



Evaluation of the Growing Up Workshops

**for parents of children and young people with
Autism Spectrum Disorders**

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Contents

Executive Summary	3
Introduction	4
Overview of Autism Spectrum Disorders	4
Issues around sexuality and ASD	4
Adaptations to RSE for young people with ASD	5
Involvement of families in RSE	6
The aims of the Project	7
Policy and Legal Context	8
The ‘Growing Up’ Workshops	9
Background considerations	9
Aims of the workshops	9
Content of the workshops	10
Presentation of the workshops	11
The evaluation of the workshops	12
Findings Part 1: Expectations of the Workshop	13
Parents’ experience of sexual health issues	13
Parental reasons for attending the workshops	16
Findings Part 2: Participants’ reactions to the workshops	19
Findings Part 3: Reactions from parents after the workshops	21
Findings Part 4: Experiences of workshop tutors and advisors	24
Conclusions and Recommendations	26
Continuing advocacy for RSE and people with ASD	26
Training for Parents	26
The provision of RSE to young people with ASD – beyond the family	27
Policy and practice guidance	28
References	30
Appendix: Members of Steering Group	31

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Executive Summary

Children and young people with autism spectrum disorders face particular challenges in gaining a full understanding of their sexuality and in forming relationships. This issue has received relatively little attention to date but this will change as larger numbers of younger children with this diagnosis move into adolescence and adulthood. Current provision of Relationship and Sexuality Education (RSE) within schools is insufficient to meet their needs but little systematic alternative provision is available. It is widely acknowledged that parents have a critical role of play in RSE even if when it is delivered by other people outside of the home.

AutismNI were resourced to develop, implement and evaluate training workshops for parents that would support them *“to improve and promote the sexual health and social well-being of young people with Autism in NI”*. A two-day workshop was devised, drawing on latest research and local experience, and in consultation with a range of partners drawn from the statutory, voluntary and community sectors with the active engagement of health promotion specialists. In all 11 workshops were held in eight locations around Northern Ireland attended by over 100 parents. Parental perceptions and experiences were obtained through written questionnaires completed before the workshops, in the closing session and after three months had elapsed. In addition group interviews were conducted with workshop tutors and members of the Project Steering Group.

Prior to the workshops, many of the themes reported in the published literature were echoed in parents' responses. But given that these were a self-selected and interested group of parents, their views may not be representative of the wider parent population. In which case it is likely that many more parents have little knowledge about their children's sexual awareness and they are unlikely to have discussed these issues with them.

Participants held clear expectations about the content of the workshops and how they could be put at ease when dealing with sensitive topics such as sexuality. This information proved valuable in preparing for the workshops but parental comments and reactions during the workshops also helped to fine-tune their delivery over the various presentations.

The workshops were rated very positively by the participants, especially the way they were facilitated by the trainers. Their style of tutoring and the relationship they build with the participants is probably crucial on training courses in this topic.

A low response was obtained to the post course questionnaire which may indicate that most participants had not as yet put their new learning into practice. This would be particularly true of those parents who preferred to wait until their child raised the issue rather than engage in any proactive teaching. However it is possible that many parents would require some form of ongoing support and advice in order for them to implement their learning in both informal and more formal contexts.

AutismNI are to be commended for taking a lead in this area. From the knowledge base they have accrued, they are well positioned to further advocate for creative strategies to address the sexual health and relationship needs of young people with ASD in Northern Ireland and elsewhere. A series of recommendations are proposed around the themes of training for parents; the provision of RSE to young people with ASD beyond the family, and the need to develop a coordinated, regional RSE strategy across the various sectors. This report and its recommendations might be referred to the *Regional Sexual Health Promotion Network* to assist with their review and refinement of the current *DHSSPS Sexual Health Promotion Strategy* for Northern Ireland and the future planning for its implementation with other young people with specific needs.

Introduction

Overview of Autism Spectrum Disorders

Autism Spectrum Disorders (ASD) are now among the most commonly diagnosed developmental disabilities after general learning difficulties/disabilities. Children with ASD usually show deficits in three areas: communication, social relationships and rigidity of thought and behaviour although the extent of their difficulties (from mild to severe) and the combination of them can vary greatly hence the use of the word 'spectrum'. ASD can also occur in association with other disabilities, notably learning disabilities and epilepsy. Children and young people with ASD are also at a greater risk of developing mental health problems.

The numbers of children diagnosed with ASD or who are deemed to benefit from Autism are rising in Northern Ireland mainly due to earlier assessment within health and education services. In particular there will be a marked rise in the numbers within secondary education up until 2014 and possibly beyond (McConkey, 2010). Applying current prevalence rates to the latest estimates of the school-age population, around 6,000 are within primary education (ages 4 to 11) and 3,000 in compulsory secondary education (ages 12 to 16 inclusive).

Issues around Sexuality and ASD

As yet few studies internationally have examined the transition to adulthood for children with ASD. Instead the focus has been on early diagnosis and intervention in the preschool and early school years. Hence the topic of sexual health and wellbeing has received scant attention. Nonetheless there are indications from the research that has been conducted that young people with ASD face particular challenges in the area of relationships and sexuality. Hendricks and Wehman (2009) reviewed studies conducted mostly in the USA as did a Research Bulletin produced by the Centre for Autism (Undated). These reviews concluded:

- There is no lack of sexual interest in young people with ASD and sexuality education should begin early, especially in those with significant cognitive impairment. Sexual expression, such as masturbation, is commonly found among boys and girls although romantic relationships are much less common.
- Their rate of psychological and social maturity may not keep pace with their physical maturation.
- They possess less knowledge about romantic relationships and sexual behaviours than typically developing peers, due largely to limited access to available and appropriate educational resources and the lack of a peer group.
- The prevalence of friendships and participation in social groups is low for these individuals irrespective of where they are on the spectrum. During adolescence, the social gap between individuals with ASD and typically developing peers often widens.
- Adolescents with ASD report wanting friends and intimate relations but most lack the necessary social understanding and skills to make this happen.
- They fail to comprehend social stimuli, social rules, and to interpret the feelings that are intrinsic to social interactions. This leaves them open to bullying and sexual exploitation as they may fail to read the danger signs and misinterpret other people's intentions.

The issue of friendships is a recurring theme. Beresford et al. (2007) interviewed 25 families whose children with ASD were aged 3 to 19 years. All parents felt that participation

in everyday activities and exposure to the social interactions of non-disabled children were essential to social learning. However, a lack of social skills was often a barrier to participation coupled with a lack of contact with classmates out of school and few opportunities to take part in social activities with local children. Similar results emerged from in a study of transitions for young people with ASD in Northern Ireland. Both parents and professionals stressed the need for young people to be supported in making and sustaining friendships and various practical means were identified for doing this (McConkey, 2010).

There is a general consensus that relationships and sexuality education (RSE) needs to be adapted to meet the particular needs of young people with ASD.

Adaptations to RSE for young people with ASD

Various authors have identified key adaptations to the style and content of RSE provided to children and young people with ASD (see review by Sullivan & Caterino, 2008).

