of participants.

Mothers attended sessions and were consulted by the researchers in rating the pre- and post-intervention outcomes (with input from the adolescent's special educator where ratings diverged). The dependent variables were checklists (developed by the researchers) of "odd sexual behaviour" and "problem behaviour". Paired t-tests indicated statistically significant decreases in reported indices of odd sexual behaviour, and of problem behaviour. In common with most studies included in the current review, the pilot study was relatively small, had no control group, and employed a convenience sample. As direct observational data was not reported, it is difficult to establish the validity or clinical significance of the reduced scores.

Dekker et al (2015) [15]

Another case series intervention study (evidence level IV) evaluated an individual psychoeducational *Tackling Teenage Training* (TTT) programme in The Netherlands [15]. The sample were 30 adolescents aged 11-19 years (mean age=14.80 years), 23 of whom were male (77%), with ASD, and IQ over 75 (mean IQ=96.7). Participants were referred from a large mental health organisation by their clinical practitioner where problems in psychosexual functioning had occurred or could be foreseen. An additional 10 eligible participants were excluded from analyses due to dropping out or incomplete data. The intensive manualised and structured intervention consisted of 18 weekly individual sessions completed over approximately 6 months. Sessions involved teaching instruction as well as behavioural rehearsals, quizzes, demonstrations, and weekly

homework assignments of practical work. Areas covered in the course were: puberty, appearances, first impressions, physical and emotional developments, becoming friends and maintaining friendship, falling in love and dating, sexuality and sex (e.g., sexual orientation, masturbation, safe intercourse), pregnancy, setting and respecting boundaries, and internet use.

Psychosexual knowledge was compared before and after the TTT programme; repeated measures ANOVA revealed a significant increase at follow-up ($M=33.80$) compared with baseline ($M=25.80$): $F(1,29)=65.20$; $p<0.001$). The greatest increases were found for knowledge relating to sexual selfhood (sexual preference) and sexual behaviour (foreplay). Improvements were greater for younger adolescents and those who the trainers perceived as having more difficulty during training. At post-test, the high majority (86%) of parents reported that their child applied acquired knowledge in everyday life, but no behavioural verification was undertaken.

The authors of this small pilot study acknowledge the limitations and recommend a large, randomised controlled trial (RCT) be undertaken to address these. Members of this research team evaluated the TTT in a RCT in 2016, which is included in this review [38].

Corona et al (2016) [50]

Another small pilot case series study with pre- and post-test measures (evidence level IV) was conducted in 2016 in the US [50]. Participants were self-selected families recruited through website promotion of local community services. Eight verbally able adolescents (6 male, 2 female) aged 12-16 years ($M\text{ age}=13$ years) with ASD received six 2-hour group sessions over 3 months. The intervention used didactic teaching and visual aids to cover topics including puberty, masturbation, privacy, hygiene, friendship development, dating behaviour, and personal safety.

Comparisons indicated that after the intervention, compared with before, parents were significantly less concerned and reported discussing more topics with their children. However there was no difference in adolescent knowledge or in parent comfort with discussions of sexuality.

Curtiss & Ebata (2016) [19]

In the same year, another US-based case series study [19] (evidence level IV) was published. It aimed at capacity building in the sector and evaluated a one-day, group-based professional development workshop for teaching sexuality education to adolescents with ASD. Participants were recruited from 300 professionals working with individuals on the autism spectrum who had registered for the sexuality education workshops held at 8 sites. Only 59 professionals responded to the online survey, 43 of whom completed both pre- and post-test assessments and were included in the study. Participants were mostly women, and the majority were either social workers, adult service providers, or special educators.

The comprehensive group workshop itself provided content and models for teaching, linked educators to additional resources, and encouraged exploration of values and

experiences. Outcomes were measured by the researcher-developed questionnaire one-month post intervention and compared with baseline.

Results suggested significant increases in knowledge seeking, collaborating, and readiness to provide sexuality education for people on the autism spectrum, but no difference for utilising curriculum, or for advocacy. Satisfaction with the intervention was very high. However the self-selected sample were likely to be biased toward those already satisfied and motivated. There was no difference in reported provision of sexuality education, although only 14 participants had this opportunity during follow-up. An additional feature of the study was that participants were randomised to receiving information updates by either email or Facebook. The study also compared outcomes for professionals randomly assigned to receiving online updates by email or Facebook. However the groups differed at baseline and no differences were found between conditions at one month follow-up. The authors suggest that a more intensive intervention may be necessary.

Pask et al (2016) [16]

Another US-based case series study (Evidence level: IV) evaluated a sexuality education intervention for adolescents on the autism spectrum [16]. Participants were 6 male adolescents aged 15-17 years (M age=16 years) with ASD of varying severity from the same class of a school-based autism services programme. Students received the *Healthy Relationships and Autism* curriculum intervention as a group in 45-minute sessions (once or twice a week). Whilst there were three modules, only the 6 sessions of the second module on biological facts (on puberty, biology, intercourse, pregnancy and childbirth) was evaluated in this report (modules on personal hygiene, and interpersonal relations, were not evaluated). The intervention included strategies such as repetition, rephrasing, and use of videos, with material sent home after each session to encourage practice and discussion with parents.

The main outcome was the researcher-developed assessment of knowledge of basic facts about biology relevant to sex. T-tests comparisons indicated a significant increase in sexual knowledge between pre- and post-tests. All students needed to have achieved over 85% accuracy on the post-test of a module before going on to the next module. Three of the 6 participants achieved over 85% accuracy at the initial post-test, and the other three did so at an additional post-test after receiving individualised remediation. A final follow-up assessment was timed a month after completion of the initial post-test. A one-way ANOVA across these assessment points found a main effect for change over time, with pairwise comparisons indicating that change occurred between pre-test and initial post-test, but not at one-month follow-up.

Whilst the authors conclude that the curriculum was effective in increasing sexual knowledge acquisition and retention regardless of child's level of difficulties, the sample was too small to look at any potential moderators of effect.

Visser et al (2017) [38]

Following the case series evaluation of the *Tackling Teen Training* (TTT) sexuality education programme [15] appraised above, members of the research team conducted a RCT of the same intervention (evidence level II) [38]. Conducted in The Netherlands, 189 adolescents, aged 12-18 years (M age=14 years) and 80% of whom were male, were randomised to either receive the TTT programme (N=95) or be placed on a wait list control (N=94). Included participants had received a clinical diagnosis of ASD, had an IQ within the “normal” range (full IQ of ≥ 85), and social functioning score of over 50. As being in the waiting list control group could potentially defer receiving the intervention, an ethical decision was made to exclude adolescents clinically assessed as having severe, offensive, law-violating levels of sexual problems or inappropriate sexual behaviours. This makes the study results less generalisable to those with severe problem behaviours.

The TTT intervention was given over 18, 45-minute, weekly individual sessions including quizzes and role plays, and a workbook provided to adolescents including exercises, tests and illustrations. The course included psycho-education and practice of communicative skills regarding puberty, appearances, first impressions, physical and emotional developments in adolescence, falling in love and dating, sexuality and sex, pregnancy, setting and respecting boundaries and safe Internet use. The study design included a baseline pre-test assessment, a post-test assessment 6 months later (after TTT for the intervention group), and a 12 month post-baseline follow-up assessment. Repeated assessments measured psychosexual knowledge, social functioning and behavioural outcomes, and adolescent-reported and parent-reported measures. Study quality was rated (using the SIGN checklist) as being of acceptable quality (+).

In linear mixed model analyses, compared with controls, adolescents receiving TTT had a significantly greater increase at post-test in psychosexual knowledge rated by themselves ($p < 0.01$) and by their parents ($p < 0.01$), and greater insight into interpersonal boundaries (parent-rated; $p < 0.05$). No treatment effects were found for any behavioural outcomes including social functioning, romantic relationship skills, sexual problems, or inappropriate sexual behaviour. The effects on psychosexual knowledge (rated by teen or parent) were moderated by age, with more knowledge gain for early adolescence (12-14 years) and middle adolescence, but not for older teens. Similarly, social functioning was increased in the treatment group for early and middle adolescence but not in late adolescence. There was no moderating effect for age on any other outcomes, for gender or adherence to the manual on any outcome measures. Maintenance of treatment effect at 12 month follow-up was evident for psychosexual knowledge (rated by adolescents) only.

The authors concluded that the TTT is an effective psycho-educational program in providing sexual knowledge and insight in early adolescence (12-14 years). However, they acknowledged that there was no evidence that the TTT programme improved skills needed for romantic relationships or reduced problematic sexual behaviour. Like other studies, there was no direct observational data of social behaviour collected and the

authors suggest that as training is individualised, adolescents may not have had the opportunity to practice skills with peers and learn behavioural skills.

Notably there was improvement over time regardless of condition for almost all the behavioural outcomes in this study which may relate to test-retest effects, but also may reflect developmental improvements over time and the influence of other sources of information. This finding is significant because it demonstrates the importance of including a control group to identify benefits of an intervention over and above maturation and learning effects, and other background factors. The authors [38] recommend that future research investigates how increased knowledge and insight can subsequently ameliorate improvements in romantic skills and prevent the development of problematic sexual behaviours and victimisation.

2.4 Synthesis of results

Five publications were identified representing secondary evidence, two systematic reviews [31, 36], and three practice guidelines that were informed by good quality systematic reviews [47-49].

The systematic reviews did not specifically investigate sexuality education, but provided background evidence which strengthens the rationale for interventions in this area. Review findings and guideline recommendations included evidence of higher rates of gender dysphoria, sexual abuse, and problem sexual behaviour in the autism community; sex differences in knowledge and behaviour; and the need for sexuality information and education for people on the spectrum and their parents/carers/support people.

Seven primary studies met selection criteria for inclusion in the review [15, 16, 19, 29, 38, 44, 50]. All evaluated sexuality education programmes targeting either adolescents on the autism spectrum, their parents, or professionals working in the field.

Features of sexuality education interventions

Considering the interventions directed at providing sexuality education directly to adolescents (or indirectly via their parents) appraised in the current review, topics commonly covered included:

- privacy [29, 44, 50];
- hygiene [16, 29, 44, 50];
- puberty, changes in biology and personal appearance [15, 16, 38, 44, 50];
- sexuality and sex (e.g., sexual orientation, masturbation, safe intercourse) [15, 16, 29, 38, 50];
- pregnancy [15, 16, 38];
- social behaviour, communicative skills and friendship development [15, 29, 38, 44, 50];

- attraction and dating [15, 16, 29, 38, 50];
- recognition of emotion [15, 38, 44];
- setting and respecting personal boundaries [15, 29, 38];
- abuse prevention [29];
- internet use [15, 38].

