

CENTRE FOR AUTISM  
MIDDLETOWN

# Relationships and Sexuality Education Volume Two



# CONTENTS

|  |    |
|--|----|
| Introduction   | 5  |
| Interview with Sarah Hendrickx   | 6  |
| Research Articles Summarised   |    |
| 1. Study Protocol: A Randomized Controlled Trial Investigating the Effects of a Psychosexual Training Program for Adolescents with Autism Spectrum Disorder            | 8  |
| 2. Inappropriate Sexual Behaviour in Adolescents with Autism Spectrum Disorder: What Education is Recommended and Why  | 12 |
| 3. Autism Spectrum Disorder and Sexually Inappropriate Behaviours: An Introduction for Caregivers and Professionals  | 16 |
| 4. Adolescent Boys with Autism Spectrum Disorder Growing Up: Follow-Up of Self-Reported Sexual Experience  | 18 |
| 5. Generalized Effects of Social Stories with Task Analysis for Teaching Menstrual Care to Three Young Girls with Autism   | 20 |
| 6. Parental Perspectives of Communication about Sexuality in Families of Children with Autism Spectrum Disorders   | 22 |
| 7. Sexuality and Sexual Health in Children and Adolescents with Autism   | 24 |
| 8. Sex Education, Sexual Health, and Autism Spectrum Disorder  | 26 |
| 9. The Longitudinal Relation between Childhood Autistic Traits and Psychosexual Problems in Early Adolescence: The Tracking Adolescents' Individual Lives Survey Study | 29 |
| 10. Providing Education on Sexuality and Relationships to Adolescents with Autism Spectrum Disorder and their Parents  | 31 |
| Conclusion   | 34 |

## INTRODUCTION

This is the twenty second Research Bulletin produced by Middletown Centre for Autism and it provides summaries of ten articles spanning from 2012-2016.

The Bulletin commences with an interview with Sarah Hendrickx.

Sarah Hendrickx is an independent trainer, international conference speaker and six times author in the field of autism. She has an autism diagnosis and has an autistic partner and son. Details of her work can be found at: [www.asperger-training.com](http://www.asperger-training.com).

*Please note that the views represented in this document do not necessarily reflect the views of Middletown Centre for Autism. Reviewers have, where possible, used the original language of the article, which may differ from UK and Ireland usage and the usage of a range of terminologies for autism.*

## INTERVIEW WITH SARAH HENDRICKX

### 1. Is there an ideal age that the topic of relationships and sexuality should be introduced to a child/young person with autism?

This is likely to vary depending on the intellectual ability and general maturity level of the child. Whilst some children will be oblivious to gender and sexual concepts until even into puberty or beyond, others will start to show an interest or awareness of their own feelings and needs much younger. Obviously, any conversation on this topic must be both age appropriate and autism appropriate.

### 2. In your opinion, how should the topic of relationships and sexuality be introduced to children/young people with autism?

Any discussion or programme must take autism into account. Often assumptions are made as to the understanding of what many may consider to be fundamental social concepts that typical children would just 'get' at a young age. For young people and adults with autism, sometimes these basics are not intuitively learned regardless of the intellectual capability of the individual. Being academically able does not mean a greater understanding of all things social. Things like consent, reading signals, uninvited physical touch, social boundaries, how acceptability of behaviour changes as one grows (e.g. sharing a bath with Mum is considered appropriate at age four years, but is less so at age 14 years) may not be organically picked up by autistic children. Isabelle Henault's workbook on sexuality is a good place to start for practical activities. Otherwise, short videos, conversations or visual materials which encourage discussion would be a good start. An open approach which is accepting of the child's perspective and needs, rather than a prescriptive approach is helpful.

### 3. How should the topic of relationships and sexuality be tailored for children/young people who are verbal and those who are non-verbal?

Materials and communication methods need to be appropriate for every child. Some young people may have typical sexual feelings and needs, but not the understanding to engage safely with others and will need additional support. It is important that we recognise the right of all people to have their needs supported and as practitioners we need to find ways to do this. For a learning disabled person, simple clear rules and boundaries may be the best way forward using Makaton or pictures to give clear signals. For a verbal, non-learning disabled person, more in-depth information and discussion may take place, but those boundaries and rules will still need to be clear.

### 4. How would you recommend teaching the concepts of staying safe in terms of sexual health and appropriate behaviours to a child/young person with autism?

To my knowledge there are very few specialist programmes for autistic young people on this topic and it is vital that this is taught. I have worked with a number of young people who have unknowingly committed criminal offences through not knowing the social rules and boundaries of relationships. There are a number of resources and books for young people around safety and although these are not all autism specific, they are a start. Robyn Steward, Lianne Holliday-Willey and Debi Allen have all written books on safety for autistic women and there are several autism dating and relationship books for all genders.

### 5. From your experience, what would you say are the main difficulties specific to children/young people with autism in respect to the varying degrees of relationships?

There are difficulties in simply initiating any chat or contact with a potential friend or partner, after which this has to be maintained and developed; signals have to be read to understand what the friend/partner wants and doesn't want. At every step of the way, the potential for faux pas or failure is huge and often anxiety provoking for autistic people who may struggle to 'play the game'. It seems to me that certainly for some autistic people, solitude is easy and the relationship is the compromise whereas I suspect that for some non-autistic people it is entirely the other way round.

### 6. What advice would you offer professionals to support children/young people with autism more effectively as they gain experience in various forms of relationships?

I think professionals have a responsibility to guide, teach and tell young people when they see they are getting it wrong socially. Having seen young people end up in prison or assaulted because they didn't know the social rules, I feel very strongly that if we don't tell them, who will? These young people may lack a peer group from which to learn and without some of the intuitive people reading abilities can be vulnerable and naive at a time of their lives when they may be desperate to fit in and participate. We have to step in and do what we can to give them the skills that they need. And to repeat: do not assume that academic ability equates to social understanding.

### 7. Should we have specific programmes for girls and a separate one for boys or can we offer an integrated Relationships and Sexuality Education Programme?

An integrated programme would be beneficial but I feel that young people need to have gender specific learning and sharing opportunities in order to focus on their individual potential vulnerabilities. Some early research suggests higher numbers of autistic young people in gender identity clinics and also possibly higher numbers of gay, bisexual, asexual and transgender young people in the autistic community. Any sexuality programme must be open to addressing these facets too.

### 8. What advice would you give parents and professionals who are concerned about sexual exploitation for the child/young person with autism who is accessing online material and using online communication forums?

Young people with autism often want to fit in with peers and believe that a Facebook 'friend' is a real friend, for example. Autistic people can be very trusting and take people at face value, believing without question who or what someone says that they are. Parents and professionals need to keep an open dialogue with their children to assess their understanding of social concepts and to teach them gently and on an on-going basis about how to make good judgements and be safe.

# STUDY PROTOCOL: A RANDOMIZED CONTROLLED TRIAL INVESTIGATING THE EFFECTS OF A PSYCHOSEXUAL TRAINING PROGRAM FOR ADOLESCENTS WITH AUTISM SPECTRUM DISORDER

## BACKGROUND

Adolescence is a transition phase in life that can present challenges for people with autism. Prior research has shown that adolescents with autism experience risks in their psychosexual development and that they can have limited access to reliable information on puberty and sexuality. As a result of the challenges faced, the need for specific guidance for people with autism in relation to their psychosexual development is important. Few studies have investigated the effects of psychosexual training programmes for adolescents with autism and no randomised control trials are available for this target group. Therefore, in order to fulfil this need, the Tackling Teenage Training (TTT) programme was designed with the aim of targeting the psychosexual development of adolescents with autism.

## RESEARCH AIMS

The current study investigates the effects of the TTT programme on the psychosexual development of adolescents with autism. The aims were as follows:

1. To investigate whether the TTT programme increases psychosexual knowledge.
2. To increase skills needed for friendships.
3. To increase insight into acceptable and inappropriate sexual behaviours.
4. To reduce inappropriate sexual behaviour and vulnerability.
5. To increase self-esteem.
6. To reduce current concerns and concerns about the future of adolescents with autism and their parents.

## RESEARCH METHODS

Participants included 200 adolescents in the age range of 12-18 years with a diagnosis of autism as per DSM-IV. Eligibility criteria for participants required a score of 51 or above on the Social Responsiveness Scale (SRS), and an IQ level in the normal to high range, (85 or above). Participants were equally randomised to a control condition or intervention condition after the baseline measurement (T1). The adolescents in the intervention condition started the TTT programme shortly after, while those in the control condition were placed on a waiting list.

### Intervention

The TTT programme was conducted over 18 sessions and included the following topics: puberty, appearances, first impressions, physical and emotional development, how to make and maintain friends, falling in love and dating, sexuality and sex, pregnancy, boundaries and internet safety. A session typically involved the discussion of one topic, and exercises relating to that were practiced in a structured manner. Take home assignments were included which involved role-play with parents or interviews with friends. A contact report was provided weekly to parents to ensure they were prepared for potential questions or discussions that arose following the session. Information about the motivation of the adolescent was scored every week, as well as rating the resistance, difficultness and openness displayed during sessions. These were averaged over all sessions to compute an average index for analytical purposes. Furthermore, after each session a TTT protocol was filled in to determine the extent to which the programme was followed.