- The content should address three main themes: the prevention of sexual exploitation and victimization, instruction in healthy sexual behaviors, and the implementation of techniques to increase self-esteem.
- Understanding the sexual behaviour of other people should be a key feature.
- Instruction should be concrete, specific, brief and repetitive.
- Imitation and role play should be incorporated and instruction should take place in naturalistic settings.
- Desired outcomes should be reinforced and inappropriate behaviors should be immediately addressed whether through redirection, differential reinforcement, or other behavioral interventions.
- Both the curriculum and instructional techniques, needs to be individualized and developmentally appropriate and must take into account the strengths, limitations, and needs of the individual.
- The curriculum should provide a comprehensive approach and encompass topics such as: body parts and function; physical maturation; personal hygiene and self-care; health; appropriate social and sexual behavior; privacy issues; understanding emotions and impulses; self-image; abuse prevention; assertiveness; attraction; and interpersonal relationships.
- A 'building block' approach could be used so that sections of the curriculum can be used depending on the development of the individual child. For example it may only be appropriate and necessary to cover basic topics such as body parts, personal hygiene, and modifying inappropriate sexual behaviours with severely impaired individuals, while higher functioning individuals may receive more extensive instruction in specific social skills and relationship development.
- Sexuality needs to be embedded within the young person's social environment (e.g., friendships), so it is essential that sexuality education has a strong social skills component, and that concepts related to sexuality (e.g., where to be naked) are not taught in isolation from their social context (e.g., *why* you can be naked in some places and not others).
- Issues of gender identity and sexual orientation may also need to be addressed.

A dominant message is that RSE must be individualized and developmentally appropriate to the young person. It needs to take into account their particular strengths, limitations, and

needs. Moreover the social deficits that are characteristic of these adolescents mean that they do not gain an understanding of social rules through the informal process of socialisation as do most teens and adults. Instead, morals and expectations must be explicitly taught to these students.

The latter point raises the potential for a conflict between what professionals such as teachers may perceive to be the needs of the child and the values and beliefs of their family. Hence the involvement of families in RSE is critical to its effectiveness.

Involvement of Families in RSE

The rationale for the involvement of families is clear (see Nichols & Blakeley-Smith, 2010; Travers & Tincani, 2010).

- It is generally accepted that sexuality needs to be taught within the context of human relationships and that parents are the most important and best sex educators for their children through demonstrating and modelling appropriate relationships within the home .
- Parents are responsible for explaining their moral standards to their children.
- They are more likely to know their child's particular needs than professionals and, as a result, are better equipped to teach their child about sexuality.
- The primary source of sexual and romantic knowledge for most young people with ASD was their parents.

Understandably, parents of children with ASDs may be apprehensive about teaching related to sexuality or are unsure how to respond to their child's emerging sexual behaviours, particularly if the child is engaging in inappropriate behaviours (e.g., violating boundaries). Various reasons have been proposed for this reluctance based on parental surveys and consultations. Thoughtful responses are needed to overcome the following:

- Parents expressed many uncertainties including not knowing what their child understands, being unsure of how much information to give their child or how long to wait until discussing particular topics, and what strategies to use for teaching.
- Although motivated to teach their child, they lacked knowledge, skills, and resources to do so independently.
- Parents have limited training to teach about sexuality and few opportunities to access training.
- Parents were concerned that not enough professionals working in the field of ASDs could provide the assistance they required in relation to sexuality and were reluctant to embark on this topic on their own.
- Sexuality may be a particularly sore topic for parents of adolescents with autism or other developmental disabilities because they perceive sexuality to be an extra burden for their child, and because they view their child to be asexual or unable to make independent decisions about sexuality
- Parents may prefer sexuality education to be the school's responsibility or they may ignore the issue of sexuality altogether.

Very few examples are available of training courses that have been developed for parents and to date the numbers participating in them have been small (around 10) – see Nichols & Blakeley-Smith (2010). The content and style of presentation were guided by the recommendations noted in the previous section. The main gains reported by parents who participated were:

- Being able to hear other parents' experiences and the strategies they were using with their children;
- The group problem-solving with one another.
- Acquiring information and materials that they would be able to use once group was over and that they could share with professionals involved with their child such as teachers.
- Receiving information from a professional with knowledge and experience in the area who was comfortable with the issues and supportive.
- Feeling "heard" in that they were able to present situations during the group sessions and get helpful advice on how to handle them.

The Aims of the Project

The foregoing literature review (albeit updated to include recent papers) provided the rationale for the present project and the funding bid to the DHSSPS.

The aim of the project was:

"to improve and promote the sexual health and social well-being of young people with Autism in NI ... by providing them with specialist and Autism-specific training resources, advice and support".

This was further refined through consultations with professionals, parents and young people with ASD in that the aim would be achieved:

This would be done through the development, delivery and evaluation of education workshops to equip parents with the knowledge, skills and resources to provide relationships and sexuality education to their sons or daughter in a personalised way.

The move away from workshops aimed at the young people was based on a number of considerations.

- Families would need to be fully informed about the style and content of any workshops that would be provided in order for them to give fully informed consent for the participation of their son or daughter. Moreover their active support would be required to make any educational inputs fully effective. Hence informing and equipping families was a necessary first step and presented a major challenge in its own right.
- The practical constraints of organising group-based learning opportunities for young people became evident through a social skills training project undertaken by AutismNI (McConkey, 2009): notably travel to/from a central location and coping with the varying levels of functioning among the participants.
- Gaining ethical approval to work with groups of vulnerable children outside of the usual structures of education, health and social services presented additional challenges that were not easily resolved in the time available.
- Consultations with families highlighted their need for training and support in RSE (McConkey, 2007) as the basis on which further training could be developed for the young people. Also queries around sexuality and friendships were among the most frequent calls to the Helpline operated by AutismNI.

The further objectives of the project remained unchanged. These were:

To work in partnership with a variety of agencies

- *to provide ASD training to the relevant sexual Health Organisations in Northern Ireland;*
- *to help raise awareness of sexual health issues in other ASD organisations and training providers;*
- *to provide appropriate and accessible (i.e. ASD friendly) sexual health information and support.*

Policy and Legal Context

The project was conceived as a response to various policy and legal requirements. These included:

- **United Nations Convention on Rights of the Child (1990)** various articles cover a child's rights to education, protection from sexual exploitation and support to families.
- **Disability Discrimination (Northern Ireland) Order (2006)** which was extended to include persons with social and communication difficulties.
- **Investing for Health (DHSSPS, 2004)** in that it furthers equality of opportunity and tackles social inclusion of a marginalised group of young people and families.
- **Sexual Health Promotion: Strategy and Action Plan (DHSSPS, 2008)** in particular Action 8 which is to further develop community based programmes and courses in parent/child communication.
- **Strategies for ASD produced by the former Health and Social Service Boards** for example the WHSSB document Spectrum for Change (2007) has as a key recommendation around the promotion of health and wellbeing in which sexuality is a key topic.
- **Autism: Guide for Parents. Health and Social Care Board (2011).** The recently published guide acknowledges that contribution that parents can make to RSE although offers no advice as to how they can be supported to in this role.

Finally this report focuses on the main work undertaken by the project, namely the development and evaluation of the training workshops for parents. However project staff have made various other contributions including:

- Raising awareness to the Autism NI support network and membership.
- Involving statutory personnel during trainings to observe, liaise with parents/carers with a view to ongoing support.
- Professional training and specific ongoing support on Autism to various agencies such as Family Planning, YMCA, Brook clinic staff and Mencap
- Offered proposals regarding Autism to relevant agencies connected with supporting individuals with Autism.
- Autism NI are also partners with Bangor and Glasgow Universities; Scottish Autism; Ambitious about Autism (Formerly Treehouse); and Autism Cymru on a three year Project Advisory and Evaluation Group looking at Sexuality, Autism, Young people and families: Impact through research.

Note: This evaluation did not cover the managerial and financial aspects of the project as they are covered by the reporting arrangements provided by AutismNI to DHSSPS

The 'Growing Up' Workshops

Background considerations

In developing the parent workshops, AutismNI recruited a number of partners from across the statutory, voluntary and community sectors to help steer the project. The membership of the steering group is given in Appendix 1.