A range of strategies were employed within the educational programmes targeting adolescents to increase learning. These included traditional didactic teaching approaches, as well as the following strategies and tools:

- repetition, rephrasing [16];
- demonstrations [15];
- videos, visual aids [16, 50];
- role plays, behavioural rehearsals, practice of communicative skills [15, 38];
- quizzes [15, 38];
- workbook including exercises, tests and illustrations [38];
- weekly homework assignments of practical work [15, 16].

The intervention for parents of teens on the autism spectrum facilitated sharing and support between parents, goal setting, and provided advice on communication [29].

The workshop for professionals included content and models for teaching, linked workshop participants to additional resources, and encouraged their exploration of values and experiences [19].

Effectiveness of sexuality education interventions

The relatively low intensity (8 hours) intervention targeting 10 parents had mixed results, with self-reported measures indicating significantly increased parental confidence in discussing sexuality with other parents and school staff, but no change in reported discussion of sexuality with their child, the rest of their family, or their physician [29].

Similarly, there were mixed results for the all-day workshop offered to 43 professionals who work with people on the autism spectrum [19]. Again using self-report measures, there were significant improvements at one-month follow-up in knowledge seeking, collaboration, and readiness to provide sexuality education, but no difference in their reported use of the sexuality curriculum, advocacy or provision of sexuality education. It is possible that the lack of behavioural change may be related to lack of opportunity to teach adolescents on the autism spectrum. Researchers suggested a more intensive intervention may be necessary.

Of the 5 studies targeting adolescents directly, statistically significant improvements between pre- and post-intervention assessments were evident for half of the 16 outcomes measured. There was no clear pattern of what type of outcomes (psychosexual knowledge, attitudes/comfort, social functioning, and problem behaviour) were improved.

Considering the study involving adolescents on the autism spectrum which was least effective in terms of improvements to outcomes measured, no change in psychosexual knowledge was observed for 6 teenage boys following a brief 4.5 hour intervention [16]. Mixed results were found for the other group intervention of 12 hours duration [50], with self-reported decreases in parental concern and an increased number of topics discussed with the adolescent, but no changes found in parents' comfort in discussing sexuality with their child, or the adolescents' psychosexual knowledge.

By comparison, results for individually provided interventions were more promising. Further, there is evidence of a dose-response effect such that more intense interventions, offering more hours of contact time over a longer period, appear to have been more likely to lead to improvements in at least some outcomes.

Following 18 one-hour sessions, self-reported psychosexual knowledge was significantly increased in a sample of 30 cognitively able adolescents [15]. The most intense intervention of between 20 and 40 hours of individually provided curriculum led to decreased clinician assessed (based on parent reports) incidence of "odd sexual behaviour" and decreased problem/inappropriate behaviour for the 45 adolescents on the autism spectrum [44].

The fifth primary study of adolescents was also individually delivered and relatively intense. In contrast to the four observational case series studies, this was an experimental study; a well-conducted randomised controlled trial of 189 adolescents conducted in The Netherlands [38]. The 13.5 contact hours of the Tackling Teenage Training intervention was delivered individually to the treatment group of adolescents on the autism spectrum across 18 sessions, and changes in outcomes from baseline to post-assessment were compared to the waitlist control group. Compared to controls, the intervention group reported increased psychosexual knowledge (according to both self-report and parent measures), and increased adolescent "insight into interpersonal boundaries", as reported by parents. The psychosexual increase was maintained 12 months after baseline, which equated to approximately 6 months after the intervention ended. No difference was evident for the behavioural measures of adolescents' social functioning, romantic relationship skills, problem sexual behaviour, or autism-related problem sexual behaviour.

Across these five studies, the majority (75%) of significantly improved indices were found for interventions delivered to individuals rather than to groups, which were also the interventions of greater intensity (i.e. more contact hours over a longer period). It is possible that mode of delivery and/or intensity may moderate effectiveness. However, as only 5 primary studies of adolescents were appraised, and all but one were small sampled uncontrolled observational studies, this association is tentative and requires further, systematic investigation.

Moderators of effectiveness were generally not investigated due to samples being too small, however was explored in the two evaluations of the *Tackling Teen Training* sexuality education programme from The Netherlands. In the initial pilot case series study, improvements were greater for younger adolescents and those perceived by

trainers as having more difficulty during the programme [15]. The randomised controlled trial of the same intervention also found that some outcome gains were moderated by age in the treatment group, such that there with significant knowledge gain for early adolescence (12-14 years) and middle adolescence, but not for older teens. Also, social functioning was increased in the treatment group for early and middle adolescence but not in late adolescence. There was no moderating effect for age on any other outcomes, for gender, or for adherence to the manual [38].

2.5 Review limitations

Limitations of review methodology

The current study used a structured approach to review the literature. However, there are some inherent limitations with this approach. The review is limited by the quality of the studies included in the review and the review's methodology.

This review was limited by the restriction to English language studies. Restriction by language may result in study bias, but the direction of this bias cannot be determined. The inclusion of systematic reviews which did not apply an English language only restriction [47] is likely to reduce the impact of such biases.

The review was limited to the published academic literature, and has not appraised unpublished work. Such restriction is likely to lead to publication biases since studies that show an absence of effect are less likely to be published.

Studies were initially selected for appraisal by examining the articles' abstracts. Therefore, it is possible that some studies were inappropriately excluded prior to examination of the full text article. To minimise this possibility, where detail was lacking or ambiguous, papers were retrieved as full text.

The review had a broad scope. Searching for articles using the terms sex or gender would have identified countless articles where sex is mentioned as a sample characteristic. A pragmatic decision was made to focus the review on studies explicitly investigating sexuality as a key objective. Thus, articles were initially identified where they included any of the following as key terms: sexual health, sex education or sexual behaviour, puberty (in their Subject Heading or abstract), transgender, gender dysphoric, asexual, sexual intercourse, sexuality, sexual relationship, intimate relationship (in their abstract). By contrast, the search strategy was unrestrictive with respect to study design.

All studies included in this review were conducted outside New Zealand, and therefore, their generalisability to the New Zealand population, culture and autism service context may be limited and needs to be considered.

Studies were limited to those with a total sample size of at least 6, which included people from all comparator groups combined. Though this sample restriction is low for comparative studies, it may have excluded some qualitative studies.

Data extraction, synthesis and report preparation was performed by a single reviewer over a limited timeframe (July 2017 to mid-November 2017). For a detailed description of interventions, methods and results of the studies appraised, the reader is referred to the original papers cited.

Limitations of appraised studies

The current review's conclusions are limited by the methodological quality of included studies. All but one study, the good quality randomised controlled trial (RCT) of 189 young people [38], were uncontrolled case series. These cannot control for increases in sexual knowledge and skills gained over time (maturation effects), improvements from the repetition of questions (learning effects), or participants and observers biased towards seeing an improvement (reporting biases) given the time and effort invested in the training and research.

The case series studies were also limited by having small samples, with an average of 23 participants (ranging from 6-45). Samples were commonly self-selected [15, 19, 50] or identified by convenience [29, 44]. Such samples may be biased in unpredictable ways. For example, the study targeting professionals had a low recruitment rate (14% of 300 participating in the workshop responded) which may have identified people particularly motivated or interested in the area of sexuality education [19]. Another study selected participants from adolescents referred because they have, or were perceived as likely to have, psychosexual problems [15], whereas as the RCT [38] excluded adolescents with "severe problems" in its selection criteria. These methods can reduce the generalizability of the study findings to the broader population the interventions are intended for. Given the low sample sizes, studies may also be biased by significant drop-out rates or missing data, especially when these are not accounted for in data analysis.

The appraised studies also suffered from the lack of standardised, validated assessment scales. Most questionnaires were developed "in-house" by the researchers, tailored for their intervention. These questionnaires have not been psychometrically evaluated and the use of different instruments makes it difficult to compare outcome measures between studies. Exceptions were standardised measures (used at pre- and post-test assessments) of sexual problem behaviours (measured by a subscale of the Child Behavior Checklist, or the Sexual Behavior Scale) and social functioning (measured by the Social Responsiveness Scale) used in the RCT [38]. The veracity of measures is also threatened by the lack of blind assessment (i.e., informants such as parents and clinicians knowing that the adolescent has received the intervention) and reporting biases mentioned earlier. No studies collected direct observational data of interactions with the adolescent on the autism spectrum to determine whether behavioural improvements (e.g., in increased social behaviour) were evident.

A lack of a (statistically) significant treatment effect post-intervention may be due to the intervention not being effective, but modest differences are also less likely to be identified if a study is under-powered due to small sample sizes. Some outcomes also suffered from "ceiling effects" such that high scores evident at baseline reduce the likelihood of

significant increases occurring; for example, parental comfort in discussing sexuality with their child being high initially [29, 50]. Lack of improvement could also be related to lack of opportunity, particularly given that post-intervention assessments tended to be undertaken quite soon after the programme ended. Participants may simply not have had the opportunity to try out some of the new techniques or strategies. For example, in the study aimed at improving sexuality education delivery skills for professionals, only 12/43 professionals currently worked with providing sexuality education to people on the autism spectrum [50]. Longer follow-up may be required to allow such opportunities to arise.

Longer follow-up is also essential in order to determine whether any demonstrated improvements are maintained over time. Only two studies in the current review included an additional follow-up assessment; a small case series study included an additional follow-up one-month after programme completion [16], and the RCT study included an assessment approximately 12 months post-baseline follow-up, which was about 6 months after the intervention was completed [38]. The only outcome to remain statistically improved at follow-up was psychosexual knowledge as reported by adolescents (but not their parents).

2.6 Summary and conclusions

Overview

This systematic review updates evidence for the New Zealand Autism Spectrum Disorder Guideline [10] with respect to the effectiveness of educational interventions around sexuality for adolescents and young adults on the autism spectrum. Following a comprehensive database search and reference checking of primary studies and systematic reviews published since 2004, 12 studies met selection criteria for inclusion: 3 guidelines, 2 systematic reviews, and 7 primary studies. Of the primary studies, 6 were case series studies with before-and-after intervention assessments, and one was a randomised controlled trial, representing higher-order evidence [45]. The majority of primary studies were conducted in the United States (US), two were based in The Netherlands, and one in India. The secondary reviews were all conducted in the United Kingdom, with the exception of a systematic review produced by Australian researchers.

Secondary reviews

The five appraised systematic reviews (3 of which informed clinical practice guidelines) were not designed to investigate sexuality education specifically, and had somewhat different or broader scopes [31, 36, 47-49]. These recently published systematic reviews were considered as providing background to the current review.

Review findings and guideline recommendations included evidence of higher rates of gender dysphoria, sexual abuse, and problem sexual behaviour in the autism community; sex differences in knowledge and behaviour; and the need for sexuality

information and education for people on the spectrum and their parents/carers/support people. These findings support the necessity of effective and comprehensive interventions for young people on the autism spectrum which provide education, training, strategies and support relevant to sexual development, sexual health, and sexuality.