Parents completed questionnaires at three stages during a one-year time-frame, which included baseline (T1), after the inclusion criteria was reached post-intervention (T2) and post intervention (T3). Following the 18 sessions, the parents and adolescents also completed an evaluation form with 16 questions for a more subjective evaluation of the topics learned in the TTT programme.

## RESEARCH FINDINGS

The results of this study are currently pending.

## REVIEW METHODS

### (Outcome measures)

In order to investigate the effect of the TTT programme a range of tests were used. The Teen Transition Inventory (TTI) is a self-report and parent report covering the experience of various transitions that take place in adolescence such as psychosexual development, school transitions and so forth. These reports were administered at T1, T2 and T3.

### Psychosexual knowledge

A psychosexual knowledge test was also provided at T1, T2 and T3. This included 35 multiple choice and two open-ended questions. Parents were further questioned about the sexual knowledge of their child in the TTI.

### Skills needed for friendships and intimate relationships

The 'friendship skills' scale of the TTI was used to measure the ability of the adolescents to make and maintain friends. This involved self-report and a parent report. The romantic ability scale was a self-report in the TTI that measured the self-perceived romantic relational skills of the adolescent. The Social Responsiveness Scale (SRS) was issued to measure the severity of autism symptoms and social impairment.

However, this was also helpful for measuring treatment effect. This was administered at T2 and T3.

### Insight into acceptable and inappropriate sexual behaviours

To investigate whether the TTT programme increased insight into various sexual behaviours the 'adequate boundaries' scale was used. A flag system was also administered, and involved drawn illustrations of sexual behaviours in various situations. The adolescents were required to discuss these, and a scoring criteria was administered based on their judgement of the behaviours.

### Inappropriate sexual behaviour and vulnerability

Several items from the TTI report (both self and parent report) were measured to address the effectiveness of the TTT programme on reducing inappropriate sexual behaviours and vulnerability. In addition to this, the sex problems scale of the Child Behaviour Checklist (CBCL) was measured at T1, T2, and T3 to determine the occurrence of psychosexual problems.

### Self-esteem

The self-esteem scale of the Dutch Personality Questionnaire was administered at T1, T2 and T3 to investigate whether the TTT programme increased the adolescents' self-esteem. In addition, the TTI 'perceived social competence' (self-report version) and 'self-esteem' (self-report version) were used to measure changes in self-esteem.

### Concerns of the adolescents with autism and their parents

Several questions from the TTI report were analysed to investigate whether the TTT programme could reduce current concerns and future concerns for the adolescent and their parents.

### Other measures

The Autism Diagnostic and Observation Schedule 2 (ADOS-2) was administered at T1 to measure severity of autism. The Child Behaviour Checklist (CBCL) was administered at T1 to register emotional and behavioural difficulties, and assessed problems of anxiety and depression, socialisation issues, attention difficulties and aggressive and delinquent behaviour. Furthermore, demographic characteristics such as age, gender and family situation were measured at T1. Socio-economic status was determined by income level, educational level of both mother and father (or other caregivers) and occupational level. Family values and attitudes regarding sexuality were determined with the TTI in the 'openness about intimacy' scale.

## IMPLICATIONS FOR PRACTICE

### (by the authors)

- People with autism often rely on unreliable sources of information from the internet for their sexual education, resulting in limited knowledge, and increasing risk for engaging in sexually inappropriate behaviour.
- When available, the TTT programme will allow parents and teachers to have access to an evidence-based intervention programme aimed at specifically targeting the psychosexual development of adolescents, and as a result, address the issues faced by people with autism at this developmental stage.

### Full Reference

Visser, K., Greaves-Lord, K., Tick, N. T., Verhulst, F. C., Maras, A. and Van der Vegt, E. J. M. (2015). Study Protocol: A Randomized Controlled Trial Investigating the Effects of a Psychosexual Training Program for Adolescents with Autism Spectrum Disorder. *BMC Psychiatry* 207, p. 1-10.

# INAPPROPRIATE SEXUAL BEHAVIOUR IN ADOLESCENTS WITH AUTISM SPECTRUM DISORDER: WHAT EDUCATION IS RECOMMENDED AND WHY

## BACKGROUND

Individuals with autism are all affected differently. Their rate of development may not be consistent in all areas resulting in behavioural problems or underdeveloped skills. Adolescents with autism have similar sexual needs to the general population and mature sexually, both physically and emotionally via the normal developmental stages. They are said to have impaired theory of mind, meaning they find it difficult to understand that other people have thoughts and intentions different to their own; they struggle to understand and may not act suitably. Therefore, lack of theory of mind may impact on the appropriateness of sexual behaviours.

## RESEARCH AIMS

The aim of this review was to describe the type of inappropriate sexual behaviour an adolescent with autism may present with, to determine why such behaviour occurs, to identify what sexual education is recommended for adolescents with autism and to identify current gaps in research.

Despite inappropriate sexual behaviour being a common problem across settings, the authors found literature sparse, particularly regarding why inappropriate sexual behaviour occurs and effective education strategies. They found current research focuses on observations by experts and information provided by the caregivers but not from the adolescents with autism themselves.

## RESEARCH METHODS

The authors carried out database searches for relevant articles and searched EMBASE, OVID MEDLINE and PSYCINFO. A soft search using both Google and Google Scholar was also carried out. In total, 42 relevant articles were found and reviewed. The articles varied in content, comprising of both quantitative and qualitative

analyses in the form of reviews, self-help books, case-control studies and individual case studies. Studies available were based on small sample sizes and the diverse nature meant it was difficult to generalise why inappropriate sexual behaviour occurs and difficult to generalise what sexual education is recommended.

It was evident from the literature reviewed that sexuality education is taught across settings using different teaching strategies, although no formal research to determine the effectiveness of teaching strategies has been carried out.

The authors concluded that although literature is sparse there is more data for individuals with higher cognition and autism compared to lower cognition and autism and that the literature focused on prevalence of sexual behaviours neglecting sexual education.

## RESEARCH FINDINGS

Previously, it was assumed that individuals with autism had no sexual desires. Current research refutes this, showing how puberty for all adolescents, follows normal development, however, it may be prolonged or delayed for an adolescent with autism in comparison to neuro-typical peers. It is also normal for adolescents with autism to have sexual curiosity in line with their neuro-typical peers.

What differs is the worry that caregivers of adolescents with autism have about increased sexual behaviour during adolescence due to its correlation with embarrassing behaviour in public. The types of sexual behaviour causing concern include masturbation, intimate relationships, inappropriate arousal, exhibitionism, offenses, physical and sexual abuse, deviant obsessions, gender identity problems and other behaviours (see Table 2 as cited in the original paper).

**TABLE 2. Types of inappropriate behaviour that individuals with ASD may display**

| Type of behaviour         | Problems   |
|---------------------------|--|
| Masturbation              | Hypermasturbation due to inability to reach orgasm (poor masturbation technique)<br>Public masturbation in low functioning ASDs<br>Use of inappropriate objects for masturbation (e.g. belt) |
| Intimate relationships    | Inappropriate romantic gestures and unaware of consequences of such behaviours<br>Failure to form intimate relationships   |
| Inappropriate arousal     | Obsession with certain objects (e.g. hands, wellington boots)  |
| Exhibitionism             | Failure to distinguish appropriate behaviour from inappropriate behaviour, particularly regarding location (e.g. disrobing in public)  |
| Offences                  | Of a sexual nature, including touching themselves, and others, inappropriately in public   |
| Physical and sexual abuse | If abused themselves, it is more likely that they will display similar behaviours towards others   |
| Deviant obsessions        | Paraphilia (arousal via unusual objects, people or situations)   |
| Gender identity problems  | Gender dysphoria/gender identity disorder (confusion between biological sex and gender identity)   |
| Other                     | Obscene gestures, non-consensual hugging, inappropriate comments with sexual connotations  |

The authors also wanted to determine why inappropriate sexual behaviours occur. The reasons are mentioned throughout the article and the authors categorised them under ten sub-headings presented in Table 3 (as cited in the original paper) along with an explanation. They include: how the adolescent manages change, difficulties associated with autism unique to each adolescent, lack of understanding of normal puberty, lack of appropriate sex education, the increasing complexities of social demands and consequent lack of peer interaction which facilitates sex education from peers, sexual curiosity, previous sexual abuse and medication.

