



CENTRE FOR AUTISM
MIDDLETOWN

Autism Spectrum Disorder Relationships and Sexuality



RESEARCH BULLETIN ISSUE NO. 5

Supporting the promotion of excellence throughout Northern Ireland and Ireland
in the education of children and young people with autism spectrum disorders.



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This is the Centre's fifth Research Bulletin and focuses in on the important area of sexuality and relationships in ASD. The Centre's Research Bulletins are aimed at education professionals and parents and they provide a series of accessible synopses of peer reviewed articles from a range of research journals. The current Bulletin provides synopses of seven peer reviewed articles ranging in date from 2005 to 2011 and commences with an interview with Lynne Moxon. Lynne is a highly experienced Chartered Psychologist who specialises in the autism spectrum. She provides independent consultancy to 'Education and Services for People with Autism', which is a Sunderland based charity; she is also a Senior Lecturer and Course Leader for the Masters Degree in Autism at Northumbria University.

Young adults with ASD may have limited opportunities to develop appropriate behaviour and access appropriate information in relation to sexuality and developing close personal friendships and relationships. As a result of this some young people may present with inappropriate behaviour in close relationships or have a poorly formed concept of what constitutes a personal relationship. Having a poor concept of what constitutes appropriate intimate behaviour can also leave the young person open and vulnerable to being involved in exploitative and potentially damaging relationships.

The articles in this Bulletin address a range of areas including personal, parental and teachers' perspectives on sexuality and ASD and also good practice in developing sexuality education programmes for young adults with ASD.

INTERVIEW WITH LYNNE MOXON

Lynne is a Chartered Psychologist to “Education and Services for People with Autism” (ESPA) and a Senior Lecturer at Northumbria University where she is programme leader for the Masters in Autism course. Lynne has been working in the field of Autism Spectrum Disorders for 30 years and provides specialist consultancy and training to a variety of organisations and parent groups across the UK.

1. What are the pitfalls of using a mainstream relationships and sexuality education programme with children and young people with ASD?

Building social relationships by making friends and establishing intimate partners is a key developmental life stage for young adults so that all children approaching puberty, or young people who have already entered adolescence, will benefit from information and advice about sexual development and relationships. It is even more important for young people with ASD who may not learn incidentally or from their peer group, or may approach others in an inappropriate physical or verbal manner, misreading subtle social cues or body language and behaviours in others. We need to recognise that sexual development and curiosity is a normal developmental process. They may therefore not receive all the information they need from mainstream sex education, for example why do we have to have sex (teach it is not compulsory), what a real relationship is, where to meet people and what to do if things go wrong.

2. What are the particular types of difficulties that someone with ASD may have in the area of relationships and sexuality?

Young people and adolescents with ASD may experience significant problems both in regard to recognising and understanding the thoughts and feelings and actions of others, which may

be both subtle and complex (especially with regard to relationships), and in expressing their own feelings. Sexual development is a wide ranging process linked to the basic human needs of being liked and accepted, showing, giving and receiving affection, feeling valued and attractive, and sharing thoughts and feelings. It is not just physical functioning (which is often well understood), but it also relates to sexual knowledge, beliefs, attitudes, and values. There are the further complications that the adolescent peer group may not be the best source of role models or information and that the vulnerability and need for friends may be exploited by some peers.

3. Do boys and girls present with differing profiles of difficulties in the areas of relationships and sexuality?

Both need preparation for bodily change and coping with emotions – do not tell a boy that his voice will ‘break’, explain about wet dreams and how to reduce an unwanted erection. Make sure that you have good internet protection as pornography is easily obtained and distorts young people’s views on sex.

Girls need the same amount of input as boys but need to be prepared early for periods as sensory issues may make them ‘feel dirty’. Teach what to do about accidents e.g. black underwear and trousers until fully capable of managing. Unhelpful films about bodily change and birth can be frightening if they have not been prepared properly. The consequences of anxiety in girls can

lead to self harm and anorexia. They may not be ready for the intense emotions. Sometimes they just do not want to be teenagers as they have no real notion of dress and boyfriends. Others are so desperate for friendship they will behave in a sexual manner to obtain a relationship or are insecure, want to be liked and follow the crowd.