The overall vision for the project was summarised as follows.

AutismNI will work in partnership with a variety of agencies to:

- *Provide ASD awareness training to relevant sexual health and relationship agencies in Northern Ireland and in turn receive information, training and support from these specialist agencies.*
- *Provide training for parents and professionals regarding ASD and Health and sexual awareness in partnership with a range of agencies.*
- *Develop appropriate and user friendly resources and visual information for individuals with ASD.*

Moreover AutismNI developed its own policy statement with respect to ASD and Health and Sexual Awareness which was shared with all its partners and workshop participants.

"We all have to respect the rules and norms of society in relation to sexuality. In relation to sexuality it is important to recognise that in our efforts to support the individual with ASD with sexuality, it is crucial to make a clear distinction between our expectations, norms and ambitions and the persons with Autism individual style. Individuals with Autism should have the right and possibility of having a relationship in accordance with their needs and understanding. They have the right to receive guidance and support. Information regarding Sexual Health requires a positive and respectful approach from a range of agencies to give the best possible advice on sexual health matters and taking into consideration local policies and guiding legislation."

Following consultation meetings with parents and young people with ASD, five preliminary one-day workshops were undertaken in April-June 2009 in Ballymena, L'Derry, Belfast, Newtownards and Newry. These were attended by 59 participants. Based on these experiences the workshops were redesigned and presented over two days.

Aims of the workshops

The overall aim was to enhance knowledge for parents about Autism Spectrum Disorder and explore a range of intervention strategies to improve, protect and promote the sexual health and welling of individuals with Autism and to facilitate equitable access to sexual health services.

More specifically the workshop objectives were to:

- Explore how Autism manifests in the young adult with Autism and what difficulties there may be in relation to sexual health and well being
- Consider how sexual health awareness is impacted by the language ability, social functioning level, behaviour and emotional maturity of the individual with Autism.
- Be able to identify strategies that may be effective in supporting individuals with Autism to have access to information that is user friendly
- Gain knowledge about a range of resources and services available from specialists in the area of sexual health.

- Receive training which considers core skills, attitudes, values, communication skills, relationships, cultural differences and the characteristics of Autism.

Content of the workshops

A number of considerations guided the content of the workshops and their style of delivery.

- The overall theme adopted was that of ‘Growing Up with ASD’ so that families would realise that it was not solely focussed on sex education.
- Parental attitudes and beliefs need to be explored and respected through discussion.
- Parents should be supported to develop appropriate resources for use at home with their children and opportunities to see how various tools could be used.
- Teaching tools used with the young people need based around visual teaching strategies.
- Parents should be encouraged to share experiences with one another.
- Parents need to be taken through a process of building blocks in relation to sexual health and well-being so that they can start at the level most suited to their child: for example starting with body awareness self-esteem, life skills and so forth.
- Education around sexuality needs to start early, be maintained and adapted according to the young person’s development and understanding.
- Young people with autism, irrespective of the level of cognitive impairment, should be encouraged to become more independent.
- Social relationships would be a recurring theme.

The programme is outlined in Table 3.

Table 3: Content of the sessions over the two days

Day One	Content/topic
1.	Overview of workshop content: Group Agreement; Practical Exercises; Review of Handouts; Range of portfolio resources
2.	Values and attitudes to sexuality: myths; facts; issues subsumed under term ‘sexual health’
3.	Adaptations needed because of ASD: Impact of triad of impairments; social communication; presenting information – visual strategies
4.	Self-esteem: Components; development of self-esteem
5.	Social Skills: difficulties encountered; teaching methods,
Day Two	
6.	Body Awareness: Life cycle; Names for body parts; physical changes at puberty; emotional changes; use of language
7.	Personal Hygiene: Daily routines; importance for adolescents and adults; use of visual cues; menstruation; encouraging independence.
8.	Relationships: value of relationships; identity;
9.	Sexual health: sexual development; adolescence; cognitive development; social and emotional development; masturbation.
10.	Personal Safety: Saying No; modesty, keeping safe; stranger danger; alert card’ checklists for children and for adults

The workshop was tutored by two experienced trainers from AutismNI. The main teaching methods were:

- Power point presentation
- Small group work tasks
- Case studies
- Practical design of activities
- Large group discussion/flipchart
- Quiz

In addition participants received a large ring-binder which contained a variety of resources including all the worksheets and practical exercises used during the workshops; a compendium of useful books, educational resources and web sites of organisations; and samples of line drawings that could be used as teaching aids at home.

Presentation of the workshops

The workshops were publicised through local schools and the Autism Advisory Teams of the Education and Library Boards as well as through the AutismNI mailing lists of parents and professionals. No charge was made for attendance as all expenses including room hire and refreshments were covered by the project. Seven additional workshops held during 2011 were also included in the evaluation with funding obtained from the Belfast HSC trust and the Health Promotion sections of the Southern and Northern HSC Trusts.

Participants had to book places in advance and the numbers attending any one workshop were capped at 15. Table 4 summarises the location and numbers attending each workshop. In certain workshops people who had previously booked places did not attend due to family illness for example. However it was too late to re-allocate their place.

Table 4: The dates, locations of the workshops held.

Dates	Location	Number attended	Feedback forms completed
25 & 26 May 2010	L'Derry	7	5
1 & 2 June 2010	Belfast	12	11
14 & 15 Sept 2010	Ballymena	5	5
22 & 23 Sept 2010	Craigavon	6	6
16 & 17 Feb 2011	Coleraine	16	13
15 & 16 March 2011	Dungannon	6	5
21 & 22 March 2011	Newtownabbey	14	13
23 & 24 March 2011	Craigavon	10	8
29 & 30 March 2011	Newry	10	9
3 & 4 May 2011	Belfast	4	4
17 & 18 May 2011	Belfast	13	12
Totals		103	91

The Evaluation of the Workshops

As resources for the evaluation were limited, most of the information was collected from self-completion questionnaires posted to the participant's homes by AutismNI so that their personal details were not known to the evaluator (Copies are available on request). The questionnaires were returned in a Freepost envelope directly to the University so that AutismNI were unaware of the persons who had responded. Again no personal identifiers were requested.

The pre-workshop questionnaire was sent to all persons who registered for the workshop at least one week prior to its presentation. It was also distributed on the first day of the course. Completed questionnaires were received from around one-third of attenders.

The post-workshop questionnaire was sent three months after the workshop so that any halo effects from their attendance had dissipated and there would have been time for parents to implement some of the learning they had acquired through attending the workshops. AutismNI staff issued up to two reminders in order to boost responses but only 20% of attenders returned this questionnaire.

However confidentiality considerations meant that it was not possible to match parents' responses across the various questionnaires that were used.

In addition attendance records were kept and participants were requested to complete an evaluation sheet at the end of the workshop which nearly all did. Group interviews were also held with workshop tutors and members of the Project Steering Group to gain an insight into their experiences and reflections on future practice.

An online questionnaire was also developed for the young people to complete either alone or with assistance so that we could ascertain their knowledge and understanding of sexual issues (see Appendix 1). Parents were asked to encourage their sons or daughters to take part in this survey. However we had only one response despite repeated reminders at the workshops. This may be indicative of parental reluctance to broach these issues directly or young people's reluctance to do so at their parents; request. Unfortunately we did not have the resources or means to explore this further but it is a vital topic for further research.

Formal ethical approval was not sought for this study as it was essentially an audit of services provided.

The findings from the evaluation are presented in four parts.