**TABLE 3. Reasons why inappropriate sexual behaviour occurs**

|                                  |   |
|----------------------------------|---|
| Normal puberty                   | Hormonal changes, equal in neurotypicals and ASD individuals, initiate sexual development. Neurotypicals are socially mature, and despite it being a confusing stage of life, are able to cope with these changes. ASD adolescents may not have a social maturity corresponding to their sexuality, so they may struggle to interpret and deal with these changes. ASD adolescents find it difficult to demonstrate an appropriate theory of mind, so understanding people's behaviours, in addition to the confusing hormonal changes, may lead to actions of frustration or anxiety, which can be portrayed via inappropriate sexual behaviours, therefore demanding the attention of their carers. |
| ASD severity                     | Low functioning autistic (LFA) adolescents are most likely to masturbate in public, while some moderate functioning autistic (MFA) adolescents may masturbate in public; however, MFA adolescents tend to direct sexual behaviour towards individuals of the opposite sex. High functioning autistic (HFA) individuals are most likely to masturbate in private and often have a desire for an intimate relationship.   |
| Social issues                    | Individuals with ASD have reduced social awareness and communication. These are imperative for understanding when sexual behaviours are appropriate. Frustration due to the variability of social rules, particularly regarding private and public places, can cause these individuals to become confused and act inappropriately, even if the action is innocent.  |
| Sensory issues                   | Individuals with ASD can be hypersensitive to their senses. Sexual behaviours initiate pleasure, therefore satisfying their need for sensory stimulation.   |
| Differentiation of relationships | Individuals with ASD have problems identifying when affection is appropriate, including recognizing the difference between friends, family, lovers and strangers. This causes confusion, specifically regarding how to act appropriately in friendships, compared to romantic relationships.  |
| Curiosity                        | Some individuals with ASD are interested in the functioning of the human body.  |
| Previous sexual abuse            | If individuals with ASD have been abused in the past, they are more likely to act similarly towards others, demonstrating inappropriate sexual behaviour.   |
| Medications                      | Some medications (not specified) can alter sexual desires, libido and make arousal difficult. These affects can result in sexual behaviours (e.g. hypermasturbation).   |
| Pornography                      | Exposure to the Internet and to pornography has the potential to skew ASD individuals' view of sexuality. This can initiate a development of an aggressive sexuality.   |
| Poor sex education               | Individuals with ASD may possess inadequate skills and knowledge to fulfil their sexual desires (e.g. may have a poor masturbation technique), so are not able to reach orgasm, leading to hypermasturbation.   |

The authors remind readers that individuals with autism have a universal right to be taught about sexuality, but that this is often overlooked. Also, that individuals with autism are more vulnerable to sexual abuse compared to the general population, therefore education can be protective.

The authors found that 50% of adolescents with autism did not avail of sex education when compared to their neuro-typical peers, in addition because of social interaction difficulties they did not have access to sex education from peers in the way their neuro-typical peers did and suggest this must be compensated for in formal education.

Experts recommend that parents take the lead with sexuality education as they know the adolescent with autism best, but acknowledge that parents may not feel comfortable or know how to educate about sexuality. Therefore, they believe it is the school’s responsibility. This ambiguity leads to delayed sexuality education.

Two prerequisites to sexuality education for the adolescent with autism were identified: understanding what autism is and social skill development. For these prerequisites to be met, it is imperative that all interacting with the adolescent with autism (parents, teachers and friends) acknowledge and accept that the adolescent with autism is different. Parents and teachers must recognise the adolescent’s skill deficits so that realistic expectations can be set and achieved.

Parents should have access to sufficient information from the school, their children’s psychologists or other appropriate sources. Parent Support Groups are useful as they allow common problems to be discussed.

Despite not knowing the origin of inappropriate sexual behaviour, education can be used to control such behaviours, especially if education is initiated early in puberty. Each individual should receive unique education to manage the inappropriate behaviour that develops. Educating young adolescents with autism about sexuality and related issues may provide a stepping stone to reduce inappropriate sexual behaviours, preventing them from becoming learned habits.

Appropriate sexual expression and not repression of sexual desires should be the objective for sexual education.

The authors found that an adolescent with autism attending a special school placement or in supported living accommodation may have less opportunity to develop appropriate sexual behaviours from peers and advise this must be compensated for in formal education.

The authors refer to Ruble et al’s research which showed that the verbally inclined adolescent with autism would benefit from sexual education to a greater extent than those with less developed verbal skills due to their ability to learn rules. They also suggest that if understanding is reduced, it may be more appropriate to teach an individual how to act in certain situations instead of explaining why they should not do something. Recommended teaching is summarised in Table 4 (as cited in the original paper).

| Education topic          | Why topic is required   |
|--------------------------|---|
| Formation of friendships | ASD adults have reported that they would have preferred to have a greater understanding of their disability and how they were different to neurotypicals, and about formation of meaningful friendships and romantic relationships. |
| Theory of mind           | It is important for ASD individuals to understand ASD, what it is and how neurotypicals are different from themselves.  |
| Social rules             | Developing an understanding of what is appropriate and what is not, dependent on setting.   |
| Social norms             | To whom it is appropriate to show affection (e.g. the difference between a stranger and a friend). Explanation of personal space and the difference between private and public spaces are also important.                           |
| Interpretation of senses | Education differentiating touch associated with romantic relationships.   |
| Formal sex education     | The normal sex education curriculum should be taught; however, additional material may also need covering (e.g. masturbation technique if inadequate skills are present or the mechanics of sexual intercourse).                    |
| Parent education         | Parents need to provide continuity of education, so that what is taught at school is reinforced at home.  |

The final aim of this review was to identify current gaps in research. The authors suggest that future research should focus on exploring how effective different education techniques are and which methods are best suited to the different cognitive abilities of adolescents with autism. This will enable appropriate service provision for adolescents with autism.

Future research should also study how cognitive functioning affects inappropriate behaviours otherwise individuals will continue to have Individual Education Programmes that suit the caregivers and the school and not the adolescent with autism.

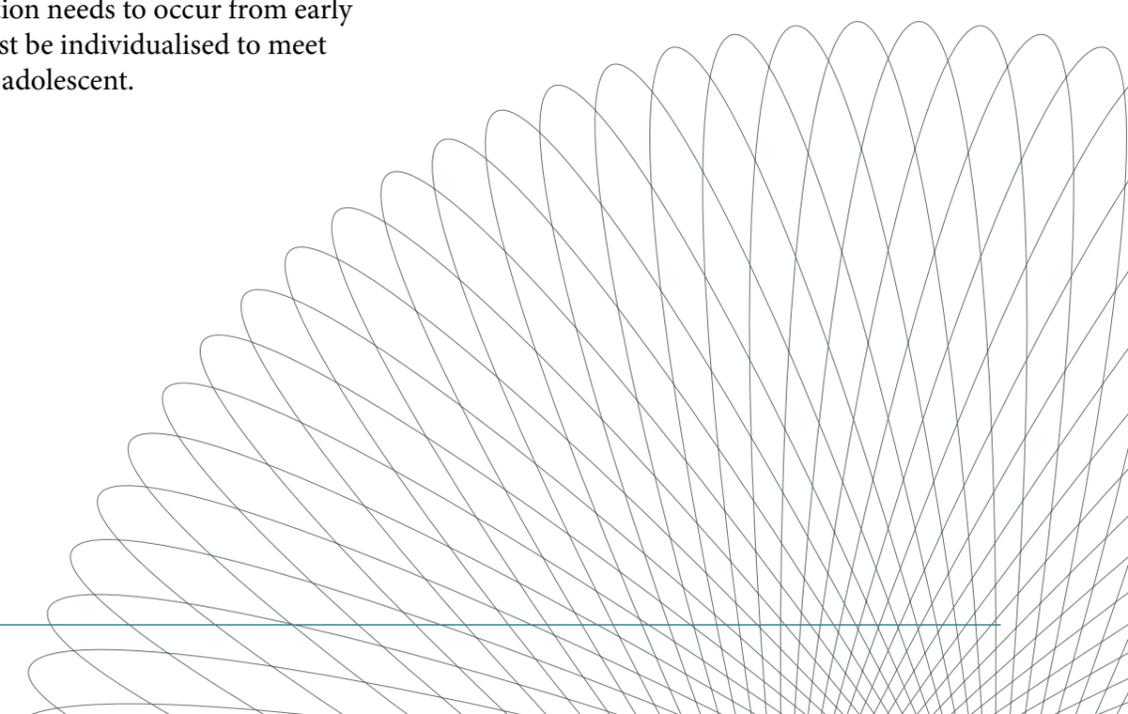
**IMPLICATIONS FOR PRACTICE**  
(by the authors)

- Adolescents with autism have sexual needs. They may not understand their physical and emotional development resulting in inappropriate sexual behaviour.
- Inappropriate sexual behaviour in adolescents with autism is a common problem across settings.
- Sexuality education needs to occur from early puberty and must be individualised to meet the needs of the adolescent.

- Sexuality education needs to be continuous from all caregivers, across all settings and should start with autism awareness and basic social skills before progressing to more complex sex education.
- Developing an individualised intervention to educate the adolescent with autism about sexuality may reduce inappropriate sexual behaviour and prevent them from developing into learned habits. Appropriate sexual expression and not repression of sexual desires should be the objective for sexual education.
- Further research focusing on the effectiveness of educational strategies used to teach sexuality is needed.

**Full Reference**

Beddows, N. and Brooks, R. (2016). Inappropriate Sexual Behaviour in Adolescents with Autism Spectrum Disorder: What Education is Recommended and Why. *Early Intervention in Psychiatry*, 10, p. 282–289.



## AUTISM SPECTRUM DISORDER AND SEXUALLY INAPPROPRIATE BEHAVIORS: AN INTRODUCTION FOR CAREGIVERS AND PROFESSIONALS

### BACKGROUND

An area of increasing interest in recent years is that of sexually inappropriate behaviours for individuals with autism. These inappropriate behaviours can result in individuals with autism becoming involved in the criminal justice system. Investigating the impact of autism would be advantageous to the criminal justice system and to those working in this area.