For both groups sensory issues can be problematic e.g. dislike of touch, reaction to smell.

4. Should children and young people with ASD commence education on relationships and sexuality at a different time / life stage to their typically developing peers?

All children should start sex and relationship education early – public, private, naming of body parts, can start with toilet training. Awareness of self and others, awareness of other gender, appropriate behaviour and developing confidence, keeping safe and managing risk are some of the basics.

Young people with and ASD need to learn friendship skills or they will not be ready for a more intimate relationship.

It is not good to be taken out of a sex and relationship class because ‘they won’t understand’ it is our job to give them the information perhaps before the class so they are on a level playing field and have been able to question ideas beforehand.

5. Is there a particular approach that teachers and parents should take with educating children and young people with ASD about relationships and sexuality?

Children and young people with ASD have a wide range of ability and needs. Visual approaches work well, as do drama, use of stories and characters (Talking Together series, www.fpa.org.uk), quizzes, interactive and group games. Teaching how to manage relationships is vital. This will take time e.g. 10 weekly sessions over a term and the information will need to be repeated in different contexts and over a number of years as the person matures. They also need to learn through social activities, putting their new information into context and learn how to give and receive consent through games and exercises.

Self-Assessed Sexuality in Young Adults with High Functioning Autism

RESEARCH AIMS

As a result of the social deficits inherent in individuals with autism, these individuals experience difficulties in sexual interactions. It is important to investigate where they obtain information about socio-sexuality and how much of it is actually applied in real life. The research literature has revealed that people with autism show an interest in sexuality and relationships but that poor social and communication skills may prevent them from having positive experiences in these areas. This study aims to obtain direct reports from people with higher functioning autism (HFA) and compare these with findings from typically developing (TD) participants. Research was focused on a young adult population (18-30) using a modified version of the Sexual Behaviour Scale (SBS). The aim was to establish if young adults with HFA were able to answer an instrument about their sexualised behaviours. The hypothesis was that in comparison with the TD population, persons with HFA would report lower levels of sexual experience, sexual and social behaviour and less understanding of the concept of privacy.

RESEARCH METHOD

Questionnaires were distributed to 90 individuals through community groups. Participants self-designated as having HFA or being TD. Questionnaires were completed in hard copy or on-line. The TD group consisted of 15 males and 24 females and the HFA group consisted of 12 males and 9 females.

The instrument used was an adapted version of the Sexual Behaviour Scale and measured

direct responses from participants. It consisted of six subscales: social behaviour, privacy, sex education, sexualised behaviour, sexual experience and future concerns.

The social behaviours subscale measured whether participants engaged in social behaviour and with whom social activities were undertaken. The privacy subscale assessed whether participants were seeking privacy for behaviours, awareness of privacy rules and how these rules were learned. The sex education subscale measured the source and level of sex education. The sexualised behaviours subscale assessed the amount and type of sexualised behaviour displayed by participants publicly, whether these were of concern and if participants had difficulty understanding sexual reciprocation. The sexual experience subscale included a direct question on whether the participants had specific sexual experiences. The future concerns subscale measured concerns for the future regarding finding a life partner and anticipating others misinterpreting the participants' behaviour.

RESEARCH FINDINGS

The results of this study support the hypothesis that persons with HFA would reveal lower levels of sexual experience, sexual and social behaviour and less understanding of privacy on the various subscales, compared to the TD population. Some scales included optional sections for participants to note additional information. In the sex education subscale, participants could list any other source from which they had obtained sex education. TD participants listed no other sources, HFA participants listed "TV" and

Self-Assessed Sexuality in Young Adults with High Functioning Autism CONTINUED

“making mistakes”. HFA participants, as well as the majority of TD participants reported that they would benefit from more sex education.

There was a non-significant result between the two groups on the privacy scale which is surprising given that anecdotally and clinically the concept of privacy is one that people with autism have difficulty with. However the researchers suggest that the generally reported lack of insight into appropriateness of behaviour led individuals with HFA to remain unaware of their failure to grasp the more subtle nuances of privacy. For example, when specifying additional activities which might require privacy, HFA participants listed “sleeping” and “dreaming”. The heightened anxiety about the future may indicate reluctance on the part of the HFA participant to engage with the risks associated with entering relationships, despite wanting to, which may give others the impression that people with HFA lack the desire for romantic relationships.