- Part 1 contains an account of parental expectations of the workshops derived from their responses to the self-completed questionnaire completed by course participants prior to attending the workshops. Information was also obtained about their past experience of sexual health issues with their son or daughter.
- Part 2 gives participants' reactions to the workshops obtained from the comment sheet distributed at the end of the workshop.
- Part 3 details participants' feedback obtained three months after attending the workshops from self-completed questionnaires.
- Part 4 summarises the experiences of the workshop tutors and members of the Steering group involved in Health Promotion activities.

Findings Part 1: Expectations of the Workshop

As this was a training course, it was important for the presenters to develop it in line with the participants' expectations and current level of experience of undertaking sexual health promotion with their son or daughter. This information would be further supplemented with participants' reactions during the workshops and in the evaluation sheets they completed afterwards. However the pre-course information would also enable a contrast to be made with reactions after the workshop.

Parents

In, 37 responses were received to the pre-course questionnaire. Most were mothers of a child with ASD (95%) but two fathers also responded (5%). The majority were aged 40-49 years (59%) with 27% aged 30 -39 and 14% aged 50 plus. Two-thirds of parents (68%) had taken A Levels or Higher Education; 27% had GCSEs or O levels and 5% had left school at 15 years. Nearly half the respondents (47%) lived in areas that are among the 30% least deprived in Northern Ireland with only 9% living in the 30% most deprived. Seven parents (19%) had previously taken a course relating to relationships and sexuality but most (81%) had not.

Children with ASD

Two of the 37 parents had two children with ASD. Three quarters of the parents had a son (76%) and 24% had a daughter. Their ages ranged from 6 to 29 years with an average of 12 years and all but one aged 18 and under. Around half were attending or had attended a mainstream secondary school; 37% a special school and 11% a special unit. One young person was in part-time paid employment. Around half were reported to have no friends (53%); 38% had one or two friends and only 9% had three or more friends. One of the 37 young people was reported to have a boyfriend/girlfriend.

Parents' Experiences of Sexual Health Issues

Information was obtained from parents about the perceptions of their child's understanding of sexual matters; their experiences of talking about these matters and the other sources of information available to their son or daughter or which they would like to see available; and the difficulties children with ASD face in relation to sexual health.

Views on the young people's knowledge

Parents were asked to rate their son or daughters about the topics listed below. (Note: These questions were introduced for later workshops and replies were received from 24 parents.) In Table 5, the items have been regrouped according to parent's perceptions of their knowledge of the topics listed. Overall these indicate low levels of understanding among the young people of issues relating to sexuality. However older children (13 years and over) were rated as knowing more of the items listed than were those aged 12 and under ($p < 0.05$). However there were no significant differences by gender, school attended or the number of friends that the young person had.

Past experiences

Around half the parents (53%) reported that had spoken to their son or daughter about sexual health matters whereas half had not. This was much more likely to occur when the children were aged 13 years and over. Together these covered the full range of issues such as body differences, periods, masturbation, sexual intercourse, childbirth and safe sex.

Table 5: The percentage of parents rating their son or daughters understanding of issues relating to sexuality. (N=24)

	Yes	Some	No	Don't Know
Names of private parts of male and female bodies	33%	33%	25%	8%
Sexual intercourse – how babies are made	17%	22%	44%	17%
Changes in male and female bodies during adolescence	9%	70%	22%	-
Personal hygiene - menstruation	9%	14%	73%	5%
Appropriate and inappropriate touching of people	9%	2%	30%	9%
Protecting themselves from unwanted advances or accusations.	4%	9%	83%	4%
Contraceptives – how to use and where to get them	4%	-	78%	17%
Appropriate and inappropriate ways of talking to people	-	44%	48%	9%
Masturbation	-	22%	52%	26%
The laws in relation to sexual behaviours	-	4%	83%	13%
Coping with fears of rejection	-	4%	83%	13%
Dating – forming relationships	-	3%	78%	9%
Coping with misunderstandings and breakups among friends	-	-	87%	13%

The main adaptations they reported making for their child's ASD were in relation to using simple language, repetition and using visual illustrations.

Kept it quiet, informal and basic as he can get very anxious re changes (6).

Plain language and simple illustrations if possible (9).

Also some of the young people raised the topics themselves or made it easier for the parents to talk about it.

My son doesn't feel embarrassed in talking about these which helps me to feel less embarrassed. To him it's like talking about a car engine! (29).

He will tell me when he has a wet dream or has sexual dreams (6).

He doesn't feel embarrassed at all which is itself a problem (19)

Overall though, half the parents rated themselves as only 'somewhat confident' in communicating with their son or daughter about sexual health and wellbeing. This was true whether or not they had already talked to the children. Just under a third (29%) rated themselves as 'not confident' (proportionately more of whom had no experience of doing it. Only 7 parents (20%) rated themselves as 'confident' or 'very confident'. However even these parents mentioned similar concerns that other parents had raised; examples are given below.

I don't have a difficulty approaching the subject but I need to know timing (3).

Can talk about anything, it's whether he understands it or not (7).

It has been an open subject for a long time, albeit in cloaked language. I answer every question asked though sometimes "when you are older it will be easier to explain". I leave out the details they don't need to know until they do it for themselves (14).

I want her to not be afraid and to know exactly everything, however, I do feel I would need to know she was at the right age to understand fully s this could lead to more anxiety (17).

When parents were asked to name other supports outside of the family that the young person had accessed in relation to sexual health and relationships, less than two in five had done so – the majority had not (62%). Schools were the most common source mentioned

by 10 families and three mentioned a disability specialist such as a behavioural psychologist or personnel from the Autism Advisory Service. One young person had been in contact with the Family Planning Service. However several parents expressed reservations about the input received from schools.

School covered biology of sex etc but not the social side of sexual relationships and friendships or body changes in a way appropriate for my son to find relevant (19)

I thought school would cover some aspects and did ask but it was just male/female reproduction through science i.e. each life cycle (6)

Sex education will soon be taught in school but as far as I am aware he would not speak to anyone directly about sexual relations, to a teacher for example (22)

Anticipated responses of the child

Parents were asked to rate their child's willing to talk with them about sexual health matters using a four point scale from 'Yes – most of the time' to 'Not at all'. The most common response was 'maybe' (39%) followed by 'most of the time' (22%); 'some of the time' (17%) and 'not at all' (14%). However those who also reported having spoken about these issues were more likely to report that a willingness on their child's part.

The reasons given for their child's willingness to talk included:

Our relationship is open and we discuss things as openly as possible so they should not have any issues (3)

It has never been hidden away. The subject is treated as any other (14)

By contrast reasons for the young person perhaps not wanting to talk were:

Not been approached before so not sure of reaction (2)

Due to very limited speech expression of such issues would be difficult (4)

I'm not comfortable (8)

When I did approach the topic, my child was reluctant to talk (32).

Nonetheless parents reported a range of ways they thought would assist young people to become more knowledgeable and confident. The most favoured was through talking together and discussion followed by the use of pictorial materials and DVDs. Other approaches included adjusting the information to the child's level of understanding, the provision of workshops for them and the use of social stories.

To sit down and find out what they know, make them feel they can talk to you about anything, watch something on TV and then casually bring up the subject (29)

Talking to them or perhaps a DVD which could help explain things and show them how they should behave (36)

Giving them the appropriate level of information for their individual level of understanding; Making it an easy subject for them to discuss with me (20).

Training courses, workshops pitched at an appropriate level; appropriate information leaflets in correct format (23).

Social stories i.e. letting them know a person they trust is available and happy to discuss anything they have questions about (3)

Parents were asked to identify what they felt were the greatest difficulties that their son or daughter faced in relation to sexuality and relationships. Nearly all the responses focussed on behaviours and emotions of which the most common were around inappropriate behaviours, vulnerability (especially for those with daughters) and making friends.