### RESEARCH AIMS

The aim of this article is to provide a review and some guidance for parents and professionals on autism and its impact, if any, on sexually inappropriate behaviours. The authors also aim to identify any gaps in the literature and indicate directions for future research.

### RESEARCH METHODS

This is a review article and as such the authors do not identify a research method.

### RESEARCH FINDINGS

The authors detail a series of difficulties in relation to autism and discuss the impact of these impairments on potential sexual behaviour.

These are:

#### Social skill deficits

Difficulties with social skills may result in an individual with autism misreading social cues; they may have difficulty recognising boundaries, have difficulty relating to peers and there may be some difficulties understanding the perspective of others. Together these difficulties may result in unintentional inappropriate behaviour and in the potential for unhealthy personal relationships.

#### Normative sexual development

The authors indicate that the core impairments of autism could impede normative sexual development and also impede the development of normal questioning and seeking information on sexuality and sexual behaviour. There is a lack of educational resources for sex education and this may result in poor quality or insufficient sex education for individuals with autism. Individuals with autism may experience difficulties with impulse control and this, coupled with social skills deficits, may result in unintended inappropriate behaviour.

#### Developmental functioning

Individuals with autism may have a delay in social and emotional development and their social and emotional development may be similar to that of a younger person. This is at odds with physical development and maturity, which may be the same as their peers. The slower development may result in fewer opportunities for the individual with autism to engage with peers and develop social relationships with them. Parents and professionals should be aware that individuals with autism need support in developing appropriate peer relationships.

#### Obsessive behaviours

The obsessive behaviours that occur in some individuals with autism may leave them vulnerable to the development of inappropriate special interests in pornography or in other people. This may lead to excessive engagement with pornographic material or in obsessive interests in particular people. This is not a common feature of autism but rather a potential red flag for parents and professionals to keep an eye out for.

#### Victimisation

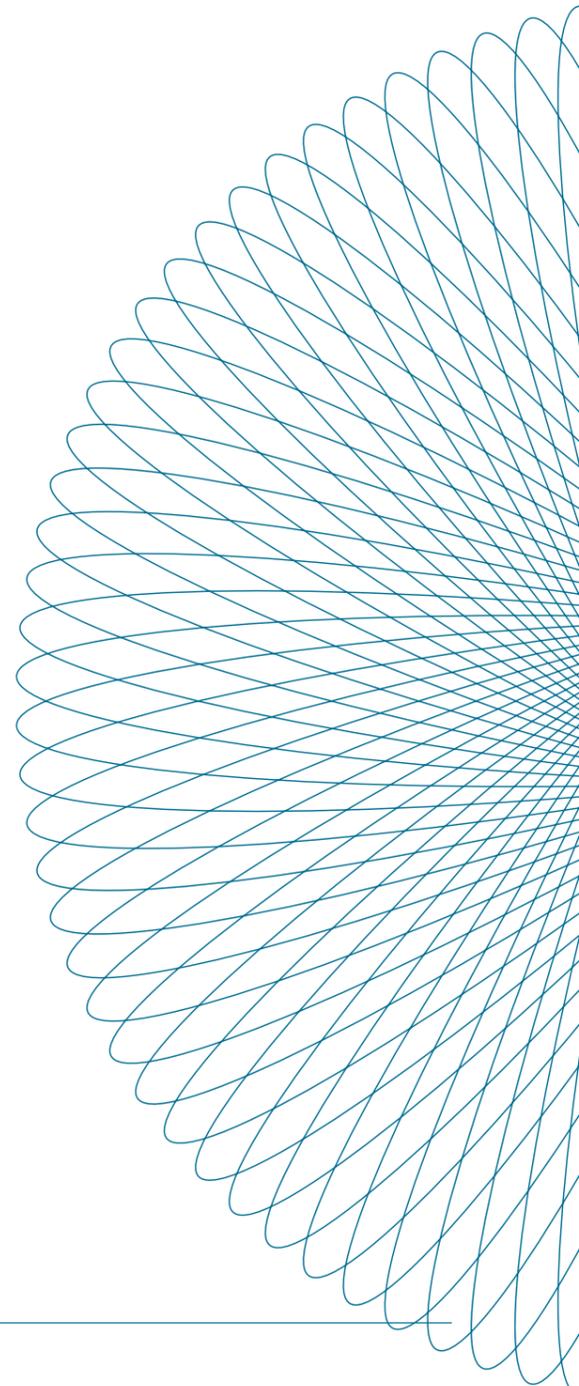
All of the difficulties detailed can increase the vulnerability of the individual with autism. Research indicates that individuals with autism may be more likely to be victims of sexual victimisation. Reduced understanding of social situations may result in the individual with autism having difficulty recognising the dangerous, inappropriate or threatening behaviour of others.

### IMPLICATIONS FOR PRACTICE (by the authors)

- Parents and professionals should work to educate individuals with autism to understand their own physical, emotional and sexual development. This should include information on friendship and appropriate behaviour for friends and information on closer and intimate friendships and what is appropriate in these relationships.
- The authors indicate that future research would be useful in the area of sexual behaviour and the likelihood and nature of any sexually inappropriate behaviour in individuals with autism.

#### Full Reference

Brown, J., Anderson, G., Cooney-Koss, L., Hastings, B., Pickett, H., Neal, D., Martindale, J., Dodson, K. and Barfknecht, L. (2016). Autism Spectrum Disorder and Sexually Inappropriate Behaviors: An Introduction for Caregivers and Professionals. *Journal of Special Populations*, 1(1).



## ADOLESCENT BOYS WITH AUTISM SPECTRUM DISORDER GROWING UP: FOLLOW-UP OF SELF-REPORTED SEXUAL EXPERIENCE

### BACKGROUND

Adolescents and adults with autism can sometimes face challenges in terms of healthy sexual functioning. These challenges can be related to the core characteristics of autism (social, communicative and repetitive behaviours and interests) and to other factors, such as the environment where a person lives, access to sexuality education and the pharmacological treatment received.

### RESEARCH AIMS

This aim of this research study was to compare the lifetime sexual experience (LTSE) of adolescent boys with autism aged 16-20 to their LTSE two years earlier and to the LTSE of adolescent boys in a matched control group.

### RESEARCH METHODS

The participants of this research project had previously taken part in a study which explored sexual functioning in adolescent boys with autism. Based on their agreement to be contacted again they were further recruited to participate in this follow up study. The 30 participants were either Dutch or Belgian with a diagnosis of autism. The researchers describe the participants as all high functioning with a full scale IQ in the range of 76-142. In comparison, the control group consisted of 60 participants who were matched to the participant group based on age, educational level, living area and were also all male.

Participants were asked to complete a computerised shortened questionnaire. This questionnaire was previously used by Dr De Graaf and colleagues 'Sex under the age of 25 II' study. In terms of statistical analysis, the main goal of this study was to compare frequencies and means for the participant group compared with the general population control group in relation to their experience with different sexual behaviours.

### RESEARCH FINDINGS

Sexual experience of autism group compared to control group

There were non-significant differences in relation to specific partnered experiences between both groups. Both groups reported their first experience with each of the listed sexual behaviours to have occurred at a similar age i.e. (1) masturbating, (2) French kissing, (3) petting, (4-6) being masturbated, receiving oral sex, sexual intercourse (7) masturbating another, (8) oral sex to another, and (9) anal sex. Both groups used the internet for sexuality-related means. Adolescent boys from both groups who had no partnered sexual experience watched porn but did not use the internet for chatting about sex or sending pictures. Boys with autism who used the internet for chatting about sex and sending pictures mostly had experience with a partner.

#### Sexual development in adolescent boys with autism

There was an average of 2.02 years between the first assessment and the completion of the questionnaire. The researchers found that the majority of the participants without partnered experience at the first assessment did not gain experience during the time between follow up. Two boys with autism gained no sexual experience at all, one did gain experience specifically in masturbation. Three boys who had reported solo sexual experience at the initial assessment reported partnered experience at follow up, and two boys who reported kissing and petting reported more intimate sexual experience at follow up.

The results indicated that fewer boys with autism had experience with French kissing and petting compared to those without autism, indicating that they did not progress to the next level in sexual experience.

Most boys who reported partnered experience at an earlier age then reported engagement in more intimate sexual behaviours such as manual or oral stimulation and sexual intercourse at follow up.

### IMPLICATIONS FOR PRACTICE (by the authors)

- This research study aimed to explore further the sexual development of high functioning boys with autism in comparison to their peers, results show that sexuality is part of adolescent development in boys with autism as it is for the general population.
- There are some differences in sexual experiences of adolescent boys with autism, specifically fewer boys with autism experience partnered sexual experience as compared to their peers at follow up. However, most of these differences did not reach significance and effect sizes remained small, therefore, these results demonstrate the normativity of sexual activity in the development of boys with autism.
- This study found no relationship between the severity of autism and sexual experience. The authors speculate that the majority of boys with autism are interested in sexuality and partnered experiences. They highlight that this does not offer insight into the quality or context of the sexual experiences.
- In this study, fewer intimate sexual behaviours occurred prior to more intimate experiences, indicating a linear trajectory in gaining sexual experience which is also the norm for the majority of boys in the general population; although a little more adolescent boys with autism were slower in starting to experiment with common first steps in partnered experiences such as kissing and petting.