IMPLICATIONS FOR PRACTICE

(by the authors)

The researchers indicate that there are methodological weaknesses in the study reviewed; the psychometric instruments used may not have been the most appropriate for the sample. The reviewer also notes that some of the sample was recruited from individuals who were receiving treatment, as inpatients, at a psychiatric hospital.

Notwithstanding the above there are still salient issues that can be taken from this study, which was one of the first to compare the performance of males and females on the core symptoms of ASD.

- There is a need for specialised sex education programmes for people with autism.
- Since social behaviour was significantly lower for HFA participants and future concerns were higher, sex education programmes need to incorporate education about social rules to enhance social communication and understanding.

Full Reference

Mehzabin, P. & Stokes, M. (2011). Self-assessed sexuality in young adults with high functioning Autism. *Research in Autism Spectrum Disorders*, (5), p. 614-621.

Sexuality and Relationship Education for Young People with ASD: Curriculum Change and Staff Support

RESEARCH AIM

Teaching staff can find it difficult to source suitable curriculum materials for Sexuality and Relationship Education for young people with autistic spectrum disorder. The authors asked able adults with autistic spectrum disorder to reflect on their curricular experiences and share what would have been helpful in preparing them for relationships. Research findings were used to design materials to develop an individualised approach to Sexuality and Relationship Education suitable for the classroom and residential settings. The authors emphasise the need for staff responsible for delivering the Sexuality and Relationship Education programme to be provided with adequate training and on-going support.

RESEARCH METHOD

The methodology consisted of three elements:

- Literature research.
- Questionnaires for pupils with ASD who had participated in discussion groups.
- In-depth semi-structured interviews with four able adults with ASD.

RESEARCH FINDINGS

1. The literature research revealed some excellent resources and teaching packs. However, it was felt by the researchers that the existing resources did not necessarily address the complexities of understanding and developing relationships, which is an area of lifelong learning.
2. The key findings from the questionnaires were that all the participants wished they had

received better instruction in school about how to form meaningful relationships. The inability to do so was adversely affecting every aspect of their lives.

3. The adult interviewees all had very different understanding and feelings about their own sexuality, and the relationships they had as adults. However, they all wished they had understood themselves better when they were younger, that they had known about their ASD, had learned about its impact and how people without ASD are different.

The research identifies a lack of understanding of self, confusion about other people and how relationships function, as core areas of difficulty for people with ASD. Questions around sex and sexuality revealed a good awareness of the mechanics of sexual intercourse and childbirth. However, comments from the interviews showed how this knowledge was of little help without a foundation of self-awareness and a basic understanding of how relationships work. Sensory issues around the understanding and interpretation of touch could also be crucial to the confusion often experienced about relationships.

IMPLICATIONS FOR PRACTICE (by the authors)

The research was conducted to determine profiles in typically developing children however, there are still salient issues for professionals working with children with ASC.

- There are building blocks to being able to have relationships and without them as a foundation for adult life the relationships do

not happen or they falter. For people with ASD these building blocks are not present unless they are explicitly taught.

- The essential building blocks for a Sexuality and Relations Education Curriculum are based upon a central theme of ***a sense of self and the growth of self-esteem***. The building blocks are: touch and personal safety, clean and dirty, public and private, health, masturbation, menstruation, relationships of different kinds and relationships that might include sex.
- The researchers recommend that this last building block is when the mechanics of sex is taught and only when the other building blocks are firmly established. It needs to be taught clearly and explicitly by a teacher comfortable with the material and open about content and recording of lessons.
- The curriculum should be highly personalised, based on the individuals, their learning needs and what it is felt he/she can cope with.
- Learning is encouraged across school, residential and home settings to ensure that knowledge is generalised.
- An essential element to ensure that the curriculum succeeds is the provision of workshops for staff, which provide time to think, plan and create with guidance from other colleagues.

Full Reference

Hatton, S. and Tector, A. (2010). Sexuality and relationship education for young people with Autistic Spectrum Disorder: Curriculum change and staff support. *British Journal of Special Education*, 37 (2), p. 69-76.