Primary studies

Seven primary studies were identified meeting selection criteria; 6 “before and after” case series studies and one randomised controlled trial [15, 16, 19, 29, 38, 44, 50]. Three educational interventions were delivered individually, and four were delivered to groups (one of which targetted parents, and another targetted professionals). Sample sizes varied widely, ranging from 6 to 189 people, although this was skewed to the lower samples with only one including more than 45 participants. Five targeted adolescents on the autism spectrum, and included young people aged between 9 to 20 years, with participants’ ages averaging in the mid-teens (13-16 years). One primary study considered group-delivered interventions for 43 professionals working with individuals on the autism spectrum, and another delivered a group intervention to 10 parents of adolescent boys on the autism spectrum.

Interventions

Interventions evaluated in the current review delivered sexuality education to adolescents and young people on the autism spectrum, either directly, or indirectly through training for parents or educators. Elements included in some or all the approaches included: the physical and emotional changes accompanying puberty; hygiene; personal boundaries and privacy; sexuality, sexual orientation, and healthy sexual behaviours; pregnancy and contraception; social and communication skills; recognition of emotion; friendship development; attraction and dating; abuse prevention and cyber safety. Beyond traditional didactic teaching, interventions included a range of teaching (e.g., repetition, quizzes); visual (e.g., demonstrations, videos) and behavioural strategies (e.g., role plays and rehearsals) to enhance retention and transfer of information and skills. Homework was also set to encourage discussion and practice beyond the programme.

The range of content and strategies employed is reflected in the varying programme intensity, measured in number of hours of providing an intervention. Parents and professionals received day-long workshops, whereas the programmes for adolescents ranged from 4.5 to 12 hours for group-delivered approaches, and 13.5 to 20 hours (potentially ranging to 40 hours for individually-delivered programmes).

Key findings of the review

- There was evidence from 7 studies, including one well-conducted RCT, for some improved outcomes following participation in a sexuality education programme.
- Targeting professionals who may have the opportunity to provide sexuality education to people on the autism spectrum in their work, a single case series study evaluated a one-day sexuality education training workshop. There were mixed results. Whilst there were some reported improvements in educators' preparation for and attitudes towards sexuality education, there was little evidence of behavioural change with respect to provision of sexuality education, although this may be related to lack of opportunity in the short post intervention timeframe [19].
- Similarly mixed were the results for a programme for parents of people on the autism spectrum evaluated in a single small-sampled case series study. Findings suggested that a one-day workshop may lead to improved reported confidence in discussing sexuality in some forums, although no difference was found in reported discussion of sexuality with the parent's adolescent child [29].
- Of the 5 studies targeting adolescents on the autism spectrum directly, there were treatment effects found for half of the 16 outcomes measured. Variability between intervention content, intensity and delivery, participants, assessment measures and informants make it difficult to identify factors predictive of improved outcomes. Looking at the pattern of significantly improved measures, there was a tendency for them to be found in studies evaluating individually-delivered (rather than to group) programmes, of greater intensity (with more contact hours and over a longer period), although these factors tended to co-vary in the studies appraised. Whether these and other factors have the potential to independently mediate effectiveness requires experimental research to compare programme features in a systematic, controlled way.
- A single randomised controlled trial (RCT) was appraised in the review [38]; a well-conducted experimental study involving 189 adolescents on the autism spectrum from The Netherlands evaluated the impact of 18 sessions of individually delivered sexuality education. There was evidence that psychosexual knowledge and insight into personal boundaries increased compared to controls. However there was no change in more behavioural outcomes including sexual problem behaviours (measured by subscale of the Child Behavior Checklist), social functioning (measured by the Social Responsiveness Scale), and romantic relationship skills. None of these or any behavioural outcomes in appraised studies were measured by direct observation.

- Moderators of effectiveness were rarely explored in multivariate analyses due to small sample sizes with the exception of the pilot case series and the RCT evaluations of the *Tackling Teen Training* sexuality education programme. There were greater improvements for younger adolescents and those perceived by trainers as having more programme difficulty [15]. The RCT reported knowledge and social functioning gains for programme participants in early and middle adolescence, but not for older teens. There was no moderating effect for age on any other outcomes, for gender, or for adherence to the manual [38].
- Maintenance of effects beyond (often immediately post) completion of the sexuality education was rarely explored. In the appraised RCT [38], improvements were maintained 6-months post intervention only for psychosexual knowledge when self-rated by adolescents, but not for psychosexual knowledge rated by their parents, or for insight into interpersonal boundaries.

Conclusions

The findings from the current review of this emerging and important field of research should be treated with caution. The evidence base consists predominantly of uncontrolled, small and selectively sampled observation studies. These were highly variable with respect to targeted participants and intervention content and delivery. Effectiveness was evaluated in the absence of direct behavioural observation and, in all studies except the RCT, did not use standardised scales.

With these limitations of the evidence base in mind, this review suggests that sexuality education programmes, particularly when provided individually and intensively over a period of 4 or more months, show moderate potential to increase psychosexual knowledge in the short term. It is not currently possible to offer clear conclusions about the *necessary content, components and teaching strategies* of sexuality educational programmes for adolescents on the autism spectrum.

Evidence for positive behavioural changes was more equivocal. The inconsistent results, lack of follow-up, and absence of independently and directly observed behavioural measures suggest that there is only preliminary evidence that sexuality education programmes may lead to improved participants' behavioural skills in targeted areas.

Evidence for maintenance and generalisation of treatment effects over time and in different contexts was scant. Many of the included studies covered a relatively narrow age range, gender, cognitive profile, and ethnicity, making generalisability to older adults, girls/women, people with below average cognitive abilities, and New Zealand-relevant cultures uncertain.

Future research

Future research is needed using rigorously conducted randomised controlled trials to confirm promising evidence of the effectiveness of sexuality education for people on the autism spectrum. Studies should develop and employ validated assessment tools to permit inter-study comparisons, including direct behavioural assessment from independent, blinded assessors in naturalistic environments, where ethically acceptable. Larger, more representative samples are needed to permit systematic assessment of the moderators and mediators of treatment effects. This will inform improvements to content, teaching strategies, timing, and tailoring of interventions to maximise benefits for people of differing gender, cognitive and verbal ability, and other characteristics. Importantly, longer follow-up assessment is needed to ensure that any outcome gains are extended, adapted and maintained in new “real world” situations. Such research will contribute to the development and delivery of high quality sexuality education for young people on the autism spectrum.

3 Recommendation development

The Living Guideline Group (LGG) was tasked with considering the systematically reviewed evidence on the effectiveness educational programmes, training and supports relating to sexuality for adolescents and young adults on the autism spectrum reported in Section 2 above, and considering this updated evidence in terms of its implications for the guideline [10]. Specifically, the LGG considered whether the evidence required revisions of existing recommendations and Good Practice Points (GPP) as well as the development of any new recommendations and GPP.

Both text of recommendations and their graded “strength of evidence” (see **Appendix 1, Table A1.2**) were revised/developed and considered at an all-day face-to-face meeting. The LGG’s decisions for text and grading of revised and new Recommendations and GPPs are presented below, and summarised in **Summary Tables I and II** (pg. xi). Where considered helpful, these decisions are accompanied by additional explanatory text, and/or with a brief rationale which highlights any particular issues that the LGG took into account while formulating the recommendations.

Decisions of the Living Guideline Group

New Recommendations and Good Practice Points

The following new Recommendation was developed.

- New Recommendation 3.2.2.6a: “Tailored sexuality education, particularly when delivered individually and intensively, should be considered for young people on the autism spectrum”. GRADE B

LGG additional text: It is not currently possible to recommend the content, components and teaching strategies of sexuality educational programmes for young people on the autism spectrum. More research is needed. However aspects found to be helpful in relation to cognitive behaviour therapy (CBT) may also be applicable to sexuality education (see Recommendation 4.3.10a in the guideline [10]).

It should be noted that whilst the research in the current review related to adolescents, gender identity and sexuality is expressed throughout the lifespan and targeted sexuality education may also be useful for older people on the autism spectrum.

LGG Rationale: Given the social and communication challenges associated with autism, people on the spectrum can misinterpret social cues and language, and have a greater openness about sexuality and sexual behaviour. This can sometimes lead to vulnerable situations or problem behaviour for people on the autism spectrum.

Sexuality education programmes aim to encourage healthy sexual development, reduce the risk of problem behaviours, and reduce the risk of exploitation, abuse, and victimisation. There is evidence that sexuality education programmes that are tailored to

people on the autism spectrum can improve psychosexual knowledge, at least in the short term.

The following new Good Practice Points were developed.

- New Good Practice Point 3.2.2.8 (and also 6.24b) “All those who support young people and adults on the autism spectrum should be sensitive to gender and sexual diversity”. ✓
- New Good Practice Point 3.2.2.9 “Sexuality education programmes in New Zealand need to be responsive to the cultural and linguistic diversity of their participants”. ✓
- New Good Practice Point 3.2.2.9a “New Zealand research is needed to develop and evaluate sexuality education programmes for young people on the autism spectrum. ✓
- New Good Practice Point 3.2.2.9b “Decisions about participating in sexuality education should be guided by whether a person on the autism spectrum values it, and whether they are expected to benefit from it”. ✓

Additional Text: Caveat: This does not refer to situations where an alternative intervention is required to target illegal or harmful behaviour.

The textual reference to the new Recommendation and GPPs above is best cited within Section 3.2.b Social development of the 2nd edition of the guideline, under a new subheading “Sexuality education” following the subsection called “The Hidden Curriculum” in which the need to teach skills in personal hygiene is referred (pg. 104).

Summary Tables I and II (pg. xi) present the revised and new Recommendations and Good Practice Points

Appendix 1: Methods

A1.1 Contributors

Living Guideline Group (LGG) members

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Declarations of competing interest

None

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A1.2 Research question

The current review updates evidence for the guideline [10] on sexuality education.

The review update's primary research question was: how effective are educational programmes, training and supports relating to sexuality for adolescents and young adults on the autism spectrum?

A1.3 Review scope

The Living Guideline Group (LGG) identified considering sexuality education as a priority topic to update in the guideline [10].

The original searching for the guideline [1] was performed in July 2004. For the original guideline, papers published before the search dates and in some cases after the completion of searching were suggested by members of all workstreams and incorporated into the text and evidence tables, where appropriate.

In the current update, the search was limited to articles published in the English language on or beyond January 1 2004. Given the overlap in search periods in 2004, and the inclusion of papers outside the date range in the original guideline, papers identified in the current search strategy which were already appraised in the original guideline [1] were excluded. However these are still considered in deliberations by the LGG as being part of the entire body of evidence.

The scope and research questions were refined after the initial search was completed.