Has sexual attraction towards people and is unable to deal with their rejection, becomes obsessive about that person (1)

Understanding social boundaries, forming relationships, coping with rejection, protecting themselves from unwanted advances (32)

Being taken advantage of; being too trusting; not understanding dangerous situations (17)

His innocence and immaturity are of major difficulty in relation to sexuality and relationships (5)

Making friends in the first place. She feels she will never meet a boy but holds on to the idea of being married and having children because she will be an adult some day and needs a future to look to and dream of (14)

Others mentioned the lack of opportunities available to their children and communication problems.

Opportunities in the first place and then lack of opportunity to ask friends for advice or their experience etc. Massive ask for him to even talk to a girl (19)

Having limited speech, communication and social skills but normal physical and possibly sexual development would provide biggest challenge (4)

When asked to name the supports outside the family that they would like to have available, the most frequently mentioned were opportunities for young people to mix socially and to support one another.

Supervised clubs for teenagers and young people to mix and make friends (12)

Support groups with people of a similar age both physically and mentally (28)

Opportunities to mix socially with other young people-youth club, discos etc-other young people with special needs (1)

Peer support from kids with Asperger's (15)

Others noted having a person who could advise the young people on an individual basis.

Someone well trained in ASD who could befriend or be available to them to help explain unanswered questions e.g. where did I go wrong in this situation etc-if they did not want to go to me (3)

Social worker, nurse (13)

However sizeable numbers of parents were unable to provide any suggestions (39%).

Concluding comments

Many of themes reported in the published literature reviewed in the Introduction were echoed in parents' responses. But given that these were self-selected and interested group of parents, their views may be not be representative of the wider parent population. In that case it is likely that many more parents have little knowledge about their children's sexual awareness and they are unlikely to discuss these issues with them. However they may well share the same concerns expressed by this sample of respondents.

Parental Reasons for Attending the Workshops

A second part of the pre-workshop questionnaire enquired about parents expectations in relation to the forthcoming workshop. They were asked to list up to three reasons for attending the workshops. Their responses were summarised as shown in Table 6 with sample quotations to illustrate the theme identified.

When asked about new information they would like to gain in relation to sexual understanding and wellbeing, the most common comment from 11 parents was in relation to knowing the best way to approach the topic and to talk to their children about it.

How to explain these topics clearly and in a way he can manage and understand (1)

I would like to have confidence in what I was telling my son-when I talk to him now I don't know if I'm right or wrong (33)

Table 6: The main reasons parents gave for attending the workshops (N=37)

Theme	Quotation	Number mentioning
Coping with puberty	23. My daughter is 12 years old and going through puberty; advice re dealing with periods when they start; help and advice relating to growing up when the child has severe learning difficulties.	13
Knowledge and confidence	37. To help equip me with knowledge, understanding, confidence	13
Techniques, approaches to use	28. To learn how to deal with and answer awkward questions from my autistic son	8
Meeting other parents	25. Hear other person's experiences, learn of the most common difficulties encountered, learn of suggestions/options for overcoming these difficulties	7
Managing inappropriate behaviours	17. To know what sort of language to use with our children and to help them know what is appropriate and what is not	5
Understanding the young person's better	1. Understand my son better; enabling me to help him	5
Getting new information	11. Update on any new information available	2

Some commented on the need for suitable materials.

Guidance and tips on how to make sure all bases are understood and materials to use to help cover subjects without patronising my son (19)

Others were keen to try and understand what these topics mean for a child with ASD.

I want to be able to understand what a child with Asperger's feels about sex and puberty compared to a child who has not and how to deal with it should the situation arise (22).

A few mentioned specific topics they hoped would be covered – STIs, contraception and personal hygiene whereas others raised the need to keep the young person safe.

How to discuss this topic and when; to protect our child from being taken advantage of by giving her the knowledge and taking away her vulnerability (17).

Parents were also asked about the information they would like to have around friendships and relationships. The two themes that were most often mentioned related to how the young people can be encouraged to make and sustain friendships and how their social skills could be improved.

Try to encourage my child to make friends, be more assertive and outgoing (16).

As I have a child with Asperger's I know that it is difficult for him to form friendships and maintain them and I would like to learn how to talk about relationships so that I can prepare him for the future (22).

To help teach my child not to be taken advantage of in a relationship, not to be "used" or to be too trusting; to teach her to defend herself and also know what is appropriate in a friendship/relationship; to give her tools and skills to deal with different situations (17).

Parents mentioned to need to ensure that the young people distinguished between friendships and relationships. Other parents welcomed the opportunity to learn from others experiences.

Meeting others in the same situation will make me feel a little less isolated (26).

Style of workshops

The parents were asked to name things that would make them feel more at ease when it comes to the topic of sexuality. Although a proportion felt they would have no difficulties other made useful suggestions such as:

Just to be open and frank as any embarrassment needs to be overcome so our relatives can gain proper knowledge of all topics (2).

Honest and practical not rude (10).

Good sense of humour/fun, I think is always the best way to put people at ease (18).

Others emphasised the need for straight talking.

Talk about the subject in a professional and scientific manner (4).

Talk in a clear understandable manner, not too medical terms (6).

Talk to one straight using proper terminology (14).

A few people made specific comments about how the workshops might be conducted, such as:

Make it a group discussion so everyone is in the same situation (9).

Perhaps no direct questions but rather voluntary answers (17).

Don't put me on the spot (28).

After the workshops

Finally, parents were asked what they would like to be able to do to help their son or daughter after attending the workshops. The dominant theme was being equipped to talk and discuss issues.

I would like to be able to talk about these matters with my son without making him feel uncomfortable and to be able to explain things to him in a way he understands (22).

Know how to answer difficult questions in a way that they will understand (28).

Some spoke of needing to become more confident.

Feel confident in broaching the subject at first-knowing how to tell them; knowing where to get external help if it is needed; having appropriate literature etc (20).

Others focussed on particular topics or techniques they might use.

Make a list of topics to cover and ensure that all are fully covered (19).

Tell them a social story or stories around this issue but still keeping it non-specific, if you know what I mean (14).

A few expressed doubts about whether they could cope.

We have already talked to him about growing up and sex but he doesn't want to talk to us. He comes out with inappropriate comments out in public to strangers, so help with this would be good (12)

As having ASD myself and needing help in these areas too. I don't know how I will help my teenager. I'm hoping the workshop will (34).

Concluding comments

Participants held clear expectations about the content of the workshops and the ways that would help put them at ease when dealing with sensitive topics such as sexuality. This information proved valuable in preparing for the workshops but parental comments also helped to fine-tune the delivery of the workshops over the various presentations.

Findings Part 2: Participants' reactions to the workshops

At the end of each workshop, participants were asked to anonymously complete a short questionnaire that gave their reactions to the workshop. Table 7 summarises the ratings given to particular aspects of the workshops (NB Ratings of poor, fair and average were combined into fair).

Table 7: Percentage of participants rating aspects of the workshops

	Fair	Good	Excellent
Trainer's communication with Group		8%	92%
Helpfulness of the training materials	1%	25%	74%
Relevance to young people you have contact with	3%	30%	67%
Workshop meeting expectations	4%	29%	67%
Participants getting on with one another		24%	66%
Rating for the venue	8%	30%	62%

These positive ratings were borne out in their written comments:

Course was very enjoyable, very relaxed approach, lots of practical information for use at home (L'Derry),

The group exercises were great – hearing other people's views on the subject (Belfast)

Fantastic file of information to refer to – great stuff! (Belfast).