Sexuality Education for Individuals with Autism Spectrum Disorders: Critical Issues and Decision making Guidelines

RESEARCH AIMS

Discussion Paper Aims

This is a discussion paper, which aims to present justification for sexuality education, from both families and professionals, for children and young people with autism spectrum disorders (ASD). The authors advise that there may be negative consequences such as isolation, inappropriate relationships and interactions and safety issues, should it be decided such a programme is not advisable. The authors claim this area has been overlooked.

RESEARCH METHOD

Basis for the Discussion Paper

The authors review a range of research papers addressing the area of ASD and sexuality education and from this review, three key areas are identified as imperative for those with ASD to ensure their personal safety and successful maturation:

1. Social difficulties for children and young people with ASD may make them particularly prone to sexual abuse including reporting this to others and recognition that ethically, it is wrong and legally, criminal, thus making it difficult for others to ascertain the root of the many causal ensuing difficulties faced by those who have been abused and to apprehend the perpetrator.
2. Children and young people with ASD have the universal right to learn about relationships, marriage, parenthood, and sexuality ensuring that those who deliver the education on those matters do not hold a bias, making it more difficult, if the individual had an associated learning difficulty, to fathom and comprehend their sexual orientation. Failure to address

these issues may leave the individual with difficulty understanding appropriate sexual and social contact.

3. Sexuality education for children and young people with ASD facilitates good hygiene, promotes health, leading to increased self-esteem and confidence, and prevents unwanted pregnancy.

RESEARCH FINDINGS

Issues Raised By the Discussion Paper

What should be taught in sexuality education for individuals with ASD

Body Awareness: As with typically developing children, many areas of sexuality education are encompassed within the curriculum from early childhood education onwards. As children in preschool learn body awareness through naming and identifying specific body parts and good and bad touching, the child with ASD must also be taught these but may need this delivered through an individualised approach rather than whole class activities. As the child grows and physically matures, others aspects, such as menstruation, ejaculation and self-examination must be included in this tailored approach whilst ensuring understanding.

Social Development: As part of the child's holistic education, social and relationship skills must be included. This will develop as the child grows and transitions throughout different stages of education and maturation to include sharing of similar interests with others, concepts of love and intimacy, appropriate ways to express emotions and relieve stress, and dealing with rejection appropriately.

Sexuality Education for Individuals with ASD: Critical Issues and Decision making Guidelines CONTINUED

Romantic Relationships and Intimacy: Teaching the concepts of romantic relationships and intimacy are complicated due to the difficulties associated with Theory of Mind (ToM) experienced by children and young people with ASD and become more acute in adolescence and young adulthood. Those with ASD must be taught specifically the social mores and subtle nuances to ensure their safety and that of others. These may include appropriate initiation of romantic relationships, rules surrounding dating, appreciating appropriate physical boundaries, developing and maintaining listening skills, and the meaning of consensual sexual activity.

Masturbation and Modifying Behaviour to Meet Social Norms: As practitioners, we need to recognise that masturbation may be more frequently engaged in by individuals with ASD as a means of relieving sexual urges and a recognised propensity for self-stimulating behaviours, thus assistance must be given for recognised acceptable practice and privacy issues. Other issues to be examined and supportive strategies designed and implemented may deal with public disrobing, inappropriate touching of members of the opposite sex, and masturbation with unusual objects.

Reproductive and Parenting Rights of Individuals with ASD: As with all individuals, those with ASD have an inherent right to learn about intimate, sexual relationships, contraception and pregnancy, yet we must all be aware that this must be taught in a manner that is accessible to each individual with ASD. The authors raise the issue of enforced sterilisation reminding readers that this does not reduce or eliminate the desire to be sexually active and that with all individuals' education, it must be delivered in a manner that recognises specific needs.