- The researchers highlight that gradually gaining experience affords the individual an opportunity to develop skills and knowledge around sexual interaction with a partner and the ability to refuse unwanted sexual experiences.
- The study showed that fewer boys with autism seemed able to anticipate their first sexual intercourse. The researchers highlight that this may influence their safe sex practices and the decision making process to consent to partnered sex. The study's findings support the need for comprehensive and autism friendly sexuality education offered at an early age.
- There are several limitations to the study including a small sample size and potential selection bias as the boys and their parents volunteered to participate in sexuality-related research. Previous studies have found that those who volunteer in this type of research tend to have more sexual experiences and a positive attitude to sex.

#### Full Reference

Dewinter, J., Vermeiren, R. R. J. M., Vanwesenbeeck, I. and Nieuwenhuizen, C. (2016). Adolescent Boys with Autism Spectrum Disorder Growing Up: Follow-Up of Self-Reported Sexual Experience. *European Child and Adolescent Psychiatry*, p.1-10.

## GENERALIZED EFFECTS OF SOCIAL STORIES WITH TASK ANALYSIS FOR TEACHING MENSTRUAL CARE TO THREE YOUNG GIRLS WITH AUTISM

### BACKGROUND

The National Commission on Adolescent Sexual Health defines sexuality as 'the sexual knowledge, beliefs, attitudes, values, and behaviours of individuals' and recognises the importance of sexual expression regardless of ability. Experts emphasise the need for all individuals, including those with autism, to be taught how to care for their bodies as well as express themselves sexually in an appropriate way. Given that puberty and menstruation are critical developmental milestones for young women, further research is needed to evaluate the effectiveness of interventions to prepare those with autism for developmental changes, including menstruation, and to promote independence in their self-care at this time.

### RESEARCH AIMS

The aim of the current research is to evaluate the effectiveness of a parent implemented social story intervention, with an additional visual task analysis to teach menstrual care skills to three young girls with autism.

### RESEARCH METHODS

Three adolescent females with a diagnosis of autism participated in the study. The following criteria applied: gender, onset of menstruation had not yet occurred, menstrual care had not been taught, parents viewed menstrual hygiene as important and female parent was willing to collect data. The target behaviour for the research was independent completion of a typical bathroom routine for changing a sanitary towel, and this was broken into an eleven step task analysis which included:

1. Grasp 'dirty' pad.
2. Remove 'dirty' pad.
3. Fold in half and wrap 'dirty pad'.

4. Place pad in trash.
5. Pick up clean pad.
6. Take pad out of package.
7. Grasp strip on back of pad.
8. Remove strip.
9. Place clean pad on underpants.
10. Pull up underpants.
11. Wash hands.

The mothers of the participants used the task analysis to collect data at baseline and during intervention and were trained to do so by the researcher. A menstruation knowledge checklist was developed and utilised pre and post intervention to assess the participant's knowledge of menstruation. A second questionnaire was also developed to assess and monitor the participant's understanding of the Social Story that was being implemented during intervention. The Social Story was developed using excerpts from Taking Care of Myself, and included two to five descriptive sentences, perspective and/or affirming sentences for each directive or control statement as per Social Story guidelines. Visual cues and demonstration pictures were also paired with these as part of the story.

During intervention, the parents were required to read the Social Story with their daughter, while encouraging turn taking in doing so. The participants were then asked a corresponding question by their parents to assess their understanding of the story and all responses were recorded. Simulated sessions were also created, where parents placed red syrup on a pad, and placed it on the participant's underwear while giving the instruction 'change your pad'. This data was recorded on the above task analysis.

### RESEARCH FINDINGS

In relation to the independent completion of the menstrual care routine, the results were as follows:

- Participant 1 averaged 31% of correct responses during baseline, and increased to 73%, 86.5% and 98% during intervention, simulation and in vivo sessions respectively.
- Participant 2 averaged 38% of correct responses during baseline, and increased to 48% and 66% for the intervention and simulation sessions.
- Participant 3 averaged 66% of correct responses during baseline, and increased to 86% and 92% during intervention and simulation phase.

All three participants showed an improvement in general knowledge as per the menstruation checklist and comprehension questions. All participants improved from 66% -100% during baseline and post-intervention phases in the menstruation checklist, and similar improvements were measured for the comprehension questions about the Social Story.

A parent questionnaire given post-intervention found that the mothers strongly agreed with the intervention procedures and enjoyed using Social Stories as an intervention method for menstrual knowledge and care. Two parents were interviewed one year post intervention, and they found that Social Stories were very helpful for addressing the skill of menstrual care in young women with autism. One parent reported that her daughter was independent in carrying out her menstrual care routine at home and at school. Another parent stated that the intervention will be revisited with her daughter once her menstrual cycle begins.

### IMPLICATIONS FOR PRACTICE (by the authors)

- The study was designed to overcome gaps in the literature by using Social Stories to explicitly teach basic skills and concepts related to menstruation and puberty among young females with autism.
- The findings demonstrate that Social Stories in isolation with visual demonstration pictures can be an effective strategy for teaching self-care skills to young females with autism.
- Parents reported high satisfaction that the stories were individualised for their children's needs, and through regular practice it promotes valuable interaction time for mother and daughter about a difficult topic.

### Full Reference

Klett, L. S. and Turan, Y. (2012). Generalized Effects of Social Stories with Task Analysis for Teaching Menstrual Care to Three Young Girls with Autism. *Sexuality and Disability*, 30, p. 319-336.

## PARENTAL PERSPECTIVES OF COMMUNICATION ABOUT SEXUALITY IN FAMILIES OF CHILDREN WITH AUTISM SPECTRUM DISORDERS

### BACKGROUND

Developing sexual interests is a developmental milestone which usually occurs around the age of 9-13 years and coincides with puberty onset. While the development of social communication skills is typically delayed in individuals with autism, the onset of puberty and interest in sexuality is typically not delayed. Due to difficulties in reading social cues, forming relationships can be difficult and can result in a vulnerability to sexual behaviour outcomes for individuals with autism including sexual abuse and normative sexual behaviour associated with maturity. These social deficits can result in difficulty in understanding the concepts of public and private behaviours which can result in unsolicited sexual contact, committing illegal offences or engaging in risky sexual behaviours. As a result, information on sexuality is often given as a response to inappropriate behaviours. It is therefore important that parents are equipped with age appropriate sexuality information so they can be effective sexuality educators for their children with autism. Communication between parents and children with autism occurring at the right time can lead to reduced or delayed sexual behaviours.

### RESEARCH AIMS

The aim of this study was to explore the content of the communication about sexuality between parents and children with autism aged 6-13 years to inform the design and development of a parent-based psychoeducational intervention for parents.

### RESEARCH METHODS

Parents of children living in the New Jersey area of the US attending public school were randomly selected. To be eligible to participate, individuals had to be either mothers, fathers or legal guardians of the children. Semi-structured interviews were held with 18 parents of children with autism aged 6-13 years, representing a total of 20 children with autism. Children were not present during any of the interviews, nor were they interviewed. Interview questions focused on two main themes:

1. What knowledge and skills are needed for parents to communicate with their children with autism about sexuality?
2. What types of support are necessary for parents to provide sexuality information to their children with autism?

Content analyses and ethnographic summaries were used to interpret the data.

### RESEARCH FINDINGS

Four content-related themes about sexuality were identified and included:

1. Misperceptions of children's non-sexual and sexual behaviour

The majority of parents (89%) felt that non-sexual behaviours would be misconstrued as having sexual content. Parents perceived the psychological and behavioural functioning associated with autism lead to non-sexual behaviours resulting from a lack of understanding regarding personal space, sensory processing problems and misperceived social cues.

2. Challenges in discussing sexuality with children and professionals

Parents felt apprehensive about communicating with their children or professionals about sexuality. Almost 90% of parents reported that they felt comfortable talking to their children about sexuality but had issues with their child's ability to comprehend the information fully. Parents acknowledged the disparity in chronological age and emotional maturity and struggled with knowing when the 'right time' was or what was considered 'age appropriate'. 39% of parents had children with self-stimulation behaviours and they were concerned that masturbation would replace current behaviours like hand-flapping or rocking.

3. Sexuality information communicated to children

Discussions between parents and children focused on limited themes, safety and social acceptance. Topics that were reported most frequently included sexual abuse prevention and personal hygiene issues. Parents felt they needed more information on how to detect abuse and also wanted to be able to enhance their children's skills for recognising and reporting abuse.