Primary research studies were included where primarily investigating how effective are educational programmes, training and supports relating to sexuality for adolescents and young adults on the autism spectrum. Participants were people (aged between 12 and 44 years) on the autism spectrum, or their family members/carers, or autism service providers. Studies of at least 5 participants were included. Specific inclusion criteria are presented in the body of the report (**Section 2.1**).

A1.4 Search strategy

Search strategies were limited to publications from January 1 2004 onwards. Database searches were conducted on 17 and 18 June 2017, and updated on 15 August 2017.

The INSIGHT Research lead researcher set the inclusion and exclusion criteria for the review in consultation with the Ministry of Health. Systematic database searching was designed and conducted by the INSIGHT lead researcher. Full search strategies are available upon request.

Search databases

Bibliographic, health technology assessment and guideline databases were included in the search strategy, listed below.

- Medline
- Embase
- Cinahl
- PsycInfo
- ERIC
- Cochrane Database of Systematic Reviews (CDSR)
- Central Register of Controlled Trials (CRCT)
- Database of Abstracts of Reviews of Effects (DARE)
- Health Technology Assessment Database (HTA Database)

A combination of search terms were used in subject or mesh headings (MH), article titles (TI), abstracts (AB), and Subject (SU) and adapted for different databases. The following illustrative search is offered:

- MH "Child Development Disorders, Pervasive+" OR TI (pervasive development* disorder\$ or PDD) OR AB (pervasive development* disorder\$ or PDD) OR TI autis* OR AB autis* OR TI Asperger\$ OR AB Asperger\$
- AND
- SU (sexual health) OR (sex education) OR (sexual behavio\$r)
OR AB puberty OR transgender OR (gender dysphoric) OR asexual OR (sexual intercourse) OR sexuality OR (sexual relationship) OR (intimate relationship) OR (sexual health) OR (sex education) OR (sexual behavio\$r)

NOT

- limit to English language, 2004-current, peer reviewed journals, human, age groups of 13 to 44 years.

Hand searching of journals was not undertaken.

A1.5 Appraisal of studies

Table A1.1: NHMRC levels of evidence relevant to review scope

Level	Intervention
	Studies
II	A randomised controlled trial
III-1	A pseudorandomised controlled trial (i.e. alternate allocation or some other method)
III-2	A comparative study with concurrent controls: <ul style="list-style-type: none"> - Non-randomised, experimental trial - Cohort study - Case-control study - Interrupted time series with a control group
III-3	A comparative study without concurrent controls: <ul style="list-style-type: none"> - Historical control study - Two or more single arm study - Interrupted time series without a parallel control group
IV	Case series with either post-test or pre-test/post-test outcomes

Source: NHMRC [45]

For this review, a single researcher performed study selection, narrative reviews and synthesis. Evidence tables (see **Appendix 3**) were completed for each appraised study. Evidence tables present the key characteristics of each of the appraised studies including sample characteristics, methodology, results, and the “level of evidence”.

The level of evidence indicates how well the study eliminates bias based on its design. INSIGHT Research uses a published evidence hierarchy, designed by the National Health and Medical Research Council of Australia (NHMRC) [45]. These describe research designs which are broadly associated with particular methodological strengths and limitations so as to rank them in terms of quality, from I (systematic reviews of level II studies) to IV (case series).

In the hierarchy of evidence employed (described in **Appendix 1, Table A1.1**), systematic reviews which included level II studies are ranked as level I evidence whereas systematic reviews of lower order evidence rank at the same level as that order of evidence.

Each study may be designed and/or conducted with particular strengths and weaknesses which can be assessed using critical appraisal tools. In this review, included studies were formally appraised using the quality checklists from the Scottish Intercollegiate Guidelines Network [49] as appropriate to study design, including those for systematic reviews and randomised controlled trials.

No checklist is available for cross-sectional or case series studies (level IV).

The quality and resistance to risk of bias of an individual study was scored as follows:

- **High quality (++)**: Majority of criteria met. Little or no risk of bias.

- **Acceptable (+):** Most criteria met. Some flaws in the study with an associated risk of bias.
- **Low quality (-):** Either most criteria not met, or significant flaws relating to key aspects of study design.
- **Reject (0):** Poor quality study with significant flaws. Wrong study type. Not relevant to guideline

A1.6 Preparing recommendations

Developing recommendations

A one-day face-to-face meeting was held on 23 November 2017 where the LGG considered the findings of the current systematic review and revised affected recommendations (and Good Practice Points) from the guideline [1] and/or developed new ones. Using their collective professional judgement and experience, the LGG discussed the body of evidence with respect to the research questions and the applicability of the evidence within New Zealand.

Developing recommendations involves consideration of the whole evidence base for the research question. The quality and consistency of the evidence and the clinical implications of the evidence within a New Zealand context is weighed up by all the LGG members. The recommendations were agreed by consensus during the meeting.

Each recommendation is assigned a grade to indicate the overall “strength of the evidence” upon which it is based. Strength of the body of evidence is determined by three domains [45]:

- quality (the extent to which bias was minimised as determined by study design and the conduct of the study)
- quantity (magnitude of effect, numbers of studies, sample size or power)
- consistency (the extent to which similar findings are reported).

It should be noted that systematic reviews and meta analyses (secondary studies) considered which draw on publications over an overlapping timeframe could report on (some of) the same studies. For this reason it is important to be aware that the results from secondary studies should not be summated as independent sources of evidence as this would misrepresent the quantity of studies and give shared primary studies undue weight. Rather, recently published secondary evidence should be considered as background information and to validate the findings of the current review.

Table A1.2: Guide to grading recommendations [1]

Recommendations	Grade
The recommendation is supported by good evidence (based on a number of studies that are valid, consistent, applicable and clinically relevant)	A
The recommendation is supported by fair evidence (based on studies that are valid, but there are some concerns about the volume, consistency, applicability and clinical relevance of the evidence that may cause some uncertainty but are not likely to be overturned by other evidence)	B
The recommendation is supported by international expert opinion	C
The evidence is insufficient, evidence is lacking, of poor quality or opinions conflicting, the balance of benefits and harms cannot be determined	I

Note: Grades indicate the strength of the supporting evidence rather than the importance of the evidence.

The grades of recommendations used by the LGG, and also used in the original guideline

Good practice point	Grade
Where a recommendation is based on the clinical and educational experiences of members of the Living Guideline Group, or feedback from consultation within New Zealand, it is a Good Practice Point.	✓

[1], are presented in **Table A1.2**.

A1.7 Consultation

Seeking comments from stakeholders is vital for peer-review and quality assurance processes in developing the report. In a focused consultation 10 key stakeholder organisations/individuals were approached for feedback on a late draft of the report. These included: Altogether Autism (AA), ASK Trust (ASK), Autism New Zealand (ANZ), Explore, Office of the Children’s Commissioner (OCC), Mental Health Directorate of the Ministry of Health, Ministry of Education, the Paediatric Society of New Zealand (PSNZ), the New Zealand Psychological Society (NZPS), and the SAFE Network. ASK Trust is an autistic-led advocacy group. Autism New Zealand and Altogether Autism consulted their consumer advisory panels. Particular attention was sought regarding the relevance of the report to New Zealand services and needs, clarity and ease of use of the report, and implementability of the revised or new recommendations.

Responses were received from 8 organisations/individuals, 7 of whom completed the online survey.

The lead researcher (INSIGHT Research) collated feedback and drafted revisions for the LGG to consider. Amendments were finalised by group consensus. Suggestions identified in the consultation led to several improvements to the final report. INSIGHT Research and the LGG are grateful to those individuals and organisations who participated in the consultation process.

Appendix 2: Abbreviations and glossary

A2.1 Abbreviations and acronyms

Miscellaneous Terms

ASD	Autism Spectrum Disorder
CI	confidence interval
GPP	Good Practice Point
IQ	intelligence quotient
INSIGHT Research	Independent Network of Specialists in Guidelines & Health Technology Research
LGG	Living Guideline Group
M	mean
N (or n)	number (usually, sample size)
NHMRC	National Health and Medical Research Council (Australia)
PDD	Pervasive Developmental Disorder
PDD-NOS	Pervasive Developmental Disorder – Not Otherwise Specified
RCT	randomised controlled trial
SD	standard deviation
UK	United Kingdom
US	United States of America
vs	versus
WHO	World Health Organisation (health data and statistics)

Tests, scales and measures

ABC	Adaptive Behavior Composite
ADDM	Autism Developmental Disabilities Monitoring Network
ADI-R	Aberrant Behavior Checklist
CBCL	Child Behavior Checklist
DSM-IV-TR	Diagnostic and Statistical Manual of Mental Disorders - IV (text revision)
DSM5	Diagnostic and Statistical Manual of Mental Disorders – 5 th edition

Databases

CDSR	Cochrane Database of Systematic Reviews
CINAHL	Cumulative Index to Nursing and Allied Health Literature
DARE	Database of Abstracts of Reviews of Effects
Embase	Excerpta Medica Database
ERIC	Education Resources Information Centre
HTA database	Health Technology Assessment Database
Medline	Medical Literature Analysis and Retrieval System Online
PsycINFO	Psychology Information Database

A2.2 Glossary

Bias

Bias is a systematic deviation of a measurement from the “true” value leading to either an over- or under-estimation of the treatment effect. Bias can originate from many different sources, such as allocation of patients, measurement, interpretation, publication and review of data

Case-control study

Patients with a certain outcome or disease and an appropriate group of controls without the outcome or disease are selected (usually with careful consideration of appropriate choice of controls, matching, etc.) and then information is obtained on whether the subjects have been exposed to the factor under investigation.

Case series

Case series are collections of individual case reports, which may occur within a fairly short period of time. Cases consist of either only the exposed people with the outcomes, or people with the outcome regardless of the exposure. In neither of these examples can the risk for the outcome be determined

Challenging behaviour

Behaviour of such frequency, intensity or duration that the physical safety of the person is placed in serious jeopardy, or behaviour which is likely to seriously limit or deny access to the use of ordinary community facilities.

Cohort study

Subsets of a defined population can be identified who are, have been, or in the future may be exposed or not exposed in different degrees, to a risk factor or factors hypothesised to influence the probability of occurrence of a given disease or other outcome. Subjects are followed from a well-described starting point to determine whether the outcome/disease occurs (either retrospectively, or prospectively). The control group of people not exposed to the risk factor can be identified within the population-based cohort, and be matched by confounders known to be associated with the outcome (e.g., age, sex), or can be obtained from an historical cohort. Studies usually involve the observation of a large population, for a prolonged period (years).

A prospective cohort study is where groups of people (cohorts) are observed at a point in time to be exposed or not exposed to an intervention (or the factor under study) and then are followed prospectively with further outcomes recorded as they happen.