IMPLICATIONS FOR PRACTICE (by the authors)

Further knowledge and research into these key areas must be promoted to ensure children and young people with ASD have a curriculum that is designed to meet their needs, cognisant of the intrinsic difficulties experienced. Three overriding areas must be considered:

- **The role and structure of the concerned team, including school team, support services and parents, in the design of sexuality education programmes:**

The previously mentioned areas must all be addressed within the education plan, with roles and responsibilities assigned whilst respecting the values held, the capabilities and personal characteristics of each member. This cohesive, concerted approach is seen as preferable where recognition of individuality is apparent and a tenet held throughout all considerations. As with any team, to be successful, there must be a commitment from all of the associated members to teach, learn, and work together and collaboratively to devise, design and implement synchronised services where the individual with ASD is central to all deliberations.

- **The student's involvement in his or her own sexuality education programme:**

Whilst including the student in the design and implementation of the programme, appreciation that for success a sense of ownership and empowerment are vital ingredients thus it is recommended that an atmosphere of collaboration and motivation be created. However, to ensure informed choices and options are offered and appropriate ones made, differentiation of the concepts is required.

- **Anticipating disagreements about sexuality education among team members:**

Respect for the positions held by all team members is imperative if the programme is to be successfully implemented and meet its remit of effectively teaching and informing the child or young person with ASD. To assist with this premise, the earlier sexuality education is introduced, with the focus being age and stage appropriate, the greater chance that the programme can be developed and enhanced in line with the student's maturation.

Whilst these views are held by the authors, they clearly state that it is only one position and that further investigation is welcome to ensure the needs of students with ASD are recognised and accommodated within the curriculum in respect of sexuality training and education. They are aware that such an issue raises additional considerations, those of an ethical, moral, religious, cultural or societal nature, yet if the ultimate aim is to be met, facilitating the needs of individuals with ASD in a person centred manner, then a collaborative school/family approach coupled with a sense of honesty is recommended.

Full Reference

Travers, J. and Tincani, M. (2010). Sexuality education for individuals with Autism Spectrum Disorders: Critical issues and decision making guidelines. *Education and Training in Autism and Developmental Disabilities*, 45, (2), p. 284-293.

Establishing a Sexual Identity: Case Studies of Learners with Autism and Learning Difficulties

RESEARCH AIMS

This article explores how a residential school addressed the challenge of supporting individuals with autism and moderate to severe learning difficulties in achieving a personal sexual identity. It provides details of how these needs were met for seven students and the process of involving staff, parents and other stakeholders in establishing on-going support.

RESEARCH METHOD

The article presents seven case studies with students from Queensgate residential school for children with autism. Data was collected through analysis of notes collected at staff meetings, follow-up interviews with staff, observations of personal, social and health education (PSHE) teaching sessions and access to staff records of student progress.

RESEARCH FINDINGS

The process of change and maturation occurs in every individual. Physical maturity and development are linked to chronological age and other biological factors. However an intellectually disabled individual's psychological and social maturity may not keep pace with their physical maturity. This is particularly significant when limitation in the area of social awareness is a defining element of the disorder, as in the case of autistic spectrum disorder.

The research found a number of challenges in providing programmes addressing sexual identity.

- The views of a society, which may see those with disabilities as asexual or childlike, as individuals without interest in sexual activity, as a potential threat to non-disabled peers or as vulnerable to abuse.
- The necessity for individualised teaching strategies.
- The attitudes and belief systems of those in close relationships with the individual (i.e. parents, carers, educational staff).
- The private nature of the subject and the legal protections surrounding this vulnerable group make it difficult to teach and to measure effectiveness.

The findings outline six steps taken towards teaching sexual identity:

1. Revisiting school policy and identifying areas which needed strengthening.
2. Opening the lines of communication to families and others associated with the school including trustees and staff.
3. Several parent assemblies were held to discuss the topic and were open to all family members.
4. Volunteer members of staff looked at available teaching resources, including existing curricula and government guidance.
5. All children received the PSHE curriculum but additional individualised support was only provided when an adolescent demonstrated sexualised behaviour. This was to address the concerns of parents that this type of educational programme might increase sexual interest and activity.
6. Before starting the individualised programme, all students underwent a consultation with the therapy team, the psychologist, speech and language therapist and key staff members to ensure that increase in sexualised behaviours was not caused by medical or other problems.