4. Perceptions of children's future influencing communication topics

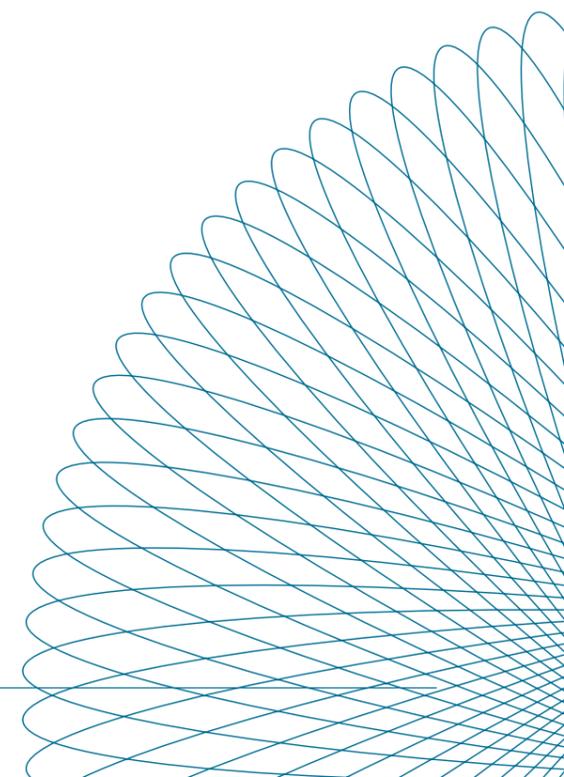
Topics which tended to be excluded from discussions with parents included dating, sexual intercourse and birth control as the majority of parents did not envisage their children's future including a partner. Many parents reported their children did not have any current friends and felt that their undeveloped social skills would prohibit any relationships of a sexual nature.

### IMPLICATIONS FOR PRACTICE (by the authors)

- Parents, educators, and public health professionals should address sexual health education proactively – not only when an issue or problem arises.
- Parent-based sexuality training programmes that rely on evidence-based interventions such as applied behavioural analysis and social stories should be developed to enhance parents' self-efficacy with communication.
- Both parents and providers need training to better attend to the unmet sexual health needs and the dearth of sexuality education programmes for young people with autism.

### Full Reference

Ballan, M. S. (2012). Parental Perspectives of Communication about Sexuality in Families of Children with Autism Spectrum Disorders. *Journal of Autism and Developmental Disorders*, 42, p. 676-684.



## SEXUALITY AND SEXUAL HEALTH IN CHILDREN AND ADOLESCENTS WITH AUTISM

### RESEARCH AIMS

The aim of this research is to consider the unique needs of children and adolescents with autism in terms of educating them in their sexual health and developing sexuality. The importance of the potential role the Nurse Practitioner (NP) during this period is highlighted.

### RESEARCH METHODS

The authors reviewed existing literature in relation to sexual behaviour, parental concerns, comorbidities, social skills teaching and the role of the NP.

### RESEARCH FINDINGS

The deficits in social skills of children with autism puts this group at an increased risk of social isolation and bullying during their adolescent period. Studies show that both children with autism and their typically developing peers view approval of their parents and their peers with the same importance. However, as individuals with autism may not learn through the same mediums as their neuro-typical peers they are at a disadvantage in terms of their acquisition of social skills and appropriate behaviours. This is of concern to the parents of children with autism; also alongside their child's ability to build relationships and be socially engaged. Many parents feel ill-equipped to educate their children around sexual education and their sexual identity.

Research indicates that romantic and sexual relationships and companionship are desired by adolescents with autism and also that they demonstrate a range of sexual behaviours. Further research is needed in the area of autism and gender identity, however it is reported that there is a greater number of individuals with autism presenting with gender identity than in the general population.

Difficulties can also arise with regard to appropriate public versus private sexual behaviours such as inappropriate references to sex, the touching of others, undressing in public and public masturbation. These difficulties are often as a result of the adolescent with autism not understanding what behaviour is appropriate and where. Equally, this lack of awareness can lead to misunderstandings surrounding the rules of courtship and appropriate behaviour when seeking a relationship.

The tendency toward restricted interests and repetitive behaviour coupled with unusual sensory responses typical in a diagnosis of autism can also influence the sexual growth of an adolescent with autism leading to atypical sexual fears, compulsive masturbation or fixations with sexual references.

Children with autism are at greater risk of physical, sexual and emotional abuse, yet are typically not taught preventative or safety strategies. In one nationwide US study it was found that one in five children with autism were victims of physical abuse, with one in six being victims of sexual abuse, and that there is an increased likelihood that children who have been physically abused will act out sexually or display sexually abusive behaviours toward other people. Of concern to parents of children with disabilities is that their children may be bullied, taken advantage of, abused, raped or assaulted. Equally, children with autism are at greater risk of difficulties due to engaging in, or displaying inappropriate behaviours as a result of a lack of understanding of what constitutes appropriate behaviour.

Some children may have additional difficulties such as obsessive compulsive disorder (OCD), gastrointestinal disorders (GI), mood and behaviour disorders and neurological disorders. The prevalence of comorbid conditions can

vary from none to several and will require consideration when tailoring interventions and treatments for children and adolescents with autism.

Education in the acquisition of appropriate social skills is essential for children with autism. Social stories and video modelling are two specific methods of teaching social skills and appropriate behaviours to children and adolescents with autism.

The approach must be individualised for each person with privacy rights being upheld. Collaboration with home, school and any other professional involved is essential to ensure that the most comprehensive care is provided. Once pertinent topics have been identified, the associated skills must be taught with referrals to external agencies or support groups if necessary.

### IMPLICATIONS FOR PRACTICE (by the authors)

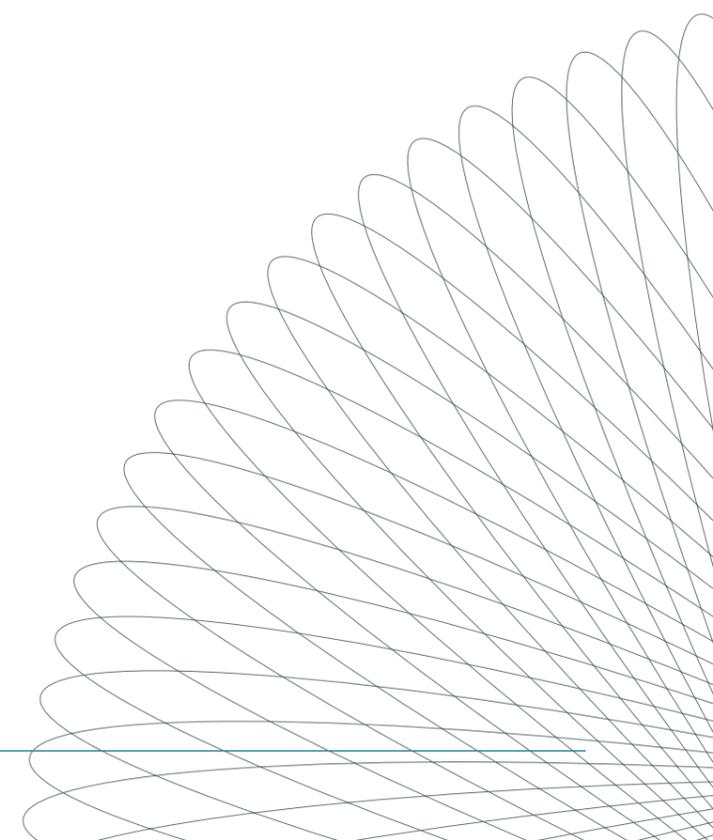
- Individuals with autism require specific instruction with regards to sexual health and social skill education.
- Parents need to be provided with support and guidance with regard to teaching sexual education to their children.
- Specific sexual education around masturbation for males with autism would be of benefit.
- Further research and understanding of gender identity for individuals with autism is needed.
- Training in appropriate sexual behaviour for individuals with autism is paramount to decrease their risk of abuse.
- Comorbidities and medication history must be taken into account when considering contraception or other pharmacological treatment.
- The availability of psychologists and other

professionals to deliver autism tailored education should be evaluated by the NP in the community.

- A variety of social skills teaching methods can be utilised to educate individuals with autism on social skills training.
- There is a potential role for a NP in the life of a person with autism.

### Full Reference

Chan, J. and John, R. M. (2012). Sexuality and Sexual Health in Children and Adolescents with Autism. *The Journal for Nurse Practitioners*, 8(4), p. 306-315.



## SEX EDUCATION, SEXUAL HEALTH, AND AUTISM SPECTRUM DISORDER

### BACKGROUND

According to the World Health Organisation (WHO) sex is an important element in quality of life and sexuality is vital to being human. It is recognised that individuals with autism spectrum disorder present with unique sexuality educational needs however these needs tend not to be adequately addressed within current educational programmes. The uniqueness of the sexual education needs for this population can be better understood when Theory of Mind (ToM) is taken into consideration. The ‘mind blindness’ theory behind ToM contends that individuals with autism have a difficulty with understanding that others have beliefs, desires, intentions and perspectives that are different to their own and also a difficulty in attributing those mental states to themselves and others. These ToM deficits impact upon successful relationship development in individuals with autism.

### RESEARCH AIMS

The aim of this research study was to highlight the need for high quality sex education, in line with the recent sexual health definition put forward by the World Health Organisation, for individuals with autism. This paper focused on the seven elements as described by WHO namely:

- Physical well-being in relation to sexuality.
- Emotional and mental well-being in relation to sexuality.
- Social well-being in relation to sexuality.
- Disease, dysfunction, or infirmity.
- Positive and respectful approach to sexuality and sexual relationships.
- Free of coercion or violence.
- Free of discrimination.

### RESEARCH METHODS

The research method used by the authors was a Boolean search of Pub Med, PsychINFO and Google Scholar using the following terms: (autism or Asperger AND ‘sex education’ AND sexuality).