A retrospective cohort study is where the cohorts (groups of people exposed and not exposed) are defined at a point of time in the past and information collected on subsequent outcomes, e.g., the use of medical records to identify a group of women using oral contraceptives five years ago, and a group of women not using oral contraceptives, and then contacting these women or identifying in subsequent medical records the development of deep vein thrombosis.

Cross-sectional study

A study that examines the relationship between exposures (e.g., risk factor) and outcomes (e.g., disease), as they exist in a defined population, at a particular time. A group of people are assessed at a particular point (or cross-section) in time and the data collected on outcomes relate to that point in time; i.e., proportion of people with asthma in October 2004. This type of study is useful for hypothesis-generation, to identify

whether a risk factor is associated with a certain type of outcome, but more often than not (except when the exposure and outcome are stable; e.g., genetic mutation and certain clinical symptoms) the causal link cannot be proven unless a time dimension is included.

Detection bias

Detection bias refers to systematic differences between groups in how outcomes are determined. Awareness by outcome assessors/respondents of whether an intervention was received or not (i.e., they are not blind to allocated condition) may increase the risk of their measurements/ratings/reports being affected by detection bias.

Effect size

A quantitative measure of the strength of a phenomenon, a standardised measure of the size of the difference between two groups.

Effectiveness

A measure of the extent to which a specific intervention, procedure, regimen, or service, when deployed in the field in routine circumstances, does what it is intended to do for a specified population.

Generalisability

Applicability of the results to other populations.

High functioning

Whilst it is acknowledged that the term “high functioning” is not universally favoured, in this report, the term “high functioning” is used to refer to people with higher cognitive functioning either as established by intelligence tests (generally indicated by full IQ scores of 70 or above), or through the diagnosis of “high-functioning autism” or Asperger syndrome (under DSM-IV criteria). In light of the removal of Asperger syndrome as a separate diagnostic classification in DSM-5, these distinctions may no longer be used clinically.

Level of evidence

A hierarchy of study evidence that indicates the degree to which bias has been eliminated in the study design. See **Appendix 1, Table A1.1**.

Mean

Calculated by adding all the individual values in the group and dividing by the number of values in the group.

Neurodiversity

An approach to learning and disability which suggests that diverse neurological conditions appear as a result of normal variation in the human genome. This term was coined in the late 1990s as a challenge to prevailing views of neurological diversity as inherently pathological, and it asserts that neurological differences should be recognized and respected as a social category on a par with gender, ethnicity, sexual orientation, or disability status

Neurotypical

An abbreviation of neurologically typical, a term coined in the autism community as a label for people who are not on the autism spectrum, otherwise referred to as typically developing people.

Non-randomised, experimental trial

The unit of experimentation (eg. people, a cluster of people) is allocated to either an

intervention group or a control group, using a non-random method (such as patient or clinician preference/availability) and the outcomes from each group are compared.

This can include:

- a controlled before-and-after study, where outcome measurements are taken before and after the intervention is introduced, and compared at the same time point to outcome measures in the control group.
- an adjusted indirect comparison, where two randomised controlled trials compare different interventions to the same comparator i.e. the placebo or control condition. The outcomes from the two interventions are then compared indirectly.

Observational studies

Also known as epidemiological studies. These are usually undertaken by investigators who are not involved in the clinical care of the patients being studied, and who are not using the technology under investigation. Distinct from experimental studies.

Performance bias

Performance bias refers to systematic differences between groups in the care that is provided, or in exposure to factors other than the interventions of interest. After enrolment into the study, blinding (or masking) of study participants and personnel may reduce the risk that knowledge of which intervention was received, rather than the intervention itself, affects outcomes. Effective blinding can also ensure that the compared groups receive a similar amount of attention, ancillary treatment and diagnostic investigations. Blinding is not always possible, however.

Post-test

Case series where only outcomes after the intervention (factor under study) are recorded in the series of people, so no comparisons can be made.

Pre-test/post-test

Case series where measures on an outcome are taken before and after the intervention is introduced to a series of people and are then compared (also known as a 'before- and-after study').

Power

The probability that a statistical test or study will detect a defined pattern in data and declare the extent of the pattern as showing statistical significance.

Prevalence

A measure of the proportion of people in a population who have some attribute or disease at a given point in time or during some time period.

Pseudo-randomised controlled trial

The unit of experimentation (e.g., people, a cluster of people) is allocated to either an intervention (the factor under study) group or a control group, using a pseudo-random method (such as alternate allocation, allocation by days of the week or odd-even study numbers) and the outcomes from each group are compared.

Quality of evidence

Degree to which bias has been prevented through the design and conduct of research from which evidence is derived.

Randomised controlled trial (RCT)

An experiment in which subjects in a population are randomly allocated into groups to receive or not receive an experimental preventive or therapeutic procedure, manoeuvre, or intervention. The groups are compared prospectively.

Reinforcement

Reinforcement is a fundamental concept of operant conditioning, whose main purpose is to strengthen or increase the rate of behaviour. Reinforcement helps increase certain behaviour with the use of stimulus, which is called reinforcer. A reinforcer can be food, money, praise, and so on.

Secondary study

An analysis or synthesis of research data reported elsewhere, including systematic reviews, meta analyses and guidelines.

Selection bias

Error due to systematic differences in characteristics between those who are selected for inclusion in a study and those who are not (or between those compared within a study and those who are not).

Sexuality

Sexuality is “a central aspect of being human throughout life (which) encompasses sex, gender identities and roles, sexual orientation, eroticism, pleasure, intimacy and reproduction. Sexuality is experienced and expressed in thoughts, fantasies, desires, beliefs, attitudes, values, behaviours, practices, roles and relationships. While sexuality can include all of these dimensions, not all of them are always experienced or expressed. Sexuality is influenced by the interaction of biological, psychological, social, economic, political, cultural, legal, historical, religious and spiritual factors” [11].

Strength of evidence

The strength of evidence for an intervention effect includes the level (type of studies), quality (how well the studies were designed and performed to eliminate bias) and statistical precision (P-value and confidence interval).

Systematic review (SR)

A literature review reporting a systematic method to search for, identify and appraise a number of independent studies.

Treatment effect

An effect attributed to a treatment (intervention), which in a clinical trial is based on a comparison between active treatment and a placebo control, or two or more treatment regimens.

Appendix 3: Evidence Tables of included studies

Tables are ordered by study type (primary then secondary studies), and then within each table, according to the following hierarchy: year of publication (oldest first), and alphabetically (by first author's surname).

Evidence Tables relating to primary studies

Table A3.1: What is the effectiveness of educational programmes, training and supports which aim to assist young adults on the autism spectrum with challenges around sexuality?"

Nichols & Blakeley-Smith (2010) [29]					
Country, study type, evidence	Participants	Inclusion and exclusion criteria	Intervention, comparison and outcome measures	Results	Conclusions
<p>Country: USA</p> <p>Study type: case series with pre- and post-test measures</p> <p>Evidence level: IV</p> <p>Aim: to evaluate a group-based sexuality education intervention for parents of adolescents with ASD.</p>	<p>Setting/recruitment: university-affiliated centre for people with developmental disabilities. Parents recruited through the newsletter, email and website.</p> <p>Participants: Parents of 5 boys and 5 girls aged 10-14 years (mean age not reported); 6 with Asperger's syndrome, and 4 with autism with "low average" to "above average" cognitive functioning.</p>	<p>Inclusion criteria: professional diagnosis of ASD</p> <p>Exclusion criteria: parents unable to attend at least 6 of 8 sessions.</p> <p>Follow-up: pre- and post-intervention</p> <p>Fidelity: not reported</p>	<p>Intervention: 8 weekly 1-hour sessions of group-based parents education and support. Two groups, 5 parents per group.</p> <p>Included didactic teaching, parent-sharing, weekly homework. Sessions on privacy, hygiene, masturbation, affection, personal boundaries, attraction & dating, monitoring of progress, abuse prevention.</p> <p>Outcomes (<i>self-report, completed by parents</i>)</p> <ul style="list-style-type: none"> - The Comfort Ratings Questionnaire – Parent Version - End of Group Evaluation 	<p>Key findings:</p> <p>Between pre- to post-group sessions:</p> <p>Significant increases in perceived comfort of parents for discussing sexuality with the group ($p < 0.02$), for discussing sexuality with school staff ($p < 0.3$), trend for discussing sexuality with family ($p < 0.10$), no significant change for discussing sexuality with child on the autism spectrum, or physician.</p> <p><u>Maintenance:</u></p> <p>not determined</p>	<p>Author conclusions: The study is "a first step in the process of aiding families to feel prepared and successful in navigating puberty and issues of sexuality."</p> <p>Reviewer's comments: Small pilot study with no control group and convenience sample. ASD independently verified. Scales not standardised or validated. Direct observational data of interactions with child on the autism spectrum were not collected. High initial comfort levels of parents may have created a ceiling effect, reducing likelihood of significant increases.</p> <p>Useful qualitative data collected in preceding focus groups and in the outcome surveys.</p> <p>Source of funding: Not reported. Authors are affiliated with academic and health services.</p>

Banerjee et al (2013) [44]					
Country, study type, evidence	Participants	Inclusion and exclusion criteria	Intervention, comparison and outcome measures	Results	Conclusions
<p>Country: India</p> <p>Study type: case series with pre- and post-test measures</p> <p>Evidence level: IV</p> <p>Aim: to develop and evaluate a sexuality and health education curriculum for adolescents with ASD</p>	<p>Setting/recruitment: recruited from different special schools of Kolkata.</p> <p>Participants: 45 male and female adolescents aged 9-20 years (mean age and gender ratio not reported)</p>	<p>Inclusion criteria: clinically diagnosed with autism using DSM-IV criteria, being of average physical health</p> <p>Exclusion criteria: those uninterested or unmotivated</p> <p>Follow-up: pre- and post-intervention</p> <p>Fidelity: not reported</p>	<p>Intervention: 40 weekly 30-60 minute individual sessions of sexuality and health education curriculum. Mothers attended.</p> <p>Included five domains: biology and personal appearance, privacy/modesty (about sexual expression), health/hygiene/ personal care, recognition of emotion, and social behaviour. Time varied to reflect individual need.</p> <p>Outcomes (<i>completed by psychologist after consultation with parents, where there was a dispute over a rating, it was verified with special educators</i>)</p> <ul style="list-style-type: none"> - odd sexual behaviour checklist - problem behaviour checklist <p>The intervention and assessment tools were all developed by the authors and based on Indian culture.</p>	<p>Key findings:</p> <p>Paired t-tests compared changes in outcomes between pre- to post-group assessments:</p> <p>Significant decreases in amount of odd sexual behaviour (reduced from mean of 31 to 25), and problem behaviour (reduced from mean of 112 to 97). P values not clearly reported (stated as 0).</p> <p><u>Maintenance:</u> not determined</p>	<p>Author conclusions: Study had a positive effect in "reducing odd sexual behaviour and problem behaviour, indicating that imparting education regarding handling of expression of sexual urge in a socially acceptable way has immense positive effect both on odd sexual behaviour and problem behaviour of the individuals with autism".</p> <p>Reviewer's comments: Small pilot study with no control group and convenience sample. ASD independently verified. Scales standardised. Direct observational data of interactions with child on the autism spectrum were not collected.</p> <p>Source of funding: Not reported. Authors are affiliated with the University of Calcutta.</p>