IMPLICATIONS FOR PRACTICE

(by the author)

- Adolescents with autism and learning disabilities may need more active support from parents and schools to develop a socially appropriate sexual identity. The full spectrum of sexuality may need to be considered.
- The challenging nature of the topic makes it a difficult programme to establish and to teach. Sexualised behaviours can result in immediate and strong reinforcement with implications for quality of life. If the adolescent cannot distinguish between concepts of “private” and “public” then engagement with the wider community becomes difficult.
- The visual teaching strategies often used with people with autism may be misunderstood or misinterpreted in unfamiliar contexts due to the graphic nature of the subject.
- The individual has a right to achieve this aspect of adulthood, with suitable support. This is not a subject that will diminish, and it may become a bigger problem if not addressed in a timely manner.

Full Reference

Tissot, C. (2009). Establishing a sexual identity: Case studies of learners with Autism and learning difficulties. *Autism*, 13 (6), p. 551-566.

Sexual Behaviour in High-Functioning Male Adolescents and Young People with Autism Spectrum Disorder

RESEARCH AIMS

This study aimed to provide a descriptive examination of the theoretical knowledge and application of self care, socio-sexual skills, the sexual behaviour and sexual problems of a group of high functioning (IQ>70) male adolescents and young adults with ASD living in institutions.

RESEARCH METHOD

Caregivers were questioned using a semi-structured, investigator-based examination entitled the Interview about Sexuality in Autism (ISA, Hellemans and Colson) which was designed specifically for this study. For ethical and practical reasons, the authors interviewed caregivers rather than service users, which included education staff and occupational therapists.

RESEARCH FINDINGS

Despite individuals with autism displaying sexual behaviour and having sexual needs, this area remains a neglected scientific and clinical issue. The authors highlight that similarly for typical individuals, for individuals with ASD sexuality can be the source of intense pleasure as well as frustration. The study found that many age appropriate sexual behaviours were evident within the group, for example most masturbated, half of the group expressed a desire for a sexual or intimate relationship and had endeavoured to make this happen and half the group had experienced a close affective and/or physical relationship, although the sexual developmental level of these relationships tended to be limited. The article underlines that while socio-sexual skills were reported to be well known in theory,

they were not often used in practice, resulting in issues such as masturbation in public, a lack of modesty and excessively frank discussion of sex. The presence of repetitive behaviour, stereotyped interests and sensory preferences in individuals with ASD may influence sexual development; for example, within this sample the following behaviours were present: compulsive masturbation, fetishism with the ritual use of objects, preoccupations with a sexual connotation and irrational fears associated with sex. Additionally, findings also highlight that even when a person with ASD has an IQ within average range, they often do not spontaneously discover how to masturbate resulting in difficulties in achieving orgasm and/or incorrect masturbation techniques, occasionally provoked stress and hypermasturbation.

IMPLICATIONS FOR PRACTICE

(by the authors)

- Given that the majority of participants were reported to have expressed sexual interest and displayed sexual behaviour, sex and relationships education is crucial for young people with ASD; furthermore, sex education programmes designed for adolescents with learning disabilities may not be applicable for the educational needs of this client group.
- The finding that some participants were reported to have difficulties in achieving orgasm and/or to be using incorrect masturbation techniques, suggests that relationships and sexuality education for individuals with ASD must be practical and include socio-sexual skills concerning masturbation practices, as well as sexual intercourse, contraception and sexually transmitted diseases.

- Individuals with ASD need to be explicitly taught how to appropriately seek physical relations as often they fail to make a satisfactory distinction between desired and undesired contact, which may be related to difficulties with social and emotional reciprocity. Therefore, relationships and sexuality education should pay particular attention to the learning of empathic and perspective taking skills.

Full Reference

Hellemans, H., Colson, K., Verbracken, C., Vermeiren, R., Deboutte, D. (2007). Sexual behaviour in high-functioning male adolescents and young people with Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders*, (37), p. 260-269.

Teachers' Perspectives of the Sexuality of Children with Autism Spectrum Disorders

RESEARCH AIMS

This study aims to ascertain the differing perceptions held by teachers as to the sexual behaviours of 56 children with low functioning autism (LFA) and 20 children with high functioning autism (HFA) or Asperger syndrome (AS), to see if the level of cognitive development impacts on the behaviours noted and the nature of education offered.