We all gelled from Day one and felt comfortable about discussing very delicate subjects (Ballymena).

The frankness (Craigavon).

To realise to talk to children with ASD about this topic at an early age (Coleraine).

New tips - and I learnt not to assume an autistic person knows things (Dungannon).

A wealth of information which can be used at any level and not just for ASD (Newtownabbey).

Well researched and presented in lay mans terms. Thank you for keeping me sane! (Craigavon)

Making you think about how I was as a teenager and then how my son would cope with changes. (Newry).

This was a brilliant course – one of the best I have attended. Group was great. Tied everything together for me (Belfast).

Participants were asked to note anything they do not like or found unhelpful about the workshops. There were only 9 from 91 responses (10%) and the main issues included:

- Adjusting the content to the developmental level of the child
- Too much on autism and not enough on practical parenting strategies.
- Too much on sexuality and not enough on other issues relating to Autism that are more pressing (for this participant).
- More time.
- Bigger room to facilitate group work.

- Discouraging masturbation when religious beliefs are not in favour of it.
- More role play.

Suggestions for further training courses were also sought. This elicited a greater response although half did not offer any comment. Most suggestions were for further courses relating to Autism and Asperger's in general rather than sexual health issues. This included post-school provision, managing challenging behaviours (especially sibling rivalry and protecting siblings from abuse) and having courses for siblings and other relatives to make them more aware of ASD. The follow-on topics to sexual health proposed were:

- Having courses for young people with ASD
- Social skills courses for teenagers with ASD
- Friends and relationships
- Course for friends and relatives on sexual health in ASD.
- Course on other healthy issues such as substance abuse and mental health.

Concluding comments

The workshops were carefully developed and thoughtfully presented. They were presented in different locations across Northern Ireland and attracted a wide range of participants in terms of children's ages and level of functioning although in some locations parents did not attend despite having booked a place. Nonetheless the workshops were rated very positively by the participants, especially the trainers. Their style of tutoring and the relationship they build with the participants is crucial on training courses in this topic.

Findings Part 3: Reactions from parents after the workshops

Three months after the workshop ended, parents were sent a self-completion questionnaire which they could return in a Freepost envelope to the University. Despite two reminders from AutismNI staff, only 16 parents completed the post-workshop questionnaire which is less than 20% of those who attended. As their replies were given anonymously it was not possible to link the questionnaires to workshops attended or to the pre-course questionnaires that had been completed.

Responses came only from mothers; half of whom were aged 40-49 years and 44% were aged 30-39 years and only one (6%) was aged 50 years and over. Half had also taken A levels or higher education with 42% completing O Levels and one (6%) completing school at 15 years. Six respondents (37.5%) lived in areas that are among the 30% least deprived in Northern Ireland but two (12%) lived in the 30% most deprived.

Learning from the workshops

Parents wrote positively about the workshops. For example:

The material was excellent, the company was good. The seminar inspired me to want to put together folders for my own children and other neurologically typical children also. (18)

The two aspects to the workshops that parents found most helpful was the folder of resources with which they were provided (six parents mentioned) and the opportunities to meet other parents (also mentioned by six parents).

The presentations, discussions and mostly the information pack (very comprehensive) that we were able to take home with us (25)

The material used in the workshop (folder) was excellent and very specific to puberty with children with ASD (14)

Knowing that I am not alone in my concerns about my child and being able to talk to other parents and sharing problems (16)

Talking to other mums and the leader about everything you were worried about (19)

Other helpful aspects were noted by other parents.

An understanding of how my child sees life/changes she's going through (13)

Most helpful was you adjust information provided to your own morals and showing me how to explain things to my son (26)

Learning how to approach the situation regarding growing up, puberty, moods, looking after themselves (27)

When asked specifically to name what they had learnt about sexual health, the more common responses related to the way parents might act:

That you have to be open and honest, try not to be embarrassed and use the correct words (27)

Learnt how to open discussion with basic visuals of boy/girl/dressed/naked pictures (12)

To be honest and open (13)

How vulnerable they are if I don't inform them first but wisdom plays such a key role (18)

(My son) has got a say - not just me (15)

Some had gained a better insight of the implications for children with ASD.

Just understanding how complex relationships can be for people with autism and their vulnerability (24)

The importance of the whole area of puberty- not just physical changes but also social/mental well-being issues which are so important (25)

Did not realise change could affect someone with autism so drastically (26)

Others mentioned new information they had gained.

Thing about boys which mums don't know (19)

Few new words I had never heard of but may be heard by my children (11)

Parents were also asked if their attitudes and perceptions about sex had changed and most cited various ways in which the workshop had influenced them.

Initially I was worried about my child going through puberty and felt in the dark but the workshop has given me more confidence when facing the future regarding puberty (14)

Things are not black and white and I had to question my values i.e. masturbation (21)

I have more knowledge and feel better equipped when it comes to talking to my children about this. I feel more understanding and confident (25)

I always knew that my child would have to be treated differently and realise that explaining relationships and sexuality has to be simple but informative (16)

As a mum I'm not as anxious (17)

They credited the tutors as creating a comfortable atmosphere in which they could openly discuss sensitive issues.

They were very approachable and down to earth. Made us feel at ease by their personalities. Added some humour too. We were all parents in the same situation (25)

They approached the topic in a fun. Easy to comprehend way, in a relaxed informal manner (12)

Told us to pretend that we were having coffee together in a comfortable place and to forget they were there (22)

They showed us how to reply to awkward questions and emphasise the need for appropriate behaviour in relationships (16)

Confidentiality was stressed all the time and it was an intimate workshop (14)

Only two suggestions for improving the workshops were made: that it might have been for longer and also

I feel that more time was needed or have two talks i.e. for those who are high functioning as opposed to those who have little communication (23)

Various topics were noted for further courses such as:

Maybe something more about their emotional relationships and dealing with behaviours (14)

What to do about internet-how to handle it without banning them completely from the internet (20)

I would like to have help in explaining contraception, pregnancy, STI (16)

Forming relationships with higher functioning autistic kids (21)

When asked how confident they rated themselves in communicating with their son or daughter about sexual health and wellbeing 25% rated themselves as very confident, 37.5% as confident and 37.5% as somewhat confident. These are indicative of higher confidence levels than in the pre-workshop questionnaire. The reasons for increased confidence were given as:

I feel I now have good resources/visual to use (11)

I have the knowledge I need and also strategies and lots of useful information, visuals etc (25)

More understanding on just getting straight (26)

The workshop has given me the confidence to deal with sexual health even with a typical child (26)

Using the knowledge after the workshops

Of the sixteen parents, 10 (62.5%) stated that they had brought the learning into practice. These were the topics that had been covered: body part names, contraception, pregnancy, masturbation, hygiene, body changes and sexual contact. The main reasons for not speaking about these topics in the family was that their child was considered too young.

Parents reported using a range of adaptations when speaking with their child:

Used visual handouts in file- they were super (11)

Used simple language-try not to frighten them and reassure them (16)

Kept it brief, used some of the handouts (17)

I used games in the talking of it (22)

Told them that if they wanted to (masturbate) t, it was OK but only in private and in the bedroom (23)

Trying to teach my son about covering up now he is getting older (26)

Moreover some had shared the approach with other family members.