Dekker et al (2015) [15]					
Country, study type, evidence	Participants	Inclusion and exclusion criteria	Intervention, comparison and outcome measures	Results	Conclusions
<p>Country: The Netherlands</p> <p>Study type: case series with pre- and post-test measures</p> <p>Evidence level: IV</p> <p>Aim: to evaluate an individual sexuality education intervention for adolescents with ASD.</p>	<p>Setting/recruitment: referred by their clinical practitioner from the inpatient and outpatient clinics of a large mental health organisation. Referrals made because problems in psychosexual functioning had occurred or could be foreseen as being future issues.</p> <p>Participants: 30 (of 40 eligible including 7 dropouts and 3 with missing data) adolescents with ASD; 23 male (77%), aged 11-19 years, M=14.80 years); mean IQ=96.7; diagnoses: 24 PDD-NOS, 3 AS, 3 AD. Group with incomplete data did not differ in their initial knowledge, age, gender or intelligence from those with complete data.</p>	<p>Inclusion criteria: clinical diagnosis of ASD: IQ 75 or higher, aged 11-19 years.</p> <p>Exclusion criteria: not completing pre- or post-tests, not completing programme.</p> <p>Follow-up: knowledge assessed one week pre- and one week post-intervention on average 7 months apart.</p> <p>Fidelity: certified trainers who had received 2-day course, manualised intervention with some flexibility in order of topics and time spent on each depending on individual's needs.</p>	<p>Intervention: 18 weekly sessions completed over approximately 6 months of individual one-to-one psychoeducational Tackling Teenage Training (TTT) programme.</p> <p>Involved didactic teaching and exercises (behavioural rehearsals, quizzes), training kit materials, and weekly homework assignments (e.g., discuss or practice a topic). Leaflets provided with life-like illustrations. Sessions included: puberty, appearances, first impressions, physical and emotional developments, becoming friends and maintaining friendship, falling in love and dating, sexuality and sex (e.g., sexual orientation, masturbation, safe intercourse), pregnancy, setting and respecting boundaries, and internet use. Parents were given weekly feedback by email on their child's strengths and weaknesses.</p> <p>Outcomes (completed by whom)</p> <ul style="list-style-type: none"> - psychosexual knowledge test (pre and post) (adolescents) - parents asked whether child applied acquired knowledge in everyday life (post-test only) (parents) 	<p>Key findings:</p> <p>Repeated measures ANOVA found significant increase in psychosexual knowledge at follow-up (M=33.80) cf baseline (25.80): $F(1,29)=65.20$; $p<0.001$.</p> <p>Increases in all but one item over time. Biggest increases (over 40% change) were for about sexual selfhood (sexual preference) and sexual behaviour (foreplay). Everyone could name the primary male sexual organ.</p> <p>Greater improvements were found for younger adolescents ($r=-.55$, $p<0.01$), and those who trainers perceived as having more difficulty in the sessions ($r=0.37$, $p=0.05$).</p> <p>19 (86%) parents reported their child applied acquired knowledge in everyday life at post-test.</p> <p>Maintenance: not determined</p>	<p>Author conclusions: TTT programme may be useful to improve psychosexual knowledge and functioning in adolescents on the autism spectrum. The findings are preliminary and a controlled trial is needed.</p> <p>Reviewer's comments: Small pilot study with no control group, few girls, and significant drop-out (said to be for circumstantial reasons but no analysis of whether they differed from study group). Those with missing data excluded. Sample selected as either having or considered as likely to have psychosexual problems, therefore not generalizable to people on the autism spectrum generally. ASD and IQ verified by study. Direct observational data of interactions with children on the autism spectrum not collected and question of parents about whether child applied knowledge was a yes or no question with a likely ceiling effect.</p> <p>Source of funding: Sophia Children's Hospital Fund; and Psychological Health Fund.</p> <p>Note: an RCT study evaluating TTT is appraised for the current review [38]</p>

Corona et al (2016) [50]					
Country, study type, evidence	Participants	Inclusion and exclusion criteria	Intervention, comparison and outcome measures	Results	Conclusions
<p>Country: USA</p> <p>Study type: case series with pre- and post-test measures</p> <p>Evidence level: IV</p> <p>Aim: to evaluate a group-based sexuality education intervention for adolescents with ASD (and parents of adolescents).</p>	<p>Setting/recruitment: participants recruited from community via local agency websites, with phone call to establish eligibility.</p> <p>Participants: 8 adolescents (6 male, 2 female) aged 12-16 years, M age=13 years) with ASD.</p>	<p>Inclusion criteria: aged 12-16, diagnosed with ASD, verbally able to communicate and participate in a group setting.</p> <p>Exclusion criteria: parent reported severe problem behaviour</p> <p>Follow-up: pre- and post-intervention</p> <p>Fidelity: not reported</p>	<p>Intervention: 6 2-hour group sessions over 3 months. Adolescent and parents sessions held simultaneously. Included didactic teaching, prompts, and visual representations. Topics included puberty, masturbation, privacy, hygiene, friendship development, dating behaviour, personal safety. Parents' sessions covered same topics and included strategies to promote their child's understanding of material.</p> <p>Outcomes (completed by whom)</p> <ul style="list-style-type: none"> - Sexual Behaviour Scale (SBS) (<i>parents</i>) – pre-test only - sexuality-related knowledge (<i>adolescents</i>) - Parent comfort questionnaire (<i>parents</i>) - Parent satisfaction questionnaire (<i>parents</i>) - post-test only 	<p>Key findings:</p> <p>Comparisons between pre- to post-group sessions (using T-tests):</p> <p>Significant decrease in concern by parents ($p<0.05$).</p> <p>Significant increase in number of topics discussed with adolescent ($p<0.5$).</p> <p>No difference in adolescent knowledge (only 75% completion rate), or in parent comfort with discussions of sexuality.</p> <p>High parental satisfaction ratings.</p> <p><u>Maintenance:</u> not measured</p>	<p>Author conclusions: Study suggests that a short-term sexuality programme is both feasible and satisfactory to families.</p> <p>Reviewer's comments: Small pilot study with no control group and self-selected sample. ASD diagnosis not verified. Most questionnaires not validated and developed for study. Direct observational data of interactions with child on the autism spectrum were not collected. High initial comfort levels of parents may have created a ceiling effect, reducing likelihood of significant increases.</p> <p>Useful qualitative data collected in surveys.</p> <p>Source of funding: Supported by New York State Department of Education and Glann Falls Foundation M&M Fund.</p>

Curtiss et al (2016) [19]					
Country, study type, evidence	Participants	Inclusion and exclusion criteria	Intervention, comparison and outcome measures	Results	Conclusions
<p>Country: USA</p> <p>Study type: case series with pre- and post-test measures.</p> <p>Evidence level: IV</p> <p>Aim: to evaluate a group-based professional development workshop for how to teach sexuality education to adolescents with ASD.</p>	<p>Setting/recruitment: professionals recruited from 300 participants registered for the sexuality education workshops held at 8 autism programme centres in the State of Illinois.</p> <p>Participants: 43 (of 59 initially recruited) professionals working with individuals with ASD; aged 23-61 years, M age=38 years); 87% female; 32% social workers, 26% adult service providers, 17% special educators, 25% other professionals.</p>	<p>Inclusion criteria: registered for the workshop, agreed to use email and Facebook as online community for study, and work with individuals with ASD.</p> <p>Exclusion criteria: none reported</p> <p>Follow-up: online survey pre- and one month post-intervention</p> <p>Fidelity: not reported</p>	<p>Intervention: 1-day (7-hour) workshop with additional follow-up updates (posts to the website) sent either by email or Facebook.</p> <p>Provided content and models for teaching, linked educators to additional resources, and encouraged exploration of values and experiences. Very comprehensive coverage of topics across sexuality and relationships.</p> <p>Outcomes (<i>self-report, completed by professionals</i>)</p> <ul style="list-style-type: none"> - instructional climate (pre-test only) - programme outcomes (pre and post test) - online content (i.e., email, Facebook posts) satisfaction (pre and post test). 	<p>Key findings:</p> <p>Significant increases on paired t-tests in knowledge seeking ($p<0.001$), collaborating ($p<0.05$), and readiness ($p<0.001$). No difference for utilising curriculum, or advocacy.</p> <p>No increase in whether professionals were actually providing more sexuality education.</p> <p>Although randomly assigned to online content condition, groups differed at pre-test with those in the Facebook update condition being much more likely to report being likely to plan on teaching human sexuality in the future compared with the email update group.</p> <p>There were no differences between pre and post-test by online update condition (email or Facebook).</p> <p>High satisfaction of participants.</p> <p><u>Maintenance:</u> not measured</p>	<p>Author conclusions: Aimed at capacity building in the sector, particularly outside the school context. The low-intensity training workshop and follow-up online education were successful for increasing instructional behaviour and feelings of readiness. Suggest that a more intensive intervention may be necessary.</p> <p>Reviewer's comments: self-selected sample likely to be biased toward those already satisfied and motivated to use training and learn more. Questionnaires developed for study although internal reliability demonstrated. No follow up of whether workshop increased instruction (no increase observed over time of evaluation). Only 12/43 professionals currently worked with providing sexuality education to people on the autism spectrum. Lack of effect may relate to lack of opportunity or require longer follow-up to determine. Randomisation was unsuccessful in that there was variation by condition at baseline.</p> <p>Source of funding: The Autism Program of Illinois.</p>

