

Developing a policy for sexual health education for children and young people with Autism Spectrum Disorders and learning disabilities

Diane Ballantyne

Abstract

Linn Moor School provides care and education for 22 children with severe and challenging behaviour. Around 80 percent of these children have a diagnosis on the Autistic Spectrum and all the students have some form of learning disabilities. Due to these difficulties, providing sexual health education has been a challenge and there has never been a whole-school approach. Aspects of sexual health education have only been taught when a crisis has arisen for individual students.

Keywords

Sexual health education, looked after children, Autism Spectrum Disorders, learning disabilities, autistic

Corresponding author:

Diane Ballantyne, Project Assessor, Linn Moor School

Introduction

Linn Moor School provides care and education for 22 children with severe and challenging behaviour. Around 80 percent of these children have a diagnosis on the Autistic Spectrum and all the students have some form of learning disabilities. Due to these difficulties, providing sexual health education has been a challenge and there has never been a whole-school approach. Aspects of sexual health education have only been taught when a crisis has arisen for individual students.

Tissot (2009) documents the risks involved from not providing sexual health education, especially to children with autism. These include risks to themselves from injury, recrimination and risks to others. This paper discusses the importance of providing sexual health education and evaluates the effectiveness of consultation and the process of change and improvement within the school. For the purposes of this paper, Autism is used interchangeably with ASD to indicate Autistic Spectrum Disorders.

Context

The school has adopted the TEACCH (Treatment and Education of Autistic and related Communication handicapped Children) approach. Therefore, the school provides a highly

structured, low arousal environment for its students. The school also uses other interventions based on the needs of each individual, such as PECS (Picture Exchange Communication System), augmentative communication aids and behavioural interventions (Lawrie and Stevens, 2009). The majority of students within the school have a diagnosis on the Autistic Spectrum and therefore it is important to consider this when planning for change within the school.

In addition to policies, procedures and protocols, the residential school must follow legislation governing both education and care. The National Care Standards (Scottish Executive, 2005) set out what service users should expect from care services, including health education. The school is continually assessing and auditing its service to comply with legislation and best practice.

Where are we now?

One specific priority was to start delivery of sexual health education and have a policy to enable us to do this, which recognised the particular needs of our students. The National Care Standards do not require the service to have a formal sex education provision in place, rather that if there are difficulties staff should seek advice from professionals (Scottish Executive, 2005). However, the school is an educational provision as well as a care provision. The Scottish Government has placed an expectation on all schools to provide sexual health education within the curriculum (Scottish Executive, 2000a) and schools must give regard to national advice set out in *the Standards in Scotland's Schools etc. Act 2000: Conduct of Sex Education in Scottish Schools* (Scottish Executive, 2000b). The main points of this advice are that schools should involve parents, have a robust policy, provide sexual health education that promotes positive and stable relationships, and that sexual health education is taught within the wider curriculum.

The service also has an ethical duty to protect the students from the risk that comes from a lack of teaching in sexual health education. Sicile-Kira (2003) examines issues with the sexual identity of people with ASD and writes that they are at a high risk of sexual abuse.

In 2006, the Scottish Executive sponsored research into sexual health education provision in primary schools in Tayside (SEED, 2007). This was a large-scale study, gathering the views of teachers, parents and pupils through questionnaires. Their findings were that teachers were not confident in the delivery of sexual health education but with the implementation of a training package, they became more confident. The confidence levels of teachers made vast differences across the schools in the topics that were taught, with fewer schools teaching more sexually explicit topics. The study also found that the timetable for sexual health education did not allow enough time and it may need to be started at a younger age. This highlighted the importance of starting a programme on sexual health education within Linn Moor as a priority as it may take longer for students with ASD and learning difficulties to understand the concepts of developing a healthy sexual identity.

Setting Priorities Collaboratively

There are various pieces of legislation and guidance on collaborative working and the importance of keeping parents involved, the main being the *Children (Scotland) Act 1995* which states that parents should have an active role in bringing up their child. In respect to guidance on sexual health education, the *Standards in Scottish Schools etc. Act 2000* recommends that parents are consulted throughout the process of their child being taught, including being involved in policy decisions. This was taken into account for the consultation stage and development of the policy. Consultation also took place with other professionals such as the occupational therapist, school nurse and the managers of the school. This would ensure that resources and support could be accessed, including funding for training staff. The HMIE (2006) recommended that professionals should work together to co-ordinate support for children with ASD.