I've told siblings and relations of child to expect these kinds of questions and how to deal with them (16)

I'm making up individual folders for each of the children and for me for quick referral to these matters (22)

When asked about the supports outside of the family that could benefit their child, the responses included these ideas:

A buddy system would help explain one on one as and when different scenarios come about (12)

I do have support from the Learning and Disability Team regarding puberty for my eldest daughter (27)

Availability of nurse/counsellor to talk to if they need help (25)

Maybe more support from school because I don't know if professionals in education have access to this type of training? (14)

Concluding comments

Although the proportion of parents was small who provided this more reflective feedback, it is likely that it captures the types of main themes common to all attenders even if they as a group are not wholly representative of those who took the course and still less of all parents in the region.

The poor response from other parents may reflect that they had not as yet put their new learning into practice and thus felt unable to answer the questions. Certainly this could be true of those parents who preferred to wait until their child raised the issue rather than engage in any proactive teaching. This would also explain the poor response that we had to young people completing the on-line questionnaire that we expected parents to introduce to their son or daughter.

However it is possible that parents would require some form of ongoing support and advice in order for them to implement their learning in both informal and more formal contexts. Given the many demands on parents in a busy family life, it is inevitable that certain issues get overlooked if they present no major problems.

Findings Part 4: Experiences of workshop tutors and advisors

The evaluator met with the two main tutors of the workshops and then together with personnel from the Steering Group with responsibilities for health promotion activities in their respective HSC Trusts.

From the tutors' perspective the elements they felt contributed to the success of the workshops were:

- *The sessions were very structured with full use of visual aids. The use of line drawings rather than photographs were advocated as this avoided accusations of exposing children to pornography.*
- *The portfolio of resources that parents could take away and use at home. Although this took a great deal of time to assemble and entailed high photocopying costs, it was an invaluable resource during the workshops as well as a continuing reference book for parents.*
- *The provision of worksheets and small group work encouraged active participation from everyone as it meant that shy parents did not have to speak to the whole group.*
- *A wider range of topics were covered – not just sex education. This included self-esteem and relationships. Controversial issues were also included such as same sex relationships.*
- *Issues raised were reflected back to parents so that their experiences could be drawn upon – we did not have all the answers!*
- *Polarisation was avoided in responses to difficult issues – instead reflection and discussion were encouraged.*
- *Generated a good sense of fun*
- *The mix of people attending – by age, religious beliefs, ethnic background. Few knew each other prior to the workshop.*
- *Having two days kept atmosphere going and enthusiasm was maintained.*

The improvements they would like to make included:

- *Have more men attending – their presence did not stifle discussion.*
- *Restrict numbers to around eight in the group – this was more manageable even with two tutors. But smaller numbers – below six – should be avoided as it places too many demands on all parents to participate.*
- *Maybe have a third day although parents can find it difficult to come on two successive days.*
- *Need to adapt resources according to the level of the child.*
- *Be clear about the appropriate age/ability level that the workshop will cover.*

The workshops certainly confirmed for them the central role that parents can make to their child's sexual health and wellbeing.

- *Parents could instil their values*
- *They knew how best to tailor the information to their child's needs.*
- *They are well placed to respond to the child's questions and behaviours.*
- *They can provide education and support on an ongoing basis that extends from childhood through adolescence.*

However they did have reservations about parents continuing these responsibilities when their sons or daughters became adults. They also appreciated the balance that needed to be drawn so that the young people could have privacy and become more independent.

In terms of follow-up to these workshops, a number of proposals were made:

- *Having a call-back day for the groups to provide further learning opportunities for parents and reflections on their experiences as they implemented the approaches.*
- *Encouraging parents to form their own mutual support groups.*
- *Organise individual consultation (clinic) session to provide more tailored advice and guidance to the parents and/or the young people.*
- *Provide training for trainers so that others could use the approach and materials and thereby reach many more parents in Northern Ireland and elsewhere. However it would not be possible to sell the resource portfolio that had been assembled until copyright clearance had been received for certain resources included in the portfolio.*
- *Organising workshops for young people and adapting the content and resource materials to suit their needs with a greater focus on acquiring social skills*

Members from the Steering Group also made a number of additional suggestions.

- *The provision of a one-day training course for professionals who are involved with parents to guide them in this area. A presentation should be made to Education Boards to alert them to the work that has been done by AutismNI.*
- *It is likely that professionals in Autism teams and teachers in school would benefit from having access to the portfolio of resources.*
- *Teachers would benefit from more extended training so that they can adapt the RSE they provide in special as well as mainstream schools.*
- *Trainee teachers should be made aware of the needs of pupils with ASD in relation to RSE.*

There were mixed views as to whether the ethos and methods of these courses for parents whose children have ASD could be incorporated into the mainstream sexual health courses offered to families. Their reservations centred around the expertise of tutors and the small number of parents with a child who had ASD attending at any one time.

Health promotion personnel also confirmed the difficulty they experienced in recruiting parents to attend workshops and commended AutismNI on the numbers they had recruited. The variation in attendance they had encountered across locations and the low uptake compared to the publicity that had been sent to families, were common to all health promotion initiatives targeted at parents. They felt that a focus on sexual health was an additional dis-incentive as parents often preferred to ignore this topic. Hence mainstream health promotion tried to be multi-faceted and to involve schools, health personnel as well as parents. There was also scope for the young people to come together in groups; perhaps through the Youth Service of Education Boards as well as schools. In addition they also recognised the need for specialist advice to be available to young people and families when they encountered particular issues that they could not easily resolve. Thus there is need for a co-ordinated multi-agency approach and no single player alone can address the range of issues that are likely to arise. However a number of barriers were noted:

- *There no policy or strategy document to drive forward this approach.*
- *The involvement of community learning disability nurses in RSE within special schools had been withdrawn.*
- *The low priority to RSE in many schools does not augur well for pupils who have special needs*

Conclusions and Recommendations

In the final section of the report the main conclusions arising from the development and evaluation of the training workshops are summarised. Various recommendations are made to guide further initiatives in Relationships and Sex Education (RSE) for children and young people with ASD within Northern Ireland. However many are applicable to other regions and much mutual learning could result from sharing experiences across countries on these islands as well as internationally. AutismNI is well placed to do this through the linkages it has formed with similar associations in the UK, Ireland and Europe.

Continuing advocacy for RSE and people with ASD

The project has successfully developed and tested a training workshop for parents on the topic of relations and sexual health promotion. In addition a valuable compilation of resources has been developed that would have wider applicability beyond parent education. AutismNI are to be commended for taking a lead in this area and from this knowledge base they are well positioned to further advocate for creative strategies to address the sexual health and relationship needs of young people with ASD in Northern Ireland and elsewhere.

Future action steps are detailed below but it is worth noting at the outset the need for some form of coordinating agency to bring together the disparate agencies that have an 'stake' in these endeavours: for example, in maintaining a database of educational resources, sharing insights from initiatives in education, health, the voluntary and community sectors and in planning and implementing new initiatives within the region. AutismNI would seem a suitable contender to take on such a role but would require the resources to make this happen.

Training for Parents

Parents valued attending the workshops which suggests that both the style and content of the workshops addressed their needs. Particular mention was made of the tutors which is a reminder that for workshops on these topics, the personal qualities of the tutor are critical alongside direct experience of providing RSE to children and young people with ASD. With this proviso, AutismNI should publicise the content and format of the workshop so that professionals in other countries could benefit from the learning that it contains. Making this report freely available through the AutismNI website would be a useful first step.

The resource portfolio produced by the project would also be of benefit outside of the training workshops. AutismNI should explore possible means for sharing the content of it. This portfolio could form the basis of a repository of resources that have proved useful to practitioners in Northern Ireland. However this will be required to be updated. Liaison with Health Promotion personnel in HSC Trusts and with the Public Health Agency could usefully identify ways of maintaining a directory of resources and of making the information available to parents and professionals.