The authors were cognisant that although there is a dearth of information available on the themes of sexuality and autism, this does not mean that such individuals do not experience sexuality issues, with many, with AS and HFA, expressing a desire to marry and have intimate sexual relationships. Those with ASD begin puberty alongside their typically developing peers, yet the core difficulties associated with ASD may lead them to expressing their interest in a socially inappropriate manner; for example:

- Discriminating where to and frequency of the performance of certain sexual behaviours, public or private.
- Having a suitable personal hygiene routine.
- Self-protection and preservation in relation to sexual exploitation.
- The repetition of sexuality terms in appropriate contexts.
- The difficulties experienced by individuals with ASD concerning sexuality issues including masturbation and menstruation.

The authors claim that although families and schools tend to focus on academic progression,

the area of sexual behaviours, including teaching social boundaries and personal self-care, must be specifically taught and learned, early in education as preparation for puberty, to ensure holistic maturation leading to greater opportunities for inclusion and integration upon adulthood.

RESEARCH METHOD

Fifty-six teachers from special schools and those schools with inclusion classes were asked to comment, using the Sexual Behaviour Scale (SBS) developed by Stokes and Kaur, (2005), on 76 children, [54 boys and 22 girls, 56 with LFA, 20 with HFA/AS], mean age of 10 years and 7 months. The SBS was originally designed for parents, thus, for this study, was modified to glean the perceptions of the individual's teacher. The questionnaire measures:

- Social behaviour.
- Privacy.
- Sex education.
- Sexual behaviour.
- Teachers' concerns.

RESEARCH FINDINGS

Those of most concern to teachers were the individuals with HFA/AS as they tend to experience greater opportunities for unsupervised social activities, even though those with LFA exhibited behaviour that is more problematic including exhibiting less socially acceptable behaviours, less mature awareness of privacy rules with limited insight to appropriate sexual responses, thus being susceptible to sexual abuse and exploitation.

In school, children with LFA have been noted to engage in masturbation. At times, this could be deemed a repetitive behaviour, a core feature of ASD, yet in the social environment, this can cause embarrassment to the adults whose duty is to protect and educate them. These instances may not be noted in any other environment due to the limited social interactions of children with LFA, but in preparation for social situations as adults outside the family home or school, teachers may be the only source information and thus can offer assistance and guidance.

Although those with HFA/AS, due to their more developed verbal cognition, may have learned the suitability of their responses to social interaction, it must be recognised that this “hidden curriculum” is an ever-changing field. However, cognisance must be given to the fact that many students with HFA/AS engage in sexual behaviour activities simply because of the pleasurable feeling accrued and are not interested in how it appears to others.

Teachers claimed that they did not have the training needed to deliver sexuality training in a differentiated manner that would adequately meet the needs of students with ASD. This could be seen as an aspect of professional development necessary to ensure the safety of the students, yet many, too, saw that religious or cultural diversity amongst teachers and families might make this difficult to teach.

IMPLICATIONS FOR PRACTICE

(by the authors)

All individuals with ASD, but in particular those with LFA, must be engaged in sexuality education early in their development in regards to self-care activities and how to be safe. Teachers may need to be aware of supportive interventions to assist those with LFA to transition to supported living, respite services or full-time accommodation.

Teachers must be aware of the social appropriateness of repetitive behaviours and be offered guidelines and supportive interventions to ensure that the young person’s behaviour meets acceptable social mores.

The importance of the “hidden curriculum” needs to be acknowledged by teachers and they must keep abreast of the changes to it, to ensure that their students with HFA/AS do not become excluded due to an immature response. Social skills training for all with ASD must be seen as an ongoing aspect of education that changes and is delivered in an accessible mode depending on cognitive development, understanding and assimilation of socially appropriate mores and nuances.

Recognition that individuals with ASD require sexuality education is imperative and not an option.

Full Reference

Kalyva, E. (2010). Teachers’ perspectives of the sexuality of children with Autism Spectrum Disorders. *Research in Autism Spectrum Disorders*, 4, p. 433-437.