Sexual Health Education Policy and Programme

The majority of students within the school have an ASD diagnosis and therefore it was important to take this into account when planning for change within the school. In 1979, Lorna Wing and Judith Gould studied a number of children in Camberwell. From their studies they found that the condition could be categorized by impairments in social interaction, social communication and social imagination and flexibility of thought, hence the *Triad of Impairments* (Cumine, Leach et al., 2000). As there is no formal medical test for ASD the Triad of Impairments is currently the basis of most diagnostic criteria.

The characteristics of autistic behaviour can be partially understood by reference to some other current psychological theories about autism. For example, it is said children affected by ASD have problems with their *Theory of Mind* (TOM). *Theory of Mind* is being able to imagine that other people have their own intentions and perspectives (Baron-Cohen et al., 1985 as cited in Cumine, Leach et al., 2000). People with ASD have said that they do not realise that others know things that they do not know, and that they find it difficult to interpret the behaviours of others (Bogdashina, 2005). People affected by ASD may also have Central Coherence deficit. Central Coherence is the ability to gather information from the environment to come to a conclusion. Uta Frith describes it as 'the tendency to draw together diverse information to construct higher-level meaning in context' (Uta Frith, as cited in Cumine, Leach et al, 2000, p. 25). This could be linked to difficulties in understanding facial expressions, body language and sarcasm and therefore social understanding.

Difficulties caused by deficits in Central Coherence, *Theory of Mind*, and the *Triad of Impairments* combine to cause misunderstandings when it comes to the teaching of sexual health education. It is therefore imperative that children with ASD are taught sexual health education in context as far as possible to aid their understanding. For instance, a bathing routine is the ideal opportunity to teach naming of body parts, which can then be reinforced through classroom tasks.

Designing a policy for children and young people affected by ASD

Examples of the difficulties that people with ASD face when they experience puberty have been well documented in the literature. Jordan (2001) reports that menstruation may be misunderstood as being caused by injury because of the blood involved, or that 'wet dreams' can be misinterpreted as being caused by toileting accidents. It may be that they do not understand the concept of private and public which could lead to the person becoming naked in public, masturbating in public or touching others inappropriately.

Henault (2006) describes sexualised behaviours in people with ASD as being suppressed, as parents or others may see the child as asexual which may lead to more challenging behaviour in the long term. However, Swango-Wilson (2008) posits from her research that caregivers question the sexualised behaviours of their children, with younger caregivers finding their child's sexuality more acceptable. Although providing sexual health education in itself is a difficult task, especially when it can cause issues if not developed to meet a person's specific needs, it is necessary to reduce the risk to the person and others in the environment. As Jordan (2001) commented:

Youngsters with autism and severe learning disabilities have to be prepared for changes in their body that will otherwise seem terrifying. They will not have friends with whom to talk things through. The absence of these normal mechanisms for anxiety reduction will have to be compensated for by support from parents and caring professionals (Jordan, 2001, p. 34).

It was therefore necessary to devise a policy that reflected the individual needs of each student and would deliver topics that were relevant to each student's stage of development. In order to reflect this there was a need for a process to assess each student's understanding. The author worked closely with the occupational therapist who designed an assessment form with instructions for its use. This enabled staff to design individual protocols for each student based on their current understanding.

Steps to development and implementation of policy

Planning meetings

I arranged a meeting between student support services manager, the occupational therapist and myself and involved a parent from the health and well-being forum within the school. This allowed me to set targets for myself in terms of the policy and delegate duties to others including setting a target for the occupational therapist to write an assessment tool. One aspect that was agreed at this meeting was that sexual health education should be delivered using a staged approach, starting from a very basic level but teaching topics that were most necessary to reduce risk to individuals with ASD. Kalyva (2010) found from research that teachers were more concerned about the lack of privacy awareness in children with low functioning autism. As most of our students are affected by low functioning ASD this was one of the areas that took priority.

I then arranged a meeting with the operational manager of the service and the occupational therapist to delegate duties and form an action plan over a three month

period between April and June. The action plan included consultation with staff and parents, setting targets, researching the available policies in the sector and writing a training course.