Pask et al (2016) [16]					
Country, study type, evidence	Participants	Inclusion and exclusion criteria	Intervention, comparison and outcome measures	Results	Conclusions
<p>Country: USA</p> <p>Study type: case series with pre- and post-test measures.</p> <p>Evidence level: IV</p> <p>Aim: to evaluate a sexuality education intervention for adolescents with ASD.</p>	<p>Setting/recruitment: participants recruited from non-profit provider of school-based autism services programme. How they were recruited was not reported.</p> <p>Participants: 6 male adolescents aged 15-17 years, M age=16 years) with ASD of varying severity (measured by CARS2-HF). All members of the same classroom from a school-based autism services programme.</p>	<p>Inclusion criteria: diagnosed with ASD and in the school-based autism services programme.</p> <p>Exclusion criteria: none reported</p> <p>Follow-up: pre- and immediately post-intervention, and at one month follow-up. <u>All</u> students needed to have achieved over 85% accuracy on post-test of a module (i.e., mastery) before going on to the next one. Individualised remediation provided where mastery was not achieved and a further post-test assessed to demonstrate this for those individuals.</p> <p>Fidelity: manualised intervention with teachers receiving 40 hours of training, spot checks, and supervision.</p>	<p>Intervention: 6 45-minute sessions (once or twice a week) on three modules from group-run, developmentally sequenced <i>Healthy Relationships and Autism</i> curriculum.</p> <p>This study only evaluated module 2, which covered (over 6 sessions) facts about puberty, biology, intercourse, pregnancy and childbirth. (Excluded modules are on personal hygiene, and interpersonal relations). Intervention included strategies such as repetition, rephrasing, use of videos. Material sent home after each session to encourage practice and discussion with parents.</p> <p>Outcomes (<i>completed by whom</i>)</p> <p>- Curriculum based measure assessed knowledge of basic biological sexuality education (<i>self</i>).</p>	<p>Key findings:</p> <p>Comparisons between pre- to post-group sessions (using T-tests): Significant increase in sexual knowledge ($p < 0.05$, standardised effect size of $d = -1.47$). Three of the 6 participants achieved over 85% accuracy at initial post-test.</p> <p><u>Maintenance:</u></p> <p>Once all 6 students had achieved mastery (with individualised remediation provided to 3 participants), and a month after completion of the initial post-test and module, knowledge was followed up again. A one-way ANOVA across the three assessment points found a main effect for Time ($p < 0.05$). Pairwise comparisons indicated that there was no change in knowledge between the Mastery assessment and the one-month follow-up ($p = 0.07$). Scores went down but “not significantly”.</p>	<p>Author conclusions: The curriculum was effective in increasing sexual knowledge acquisition and retention regardless of child’s level of difficulties.</p> <p>Reviewer’s comments: Small study of males only with no control group. Wide range of cognitive ability in sample. Questionnaire developed for study. Group had already received module on personal hygiene. Direct observational data of adolescent on the autism spectrum not collected. Sample too small to look at what characteristics may have predicted some individuals having higher knowledge at post-test assessment.</p> <p>Source of funding: Not reported.</p>

Visser et al (2017) [38]					
Country, study type, evidence	Participants	Inclusion and exclusion criteria	Intervention, comparison and outcome measures	Results	Conclusions
<p>Country: The Netherlands</p> <p>Study type: randomised controlled trial (RCT)</p> <p>Evidence level: II</p> <p>Aim: to evaluate a sexuality education intervention for adolescents with ASD.</p>	<p>Setting: Recruited from referrals from large mental health clinic, special education schools or open application.</p> <p>Participants: 189 adolescents, aged 12-18 years (M age=14 years); n=152 male (80%), with ASD.</p> <p>Randomised to either:</p> <p>Treatment group (TG): N=95</p> <p>Control group (CG): N=94</p>	<p>Inclusion: ASD diagnosis using DSM-IV criteria, ASD severity ascertained by ADOS-2; full IQ of ≥ 85; SRS score over 51; aged 12-18 years.</p> <p>Exclusion: as there is a waiting list control, adolescents assessed as having too severe, offensive law-violating levels of sexual problems or inappropriate sexual behaviours.</p> <p>Follow-up: pre-test (T1), post-test (T2, 6 months post baseline (immediately after intervention for TG). Maintenance (T3) followed up at 12 months.</p> <p>86% completion rate (to T2) 84% to T3. In total 15% dropped out, 14 dropout in TG, 14 in CG.</p> <p>Fidelity: certified trainers who had received 2 day course, manualised intervention with some flexibility in order of topics and time spent on each depending on individual's needs.</p> <p>Adherence. Six of the 112 exercises were skipped, and eight adjusted to the need of the adolescents.</p>	<p>Treatment (TG): Manualised Tackling Teenage Training (TTT) intervention given to individuals over 18, 45-minute, weekly sessions including quizzes and role-plays. Workbook provided. Course includes education & practice of communicative skills regarding puberty, appearances, first impressions, physical & emotional development, falling in love & dating, sexuality and sex, pregnancy, personal boundaries, safe Internet use.</p> <p>Control (CG): waiting list</p> <p>Outcomes (completed by whom):</p> <ul style="list-style-type: none"> - psychosexual knowledge (adolescents, and parents) - insight in interpersonal boundaries (parents) - SRS, social functioning (adolescents) - self-perceived romantic relationship skills (adolescents) - sexual problems scale of CBCL (parent) - autism-related inappropriate sexual behaviour (adolescents, and parents) 	<p>Time between T1 and T2 was longer for intervention condition cf control condition ($p < 0.01$). Time was controlled for in main analyses.</p> <p>Key findings:</p> <p>Linear mixed model analyses. Compared with controls, adolescents receiving intervention had significantly greater increase in</p> <ul style="list-style-type: none"> - psychosexual knowledge rated by adolescents; $F(2, 161.62) = 13.51$ $p < 0.01$, and rated by parents $F(2, 146.53) = 9.36$ $p < 0.01$). - insight into interpersonal boundaries rated by parents $F(2, 141.77) = 2.92$ $p = 0.05$). <p>No treatment effect for behavioural outcomes. The effects on knowledge moderated by age: more knowledge gain for early and middle adolescence, but not for older. Social functioning increased in TG for early & middle adolescence and not late. No moderating effect for age on other outcomes, or for gender. Protocol adherence had no influence on outcome measures.</p> <p>Maintenance:</p> <p>Increased psychosexual knowledge (self-rated) for intervention group maintained at follow-up (T3), but not when rated by parents. Increased insight into interpersonal boundaries not maintained at follow-up (T3).</p>	<p>Author conclusions: Tackling Teenage Training program is effective as a psycho-educational program to provide adolescents on the autism spectrum with the knowledge and insight they need to prepare themselves for a healthy psychosexual development. The programme is recommended for early adolescence (12-14 years).</p> <p>Reviewer's comments: IQ independently verified. No direct observational data collected. Parents not blind to allocation and open to reporting bias. Adolescents with severe problems were excluded for ethical reasons, reducing generalisability. As training is individualised, adolescents are not provided with the chance to practice skills with peers. Many scales employing raising the risk of Type I error (associations being found to be statistically significant by chance). Changes not evident for behavioural outcomes. Psychosexual knowledge was reduced for younger participants only.</p> <p>Source of funding: grant from the Netherlands Organization for Health Research and Development.</p> <p>Note: a case series study evaluating Tackling Teenage Training is appraised for the current review [15]</p> <p>Study Quality (SIGN checklist): + (acceptable quality)</p>

Key: ADOS-2=Autism Diagnostic Observation Schedule, 2nd edition; ANOVA=analysis of variance; ASD=autism spectrum disorder; CARS2-HF=Child Autism Rating Scale, 2nd edition, High Functioning version; CBCL=Child Behavior Checklist; DSM-IV=Diagnostic and Statistical Manual of Mental Disorders, 4th edition; DSM-5=Diagnostic and Statistical Manual of Mental Disorders, 5th edition; SBS=Sexual Behaviour Scale; SIGN=Scottish Intercollegiate Guidelines Network; SRS=Social Responsiveness Scale; UK=United Kingdom; US=United States

Evidence Tables relating to secondary studies

Table A3.2: Evidence Tables of included secondary studies for “What is the effectiveness of educational programmes, training and supports which aim to assist young adults on the autism spectrum with challenges around sexuality?”

National Institute for Health and Clinical Excellence (2012) [47]				
Country, study type	Search strategy	Appraisal methods	Results	Conclusions
<p>Country: UK</p> <p>Study type: systematic review/guideline</p> <p>Evidence level: III-2 (with respect to studies included relevant to current review)</p> <p>Review scope*: part of a larger review on recognition, referral, diagnosis and management of adults on the autism spectrum</p> <p>Aim*: within a broader review, research question relevant to the current review asked, for adults on the autism spectrum, what are the experiences of having autism, of access to services, and of management.</p> <p>Other areas of the guideline were relevant to sexuality in considering the needs of transgender people within the broader population of people on the autism spectrum.</p>	<p>Databases: 19 databases were searched including Medline, Embase, Cinahl, PsycINFO, and Cochrane Library.</p> <p>Search terms: Search terms provided for multiple searches. Filters were used to identify research studies including systematic reviews, RCTs, observational studies, case series, quasi-experimental studies, qualitative and survey research. Searches were from the beginning of the database until September 2011 with no language restrictions. Reference checking, contacting experts, hand-searching of key Journals, and prospective citation tracking from key papers were employed.</p> <p>Research questions and eligibility were defined once the evidence has been searched, and where necessary, sub questions were generated.</p>	<p>Method: Eligibility criteria for each research question applied to retrieved studies. Checklists employed for critical appraisal of methodological quality. Evidence was prioritised to reflect comparability to the UK context with respect to demographic, provider and cultural factors. Reviews and primary qualitative studies reporting first-hand experiences were identified and primary studies were thematically analysed by two reviewers, independently. Cohort and case-control studies were considered in estimating the prevalence of cross-gender people in the adult autism population.</p> <p>GRADE was used to summarise quality of evidence. In the absence of high-quality research, a narrative review relevant to the question was considered in a process of acquiring informal consensus by the Guideline Development Group (GDG).</p>	<p>Included: No study explicitly assessing the effectiveness of sexuality education was included in the review. However, relevant to sexuality broadly, in assessing the experiences of having autism, the theme of relationships was identified. Findings from qualitative studies included:</p> <ul style="list-style-type: none"> - intimate relationships where desired, however misinterpretation of social cues could sometimes lead to vulnerable situations or inappropriate sexual advances - In assessing case identification in populations with specific needs, 2 papers identified relating to transgender people on the autism spectrum. - Jones et al. [53] reported elevated autistic traits in female-to-male transsexuals - de Vries et al. [52] suggested prevalence for autism of around 6% in children and young people with gender dysphoria, considerably higher than the general population. 	<p>Author conclusions: Developed new Recommendation: “All staff working with adults with autism should be sensitive to issues of sexuality, including asexuality and the need to develop personal and sexual relationships. In particular, be aware that problems in social interaction and communication may lead to the person with autism misunderstanding another person’s behaviour or to their possible exploitation by others. “</p> <p>Reviewer’s comments: gold standard search and appraisal methodology. As the research questions were data-driven (i.e., identified from the evidence), the lack of intervention studies relating to sexuality education reflects the lack of research up until 2011.</p> <p>Source of funding: Commissioned by NICE, published by the British Psychological Society and the Royal College of Psychiatrists. Independent of government.</p> <p>Study Quality (SIGN checklist): ++</p>