High-Functioning Autism and Sexuality: A Parental Perspective

RESEARCH AIMS

The researchers aimed to establish if adolescents with High-Functioning Autism (HFA) presented differently across five areas of social behaviour, sexual behaviour and knowledge and parental concerns than typically developing peers. The researchers hypothesise that the HFA adolescents will present with:

1. Poorer social behaviours.
2. Engage in fewer behaviours related to privacy and have poorer knowledge of privacy issues.
3. Have less sex education.
4. Display more inappropriate sexual behaviours.
5. Parental concerns will be greater.

If this is shown to be the case the researchers propose that a special approach in sex education should be taken with children and young people with HFA.

RESEARCH METHOD

A specially devised questionnaire was used with the parents of 23 children and adolescents with HFA and 51 typically developing peers; all participants were between 10-15 years of age.

The parents were asked to complete the Sexual Behaviour Scale (SBS). The SBS rated the children and adolescents across five areas of social behaviour, privacy, sex education, sexual behaviour, parental concerns. The data collected was then analysed using a range of parametric and non parametric statistics.

RESEARCH FINDINGS

The initial hypotheses were shown to be accurate; the parental questionnaires indicated that the

children and adolescents scored poorly across the four measures and the parental concerns were heightened amongst this group.

Further analysis of the five domains indicated that age and social ability were significant mediating variables across the four domains of social behaviour, privacy, sex education and sexual behaviour. Difficulties with inappropriate sexual behaviour and lower levels of sex education were not as pronounced in those children and adolescents with good levels of social functioning. Similarly with age, the older adolescents presented as less impaired across the domains than younger children.

The largest differences were in areas of social functioning where, as expected, the children and adolescents with HFA engaged in less social behaviour and appropriate social behaviour than their typically developing peers. Adolescents with HFA were less likely than their typically developing peers to seek out privacy for intimate personal behaviour and also in recognising the privacy needs of others e.g. not knocking on bedroom or bathroom doors. This then did have an impact on the presentation of inappropriate sexual behaviours, which were higher in the HFA sample than in their typically developing peers.

The authors highlight a significant finding in relation to developmental patterns and social behaviours and note that the children and adolescents with HFA presented with more social behaviours as they were older and the reverse was true of their typically developing counterparts. They highlight this as an area for possible future research.

IMPLICATIONS FOR PRACTICE

(by the authors)

- Children and adolescents with HFA are at a higher risk of presenting with sexually inappropriate behaviour, a lack of understanding of privacy and lower levels of sex education. The current study highlights all of these areas as areas that will require input from parents and professionals. These findings are congruent with previous research studies, which form the basis for the current research.
- Age is an important factor in the delivery of sex education; older children did not present with as many difficulties in these areas as the younger children, however, the HFA sample still presented with more difficulties than their typically developing peers. This would support the authors' call for timely and focused sex education starting pre-adolescence.
- Social awareness has an influence on the presentation of sexually inappropriate behaviour; any sex education programme would have to have a significant element of social skills training, as this was highlighted in the current research as a mediating variable on the presentation of sexually inappropriate behaviour.
- Parents of children and adolescents with HFA had higher levels of concerns that the parents of the typically developing children and adolescents. Professionals working in this area should be aware of and sensitive to parental concerns and have positive plans to promote sex education in children and adolescents with HFA in order to alleviate these concerns.

Full Reference

Stokes, M and Kaur, A. (2005). High-functioning Autism and sexuality; a parental perspective. *Autism*, 9 (3), p. 266-289

The research articles included in the current Bulletin signpost a range of practical strategies that can be used in addressing the issues of sexuality and relationships in young people with ASD. Researchers indicate that this is an area that requires more clinical and scientific investigation. Notable recommendations of the articles included are:

- Sexuality and relationships programme development should take an incremental or 'building block' approach and also focus on the fact that building relationships with others is also incremental and that relationships are built.
- The rate of psychological and social maturity in a child with ASD may not keep pace with their physical maturity. This is particularly relevant in the area of social difficulties.
- Teaching strategies should be individualised and parents and caregivers should be involved in the process.
- There is no lack of sexual interest in young adults with ASD and sexuality education should begin early, especially in those who have significant cognitive impairment.

Middletown Centre for Autism provides training in the area of sexuality and relationships. For further information please visit the Centre's website www.Middletownautism.com.

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Survey
for Autism Spectrum Disorder
Relationships and Sexuality

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

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