Parent views

Questionnaires were sent to all parents and a meeting was held where parents were invited to the school health and wellbeing forum. The parent who contributed most to the process by attending the meeting asked for training for parents and suggested that information on the policy be added to the school website. However, when the questionnaires were returned not all parents felt they wanted to be as involved in the consultation. Six questionnaires out of 22 returned. There were comments such as:

Think it is a good idea, but not sure (child) would understand much about this; (Personal Communication).

I would like to know what (child) will be told and how it will be explained to him. I have never been in favour of him being taught this subject, but I feel he is of an age now; (Personal Communication).

Staff Views

In order to provide an efficient training package, the views of staff were sought. Due to the failure of previous questionnaires, I designed a questionnaire that would take a minimal amount of time to complete. I then asked a sample of thirty staff to complete it during a meeting, having them hand it in at the end. The rest were then disseminated to groups and classes and came in sporadically. The author was surprised by the amount of positive feedback from staff from their questionnaires. Eleven out of thirty staff members were happy to attend the advanced training to teach any topic of sexual health education.

Discussion

There are many benefits as well as challenges in implementing change, particularly in the provision of sexual health education for children with ASD. In this residential school most of the children not only have a diagnosis on the autistic spectrum but also have severe learning disabilities which impact on their learning styles. Only around 20 percent of the students have verbal language, a few understand picture symbols and others rely on objects, gestures and physical prompts to communicate. This meant that the policy has had to provide for all these different requirements. With staff training, the school will be able to provide better support to the students, protecting them as well as those children in the community, and providing more opportunities for inclusion.

The feedback from meetings and questionnaires allowed development of the policy as well as training for staff and possibly parents, if funding allows. The importance of policy in driving practice is very important. It makes real some of the issues which become hidden. If issues are not acknowledged as practice areas, it means that staff are thrown back on their own knowledge and resources. Some may not have had the confidence to tackle the

area of sexual health education at all if the policy and subsequent training had not been devised.

The importance of consultation cannot be emphasised enough. Unless staff and parents have an opportunity to explore what the policy should entail and what it will mean for their lives as carers or parents, then there is a likelihood that the policy would remain a paper exercise. Consultation in this process has encouraged real ownership. With the author of the policy being very close to practice, this has also given the policy a good degree of credibility.

References

- Bogdashina, O., (2003). *Sensory perceptual issues in Autism and Asperger Syndrome*. London: Jessica Kingsley.
- Cumine, V., Leach, J. & Stevenson, G. (2000). *Asperger Syndrome: A practical guide for teachers*. London: David Fulton.
- Henault, I. (2006). *Asperger's Syndrome and sexuality*. London: Jessica Kingsley.
- HMle (2006). *Education for pupils with Autism Spectrum Disorders*. Edinburgh: HMle.
- Jordan, R. (2001) *Autism with severe learning difficulty*. London: Souvenir Press.
- Kalyva, E. (2010). Teachers' perspectives of the sexuality of children with autism spectrum disorders. *Research in Autism Spectrum Disorders*, 4, 433-437.
- Lawrie, B. & Stevens, I. (2009). *Evaluation of behavioural support strategies at Linn Moor School*. Glasgow: Scottish Institute for Residential Child Care.
- Scottish Executive (2005). *The National Care Standards*. Edinburgh: TSO.
- Scottish Executive (2000a). *Sex education in Scottish Schools: Summary of national advice*. Edinburgh: TSO.
- Scottish Executive (2000b). *Standards in Scotland's Schools etc Act 2000: Conduct of Sex Education in Scottish Schools*. Edinburgh: TSO.
- SEED (2007). Sex education in primary school in Tayside: An evaluation of sexuality and relationships training for primary teachers. Accessed on 12th June 2011 at www.scotland.gov.uk/Resource/Doc/151683/0040755.pdf
- Sicile-Kira, C. (2003). *Autism Spectrum Disorders: The complete guide*. London: Vermilion.
- Swango-Wilson A (2008) Caregiver perceptions and implications for sex education for ASD. *Sexuality & Disability*, 26, 167-174.
- Tissot, C. (2009). Establishing a sexual identity: case studies of learners with autism and learning difficulties. *Autism*, 13 (6), 551-566.