### RESEARCH FINDINGS

**Physical well-being in relation to sexuality**

Sex education of children/young people with autism needs to begin earlier than their neuro-typical peers as more time may be necessary for the individual to learn the relevant strategies due to the associated difficulties of the disorder. Personal hygiene and self-care routines, which in general can be difficult for this cohort, can be taught via the medium of sexual education. Effective sex education is crucial to promoting physical well-being for individuals with autism.

**Emotional and mental well-being in relation to sexuality**

Autism effects emotional competence in a variety of ways and can have a significant influence on success in adulthood. The emotional development of individuals with autism is often not in line with their physical development; this delay in emotional development for adolescents with autism may result in the display of atypical public sexual behaviours with negative consequences for the individual. Clear and concrete sexual education can help to promote increased confidence, empowerment and self-enhancement during adolescence and beyond and ensure that social and sexual behaviour rules are reinforced. As mental health is closely correlated with sexual health, it is vital that mental health is also nurtured within this education.

**Social well-being in relation to sexuality**

The development of meaningful relationships for those with autism can be impeded by the social difficulties characteristic of the diagnosis. To that end, specific education in social skills is necessary alongside sexual education. The ability to initiate and maintain an intimate interpersonal relationship is of benefit both to the mental and physical health of individuals with autism.

**Disease, dysfunction, or infirmity**

Data regarding sexually transmitted diseases (STD) among the autism population is not available nor has any correlation between sexual education and this aspect of sexual health been investigated to date. However, data from the general youth population shows that comprehensive sexual education programmes resulted in positive outcomes such as a reduction in STDs, unwanted pregnancies and an increase in the use of contraceptive protection. Sexual education for individuals with autism in the area of disease and its prevention must entail clear, concise and direct instruction. While data does not exist with regard to un-medicated individuals with autism and sexual dysfunction, it has been found that certain prescribed medications affect sexual function and can have other sexual side effects.

**Positive and respectful approach to sexuality and sexual relationships**

Due to a lack of appropriate sexual education, individuals with autism are at a greater risk of displaying inappropriate sexual behaviours. Such problematic behaviours may be illegal in nature, or if not illegal, can limit inclusion and employment. Regrettably, training and education in this area is more often than not a reactive intervention.

Sexuality education in all its aspects must be taught in a positive manner and presented in way that is meaningful to individuals with autism.

**Free of coercion or violence**

Individuals with autism are at greater risk of victimisation and sexual abuse. This can in part be due to their lack of knowledge which highlights the need for autism specific extensive sexual education. The social skills impairments of this population affect the way in which they acquire knowledge readily understood by their neuro-typical peers. The fact that the acquisition of appropriate sexual behaviour and social behaviour guidelines are not facilitated through a peer group during adolescence underlines the need for comprehensive sex education throughout the adolescent years and perhaps beyond.

**Free of discrimination**

Autism, gender identity and sexual orientation is an area not well researched. However, some people with autism can identify as lesbian, gay, bisexual or transgender (LGBT). The LGBT community is at increased risk of physical and mental health issues; this risk may also be present in the autism population who identify as LGBT. Furthermore, noticeable parallels in health statistics for individuals with autism and LGBT individuals have been seen which may be as a result of discrimination in both groups. Whilst the discrimination parallel remains a hypothesis at present, this data is important for parents, educators and clinicians in enabling them to better understand and respond to the factors which may impact upon the mental health of individuals with autism.

## IMPLICATIONS FOR PRACTICE

(by the authors)

- Sexual education for individuals with autism is valuable and warranted to improve the sexual health of individuals with autism.
- Promoting positive sexual health for people with autism will have economic and societal benefits. Greater data driven research must be conducted into the area of autism, sexual education and sexual health. Future research could also investigate sexual health, mental health and sexual orientation.
- Outcome studies that reflect the effects of sexual education on the sexual health of adolescents and adults with autism must be conducted.
- Education and information is needed, for the wider public but especially for community members who may engage with individuals with autism, around the risks and sexual vulnerabilities for this population.
- Physicians should take into consideration the possible sexual side effects when prescribing medications.

### Full Reference

Loftin, R. L. and Hartlage, S. (2015). Sex Education, Sexual Health, and Autism Spectrum Disorder. *Pediatrics & Therapeutics*, 5(1). p. 230-235.

## THE LONGITUDINAL RELATION BETWEEN CHILDHOOD AUTISTIC TRAITS AND PSYCHOSEXUAL PROBLEMS IN EARLY ADOLESCENCE: THE TRACKING ADOLESCENTS' INDIVIDUAL LIVES SURVEY STUDY

### RESEARCH AIMS

This study investigated the relationship between childhood autistic traits and psychosexual problems in adolescence by means of parent reported questionnaires. The research explored:

- Particular autistic traits were related to psychosexual problems.
- The change in the level of autistic traits from childhood to adolescence was associated with psychosexual problems in adolescence.
- Other characteristics (such as, puberty, intelligence and conduct problems) influenced the relation between autistic traits in childhood and psychosexual problems in adolescence.

### RESEARCH METHODS

This study used data from the Tracking Adolescents' Individual Lives Survey (TRIALS), an ongoing longitudinal cohort study of Dutch youth focused on the development of mental ill-health and health from childhood to adulthood which started in the year 2000. Of the 2,230 adolescents who participated in the TRIALS study, 1,687 met the inclusion criteria for this study, which consisted of:

- Parents having fully completed the Children's Social Behaviour Questionnaire (used for measurement of autistic traits) and the Child Behaviour Checklist (used for measurement of psychosexual problems) at both time point one (when the children were aged 10 – 12 years) and at time point two (when the adolescents were aged 12 – 15 years).
- Children /adolescents having an IQ within the average range for the general population.
- Children /adolescents at time point one having no known psychosexual problems.

On average, the time between the two measurements was 2.46 years. Over half (53%) of the sample were female.

### RESEARCH FINDINGS

The purpose of this study was to investigate whether autistic traits in childhood predicted the occurrence of psychosexual problems in early adolescence. The results based on parent report show that autistic traits in childhood, above and beyond pubertal development and conduct problems, predict mild psychosexual problems in early adolescence.

In particular, two of the autistic traits were significant predictors of psychosexual problems, namely, limited social interest and problems in adapting behaviour were related to thinking too much about sex and playing with own sex parts too much. As such, adolescents with a lack of motivation to initiate and reciprocate social contact, overreacting and/or a lack of regulation of emotions and behaviours in social situations were more vulnerable to develop psychosexual problems.

Although this study showed that autistic traits predict psychosexual problems, it is only one of multiple predictors. This study is based on parent report and is therefore subjective to the parent. Additionally, caution should be applied when interpreting results as this study focused on a sample of adolescents with no diagnosis of autism who had an average IQ.

## IMPLICATIONS FOR PRACTICE

(by the authors)

- Although not all adolescents with autistic traits will develop psychosexual problems, as a group, these adolescents are at-risk.
- Considering the risk and potential problems, it is important to assess indicators of psychosexual problems early. In turn this will afford parents, education and health practitioners the opportunity to provide appropriate support as soon as necessary.
- Support for individuals at risk of developing psychosexual problems might be provided in the form of relationship and sexuality education and training sessions.

### Full Reference

Dekker, L. P., Hartman, C. A., Van der Vegt, E. J. M., Verhulst, F. C., Van Oort, F. V. A. and Greaves-Lord, K. (2015). The Longitudinal Relation between Childhood Autistic Traits and Psychosexual Problems in Early Adolescence: The Tracking Adolescents' Individual Lives Survey Study. *Autism*, 19(6), p. 684–693.

## PROVIDING EDUCATION ON SEXUALITY AND RELATIONSHIPS TO ADOLESCENTS WITH AUTISM SPECTRUM DISORDER AND THEIR PARENTS

### BACKGROUND

The programme was introduced to eight teenagers with a diagnosis of autism, six males and two females, between the ages of 12 and 16 years, and their parents, six mothers and two fathers, after analysis of current research into the knowledge of young people with autism in relation to relationships and sexuality education. Findings from previous research included young people with autism:

- Enter puberty at the same chronological time as their typically developing peers, yet may not have the associated cognitive and social developmental levels.
- Experience significant challenges with communication needed to develop friendships, relationships and subsequent intimate and romantic relationships.
- Have difficulty understanding the social aspect of many of the topics associated.
- Are vulnerable to sexual victimisation.
- Are definitely interested in pursuing intimate relationships.

### RESEARCH AIMS

This study presented two aims:

1. To investigate the viability of providing a short, group based programme in relation to relationships and sexuality education to a group of students with autism and another simultaneously to their parents.
2. To discover how this programme would influence the parent – teenager relationship when discussing such sensitive issues and whether parents would find these discussions easier and more comfortable post intervention.

### RESEARCH METHODS

The programme was delivered over a three-month period with six two hour sessions. The training sessions, parent and teenager, although separate, took place simultaneously, each with support from both male and female facilitators. Before the programme could be introduced, both parents and teenagers completed questionnaires, the parent report being a combination of sections of the Sexual Behaviour Scale (SBS) and the Intimate/Romantic Relationships subscale of the Courting Behaviour Scale to gauge their child's knowledge in the areas, while the teenage questionnaire had to be specifically designed to ascertain sexuality related knowledge, so that a comparison could be made when the programme was complete. The teenage sessions were delivered, where possible both verbally and visually, cognisant of the specific learning styles of those with autism, with rules of engagement presented and regularly revisited both verbally and visually.