National Institute for Health and Clinical Excellence (2013) [48]				
Country, study type	Search strategy	Appraisal methods	Results	Conclusions
<p>Country: UK</p> <p>Study type: systematic review/guideline</p> <p>Evidence level: IV (with respect to studies included relevant to current review)</p> <p>Review scope*: as part of a larger review on management and support of children and young people on the autism spectrum.</p> <p>Aim*: within a broader review, research question relevant to the current review investigated the experience of care, and organisation and delivery of care, for children and young people (aged under 19 years) and their families/carers.</p>	<p>Databases: 18 databases were searched including Medline, Embase, Cinahl, PsycINFO, and Cochrane Library.</p> <p>Search terms: Search terms provided for multiple searches. Filters were used to identify research studies. Searches were from the beginning of the database until January 2013. In addition, reference checking, contacting experts, hand-searching of key Journals, checking clinical trials registers, prospective citation tracking from key papers, and contacting study authors for unpublished or incomplete datasets were employed (if accompanied by a trial report).</p> <p>Research questions were refined once the evidence has been searched, and where necessary, sub questions were generated.</p> <p>Excluded studies were those not published in English, books, dissertation abstracts, trade magazines, policy and guidance, and non-empirical research.</p>	<p>Method: Thorough details of systematics processed for data extraction, appraisal, and checklists. Where possible two independent reviewers extracted data. Qualitative studies appraised using a matrix of service user experience, with emergent themed coded by two researchers working independently. Conclusions of qualitative analysis validated in focus groups and individual interviews with an expert advisory group or children and young people on the autism spectrum.</p> <p>GRADE was used to summarise quality of evidence. In the absence of high-quality research, a narrative review relevant to the question was considered in a process of informal consensus by the Guideline Development Group (GDG).</p>	<p>Included: No study explicitly assessing the effectiveness of sexuality education was included in the review. However, relevant to sexuality broadly, unmet needs of family and carers were identified.</p> <ul style="list-style-type: none"> - unmet needs for parent training on ways to approach the child or young person's sexuality (from one qualitative study) - 57% of parents wanted more support for sexuality education (from one survey study) 	<p>Author conclusions: Developed new clinical practice recommendation: "When the needs of families and carers have been identified, discuss help available locally and, taking into account their preferences, offer information, advice, training and support, especially if they:</p> <ul style="list-style-type: none"> - need help with the personal, social or emotional care of the child or young person, including age-related needs such as self-care, relationships or sexuality - are involved in the delivery of an intervention for the child or young person in collaboration with health and social care professionals." <p>Reviewer's comments: gold standard search and appraisal methodology, but findings of only peripheral relevance to topic.</p> <p>Source of funding: Commissioned by NICE, published by the British Psychological Society and the Royal College of Psychiatrists. Independent of government.</p> <p>Study Quality (SIGN checklist): ++</p>

Beddows & Brooks (2016) [36]				
Country, study type	Search strategy	Appraisal methods	Results	Conclusions
<p>Country: UK</p> <p>Study type: systematic review</p> <p>Evidence level: III.2 (with respect to studies included relevant to current review)</p> <p>Review scope*: to describe the type of inappropriate behaviour that presents in adolescents on the autism spectrum, explain why such behaviours occur, suggest what education is suitable, and identify current gaps in research</p> <p>Aim*: within a broader review, the research question most relevant to the current review asks what education is suitable for reducing inappropriate sexual behaviour in adolescents with ASD.</p>	<p>Databases: Medline, Embase, PsycINFO. "Searches supplemented by "soft searches" of Google and Google Scholar using the term "sexual development autism problem".</p> <p>Search terms: Search terms provided. Searches were for publications dated from the beginning of the database until May 2014.</p> <p>Non-English studies and articles not available via the university portal were excluded.</p>	<p>Method: Study designs included reviews, self-help books, case-control studies, conference presentations, and individual case studies.</p> <p>No selection criteria identified, with the authors stating "relevant" titles and abstracts were identified. No description of appraisal methods or checklists provided. "Significant articles were critically appraised". A small sub-group of studies were presented in a table reporting brief methods, strengths and weaknesses. No information for how these papers were identified.</p> <p>Conclusions from included papers were narratively and briefly summarised under a number of research questions. It was not clear whether these were all developed <i>a priori</i> or after the searches were conducted.</p> <p>Types of inappropriate sexual behaviour were collated and included: hyper-masturbation, public masturbation, inappropriate romantic gestures, inappropriate arousal, and exhibitionism, inappropriate touching, paraphilia, and gender dysphoria.</p>	<p>Included: 42 studies were "appraised" however only 7 were in the table</p> <p>No study explicitly assessing the effectiveness of sexuality education was included in the review. However, relevant to sexuality broadly; suggested causes of problem sexual behaviours reported were: a lack of understanding of normal puberty, the absence of appropriate sexuality education, the severity of the ASD, social and sensory issues, boundaries, curiosity, previous sexual abuse, side effects of medication, and use of pornography.</p> <p>5 studies were referred to with respect to education interventions. One of these was a pamphlet, and only two were included in the table of critically analysed studies. From these 5, the authors conclude that education should be individualised, and accessible; that adolescents on the spectrum are less likely to access sexuality information from their peers; and that applied behavioural analysis has been shown to be effective for replacing original inappropriate behaviour with new behaviour.</p> <p>Characteristics of sexuality education recommended included friendship development, theory of mind, social rules, social norms, interpretation of senses, formal sexuality education, and parent education.</p>	<p>Author conclusions: Noted that most studies appraised had small sample sizes, tended to rely on data from parent-informants, and tended to focus on high functioning people on the autism spectrum. Concluded that individualised, repetitive education should be started from an early age in an accessible form.</p> <p>Reviewer's comments: Limited search strategy which missed 15 relevant studies that were picked up through "soft searches". No explicit selection criteria provided or formal checklists referred to. Included articles were narratively reviewed. The 42 included articles are not clearly specified. Only 7 were presented in a table with some methodological critique however it was not stated how these studies were selected.</p> <p>Brief narrative synthesis of findings, organised by research question. Broad conclusions largely unreferenced and so difficult to establish supporting evidence these were based on.</p> <p>Source of funding: None stated</p> <p>Study Quality (SIGN checklist): -</p>

Pecora et al (2016) [31]				
Country, study type	Search strategy	Appraisal methods	Results	Conclusions
<p>Country: Australia</p> <p>Study type: systematic review</p> <p>Evidence level: III -2 (with respect to studies included relevant to current review)</p> <p>Review scope*: to synthesise the current knowledge of sexual development and expression of sexuality of females with HFA compared with males.</p> <p>Aim*: within a broader review, to investigate sexuality in individuals with high functioning autism (HFA) compared with typically developing individuals.</p>	<p>Databases: The search identified peer-reviewed Journal articles, books, and theses using the following databases: Medline, PsycINFO, PsychEXTRA, PSYCHBOOKS, PsychArticles, Psychology and Behavioural Sciences Collection, PubMed, Academic Search Complete, eBook Collection, and The Networked Digital Library of Theses and Dissertations, and Trove Libraries Australia.</p> <p>Search terms: Search terms provided for multiple searches. Searches were from the beginning of the database to April 2016. Additional searching was conducted using Google Scholar and checking reference lists of included studies.</p> <p>No restriction on publication date. Non-English language articles were excluded.</p> <p>Selection criteria: participants aged over 10 years, without intellectual disability.</p>	<p>In qualitative synthesis, evidence tables produced including sample characteristics, methodology, instruments, outcomes, effect sizes, risk of bias, and whether study was included in separate meta-analyses.</p> <p>Meta-analyses (MA) conducted separately for each dependent variable (using standardised group difference, Cohen's <i>d</i>) included in more than one study, meaning that most MA's included 2-3 studies.</p>	<p>Included: 159 articles retrieved as full text, and 27 observational and cross-sectional studies met selection criteria to be included in evidence tables and qualitative synthesis.</p> <p>Using standardised mean differences, a random-effects meta-analysis pooled data from 9 eligible studies.</p> <p>Females with HFA exhibited higher levels of sexual understanding.</p> <p>Females with high functioning autism were subject to more adverse sexual experiences than males with HFA and neurotypical peers.</p> <p>Males reported greater desire for, and engagement in both solitary and dyadic sexual content.</p>	<p>Author conclusions: Findings provide initial insight into characterising the sexuality of males and females with high functioning autism.</p> <p>Reviewer's comments: Key databases (Embase, CINAHL, ERIC, Cochrane Library) not searched, however included theses and books. No checklists mentioned for critical appraisal.</p> <p>Source of funding: undertaken by academic researchers and complying with Deakin University's ethics committee</p> <p>Study Quality (SIGN checklist): ++ (high quality)</p>

Scottish Intercollegiate Guidelines Network [49]				
Country, study type	Search strategy	Appraisal methods	Results	Conclusions
<p>Country: Scotland</p> <p>Study type: systematic review/guideline</p> <p>Evidence level: III-2 (with respect to studies included relevant to current review)</p> <p>Review scope*: part of a review update of a Clinical Guideline on assessment, diagnosis and interventions for autism spectrum disorders</p> <p>Aim*: to identify signs and symptoms for identifying adults for assessment</p>	<p>Databases: Medline, Embase, Cinahl, PsycINFO, Cochrane Library.</p> <p>Search terms: Searched from 2006 and 2014 (as an update to a previous guideline). Transparent selection criteria used. Database searches supplemented by material provided by individual members of the Guideline development group.</p>	<p>Method: Each included paper was evaluated by two members of the group using SIGN methodological checklists.</p>	<p>Included: relevant to sexuality broadly, one study identified [55]. Among the 92 participants of a gender clinic in the UK, the prevalence of autistic traits, based on assessment with the Autism Spectrum Quotient, was 5.5% compared to reports of clinical diagnoses of 0.5 - 2% in the general population.</p>	<p>Author conclusions: The appraisal of this and other included articles led to the following recommendation: "Healthcare professionals should be aware of the indicators for ASD in adults presenting with other conditions".</p> <p>Reviewer's comments: Covers the key databases using explicit criteria, and appraised by two researchers using methodological checklists. Research topic peripheral to the current review.</p> <p>Source of funding: National Health Service Scotland, through Healthcare Improvement Scotland</p> <p>Study Quality (SIGN checklist): ++</p>

Key: * relevant to review scope; AS=Asperger's syndrome; ASD=autism spectrum disorder; CINAHL=Cumulative Index to Nursing and Allied Health Literature; Embase=Excerpta Medica Database; GRADE=Grading of Recommendations: Assessment, Development and Evaluation; HFA=High Functioning Autism; Medline=Medical Literature Analysis and Retrieval System Online; MA=meta-analysis; PsycINFO=Psychology Information Database; RCT=Randomised Controlled Trial; SIGN=Scottish Intercollegiate Guidelines Network; UK=United Kingdom; US=United States

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*Asterixed references indicate articles appraised in the systematic review

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