Topics covered during the sessions included:

1. Introductions, getting to know each other, introducing sexuality.
2. Puberty, the human body and maturation, masturbation, privacy.
3. Personal hygiene, friendship development.
4. Types of interpersonal relationships, beginning to date.
5. Appropriate dating behaviour, types of physical contact, sexual activity.
6. Personal safety, legal issues, electronic communication, summary and closing.

The parent sessions also utilised the skill set and experience of the other participants, where discussion on how to discuss the issues was paramount.

## RESEARCH FINDINGS

Following the programme, the parents expressed a distinct level of satisfaction, suggesting that such a programme supports not only their needs but also the needs of the rest of the family. Parents also said that there is a definite need for such a programme for teenagers with autism and that how it was presented supported their children's needs. Therefore, parent concerns about discussing the topics were decreased and the levels of interaction with their child increased.

Several areas have been highlighted as key teaching and learning opportunities. Education is required on:

- Privacy.
- Inappropriate sexual behaviours.
- Birth control.
- Sexually transmitted diseases.
- Sexual hygiene behaviours.

Parents, during and after the programme, felt more equipped, yet not any more comfortable, to discuss more sensitive topics with their child, drawing on the support of the programme content and the experience of the other parents.

Although students reported that they have had sex education in health related classes, they have experienced difficulty generalising this to their lives and their social interaction. Therefore, it is significant that the students did not report any deeper or greater knowledge on sex after the programme, which allowed the authors to hypothesise that the issue is not knowledge but the application of the information and generalising to the social context.

The authors felt an evaluation for student engagement and knowledge in the subject does not exist and maybe the one that they used was too simplistic, which in turn influenced the results.

## IMPLICATIONS FOR PRACTICE (by the authors)

- Students with autism are interested in having sexual and romantic relationships, yet must to be taught specifically the social skills required including how to initiate, develop and engage in such relationships. These skills must be offered through a variety of genre, verbally, visually and interactively.
- Students need to be introduced to and offered social scenarios and active opportunities, where they get the chance to be a friend to someone, cultivating a range of friendships, rather than focusing on finding a life partner.
- Students may have all of the information regarding sex and relationships, but may not be able to apply them to social situations; knowing how to have a sexual relationship is completely different to initiating a friendship, knowing how to support its development and ultimately onwards to an intimate relationship.
- The area of privacy must be delivered in a manner that the student understands; the need for visual representations to support verbal interactions is apparent and essential.
- Other key areas for educators and parents include sexually transmitted diseases, birth control and sexual hygiene, again, to be delivered in a range of formats.

- Although sex education is taught, students must be supported to help them generalise this information into their social interactions. Many students will need these to be taught in meaningful ways with visual support and real life situations.
- If we are to have the support of parents, we must also address their needs. Parents need their own training component.
- Parental support and involvement in this type of programme is essential, as parents can continue supporting their child at other social outings, outside the school environment, allowing greater opportunities for skill acquisition and generalisation.

### Full Reference

Corona, L. L., Fox, S. A., Christodulu, K. V. and Worlock, J. A. (2015). Providing Education on Sexuality and Relationships to Adolescents with Autism Spectrum Disorder and Their Parents. *Sexuality and Disability*, 34, p. 199-214.

## CONCLUSION

The ten articles summarised in this bulletin provide a range of perspectives on the area of sexuality and relationships. What is clear is that children and young people with autism should receive education on this area. Some practice points for the development of education programmes are:

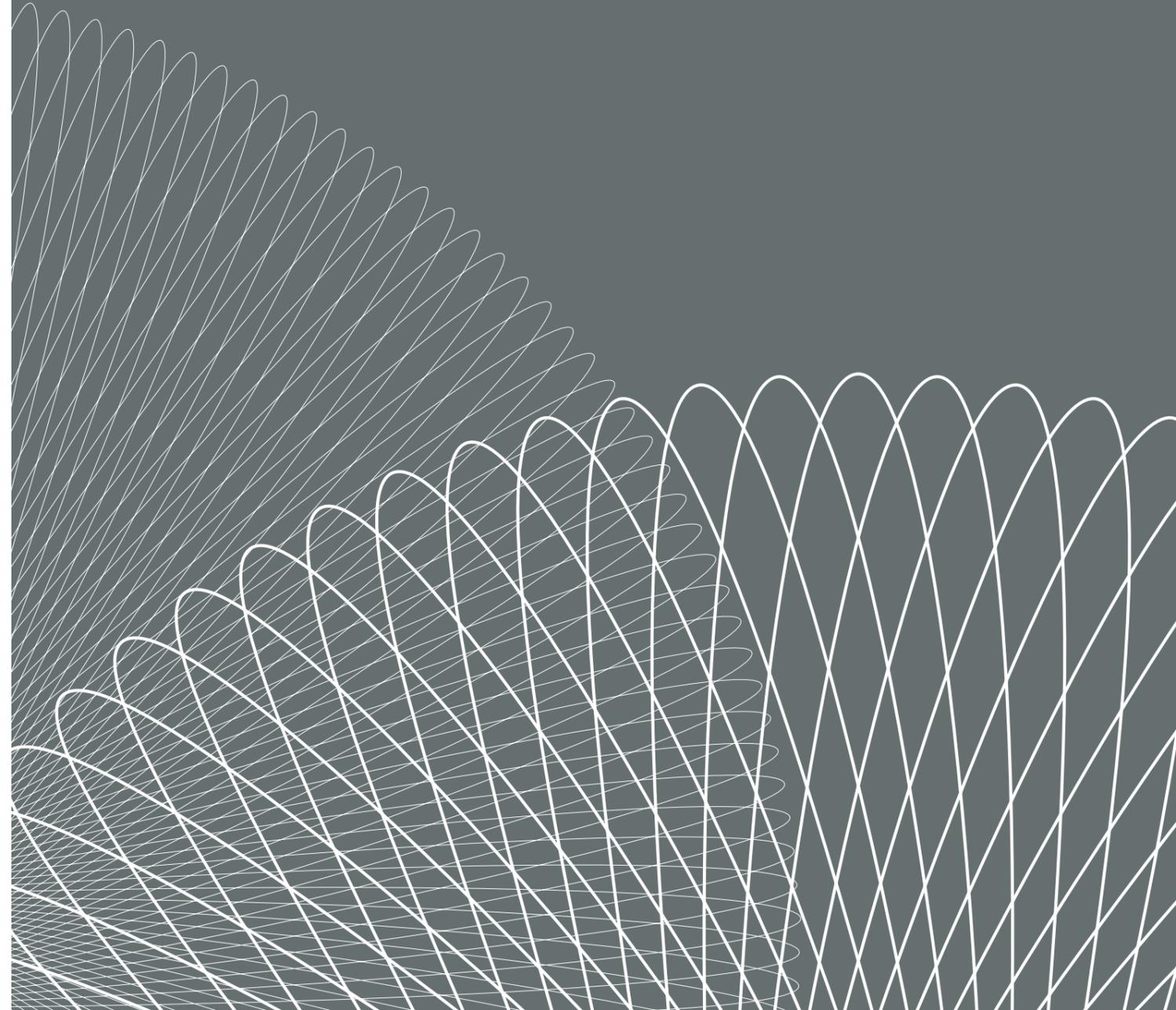
- They should be age and gender appropriate.
- When developing a programme of education, professionals and parents should consider the unique difficulties that children and young people with autism can experience and how these difficulties impact on social skills, sexual development and communication needs.
- Deficits in social communication, sensory issues and unusual patterns of social interaction and understanding can create difficulties for the young person with autism when trying to establish close personal friendships. Overtures of friendship can be misunderstood on both sides.
- Children and young people with autism are vulnerable to bullying and exploitation so protection skills should be taught often and repeated in line with social, emotional and sexual development.
- Parents and schools should work together to promote positive sexual behaviour and understanding.
- Teaching strategies that are effective for the development of social skills can also be useful in the development of positive sexual behaviour.

Children and young people with autism will experience physical, emotional and sexual development. This may not be at the same time or rate as their peers but this should not deter professionals and parents from teaching children and young people with autism the necessary skills and understandings that promote positive relationships.

## YOUR OPINION

The Centre trusts that you have found this Research Bulletin informative. It would be appreciated if you would take a few minutes to provide the Centre with feedback in relation to this bulletin by clicking on the survey link below.

### Survey for Parent and Professional Partnerships





CENTRE FOR AUTISM  
MIDDLETOWN

The Centre's Research and Information Service welcomes any correspondence including suggestions for future Bulletins to: [research@middletownautism.com](mailto:research@middletownautism.com)

Middletown Centre For Autism  
35 Church Street, Middletown, Co. Armagh BT60 4HZ  
T +44 (0)28 3751 5750 E: [research@middletownautism.com](mailto:research@middletownautism.com) W: [www.middletownautism.com](http://www.middletownautism.com)  
J G Cooper: Chief Executive, Registered in Northern Ireland, No. NI063661