The follow-up that was done to the workshops suggested that only a small proportion of parents had taken steps to actively engage with their son or daughter on the topics covered. Of course the limited time for follow-up could contribute to this low response and the workshops certainly do allow for parents to be better equipped to respond to the 'teachable moment' presented by the young people's by their asking questions or making comments relating to sexuality.

Nonetheless it is possible that parents may require extra support in order to actively promote the sexual health of their son or daughter. One option would be to organise the workshop over a period of weeks so that participants are expected to undertake activities at

home in periods between meetings. Similarly a series of 'call-back' meetings could be held of parents who have attended the workshops when they are presented over two days so that they can share experiences with one another and also receive further advice and guidance from the tutors and their peers. Individual consultation sessions by phone or in person might also be provided as part of the support package to parents presuming the organisation providing the workshops were resourced to offer this service. It could well be however, that a more promising approach to the provision of ongoing support to parents would be for this to be developed alongside RSE opportunities for young people with ASD; a point to which we will return.

A related point is the relatively low uptake by parents of places on these workshops despite them being organised across Northern Ireland to minimise travel times and at no cost to the participants. Indeed several of the workshops were under-subscribed. This raises three issues. First what more needs to be done to encourage parental recruitment? It is possible that the timing of the workshops did not suit working parents and a series of evening meetings might be better. Also recruitment might be boosted by more widespread publicity of the workshops (e.g. through presentations at Parent Teacher Association Meetings and at School Boards) and personalised invitations made to parents (e.g. in association with specialist Autism teams in schools). Greater use might be made in the publicity materials of parental advocacy as to the benefits for parents of attending the workshops. Indeed word-of-mouth recommendations might be especially effective.

The second issue is arguably more pertinent, how to overcome parental conservatism in addressing sexuality? Although not unique to Northern Ireland, parental reluctance may be accentuated here due to cultural practices and religious beliefs. Hence no amount of publicity per se will attract parents to attend workshops on this topic. This is borne out by the apparent ease with which AutismNI recruits parents to attend courses on other issues relating to Autism. Rather a broader question has to be asked: what will increase the willingness of both fathers and mothers to become involved in RSE? The strategies used to do this, will probably need to precede the provision of training events so that recruitment to them is boosted. Possible means for boosting parental willingness are discussed below.

The third issue relating to workshops is more pragmatic and relates to costs and sustainability. The estimated costs for one workshop presentation is around £2,000 which works out at around £250 per participant assuming the ideal number of participants per workshop is eight. The higher costs result from needing two facilitators and having a limited number of participants so that experiential learning methods can be used. Hence it is likely that these workshops would need to be subsidised even if parents were to make a contribution to their fees. However these workshop costs would be marginal if the workshops formed part of wider service to families whose children had ASD. Continued reliance on charitable funds or occasional grants from statutory agencies is not a reliable basis on which to build a coherent and comprehensive parent education strategy.

There may also be some merit in recruiting and training parents to be co-facilitators of training. Careful selection procedures would need to be in place but this may extend the reach and the effectiveness of the workshops in terms of encouraging the active involvement of parents in RSE.

The provision of RSE to young people with ASD – beyond the family

The experiences gained in this project strongly supports the need for children and young people with ASD to have access to education around relationships and sexuality beyond the family. However it seems that current arrangements for RSE in schools are not appropriate to their needs in that the information is not adapted to their communication needs and the focus tends to be on reproduction rather than addressing the social and

emotional needs of young people (Hatton & Tector, 2010). Moreover the dearth of peer friendships that is commonly reported for these teenagers means they are denied another source of learning.

At a minimum the young people need to be informed about reliable sources of educational materials. This could be done through the provision of an accessible information leaflet that gives details of recommended booklets, factsheets, web pages and local organisations. Although written with young people in mind, this type of information leaflet would greatly benefit parents and professionals. Indeed they are well placed to identify the resources that are most suited to the young person. These information leaflets could be downloaded from websites such as AutismNI and Health Promotion Agency.

There is a strong case for the provision of awareness raising courses on the topic of RSE for educational, health and social care professionals. AutismNI has started to do this on a self-funding basis and has had an encouraging response. However a systematic training programme is required across the various sectors if a regional impact is to be made. In addition more specialised courses could be offered to particular groups of staff, including a 'training for trainers' workshop of personnel directly involved in the delivery of RSE to young people with ASD (Moxon, undated).

One mechanism for encouraging increased professional interest and ownership of RSE is by ensuring that the topic is included within the Individual Educational Plans and transition plans that are legally required for pupils with Special Educational Needs. The annual reviews would be an opportunity to plan to meet the needs identified by parents, teachers and the young people themselves. The provision of school-based training workshops attended by parents and professionals would provide further opportunities to build partnerships for taking forward RSE initiatives with the young people.

There is a strong argument to be made for group-based training workshops to be provided for teenagers with ASD with a focus primarily on the acquisition of social skills but these workshops would also cover self-protection, making and maintaining relationships, and coping with emotions. The workshops would require parental consent and the assent of the young participants and most likely would occur outside of school and at evenings or weekends. This raises issues regarding the agency and personnel best placed to deliver such training to the young people: for example incorporating the use of peer tutors as role models. AutismNI had a bid with the Big Lottery to develop and pilot such courses using Youth Workers as the main facilitators. If successful, this project would provide valuable insights into how this approach might be realised more widely throughout Northern Ireland.

Arguably the simplest, but ironically what seems the most difficult initiative, is for young people with ASD to have more opportunities to develop friendships through shared leisure activities. This would directly meet the aspirations and concerns of many parents and of the young people themselves. It would offer opportunities for them to develop social skills in natural settings while providing informal education and advice from peers and leaders on relationships and sexuality. By and large such initiatives will need to emanate from the voluntary and community sector although the Youth Service of the Education Boards could have a vital contribution to make. Moreover there is evidence from projects undertaken by AutismNI of a willingness among mainstream youth and community groups to welcome members with ASD but training and support for this is often lacking (McConkey et al., 2011). To date their contribution is largely overlooked in planning ASD adapted services but hopefully this neglect will be rectified in the future.

Policy and practice guidance

At present there are various agencies and some, if not sizeable numbers of professionals, who have the skills and experiences to be more proactive in the provision of RSE to

teenagers with ASD either directly or by supporting other personnel. The major impediment is that they are scattered across different sectors with no 'joined-up' strategy to instigate and coordinate their efforts. In particular the work of the Autism Advisory Teams in the Education Boards plus the Centre for Autism at Middletown needs to mesh with the Regional Network planning underway in Health and Social Care and the work of HSC Trust staff in Children's and Disability services such as community nurses, social workers and clinical psychologists. Likewise the contribution of Further Education and of specialist employment agencies should be encouraged and developed. But as often noted, this requires a lead agency to take forward the required planning and coordination. The proposed cross-departmental group for Autism led by DHSSPS might provide such leadership. However mechanisms will still have to be found to ensure that multi-agency working occurs at a local level.

A stimulant to action would also come from a review of progress with respect to the DHSSPS Sexual Health Promotion: Strategy and Action Plan (2008-2013). Five action points in the plan have particular relevance to young people with ASD and other developmental disabilities with responsibilities assigned to various Government Departments and agencies, namely:

Action 5: To continue to implement guidelines on Relationships and Sexuality Education (RSE).

Action 7: To provide opportunities for young people in school and youth settings to develop the skills they need for life to support them in appropriately managing their relationships including sexual lifestyles.

Action 8: To further develop community based programmes and courses in parent/child communication.

Action 11: To ensure that general training is provided for staff involved in sexual health issues. To cover core skills and issues such as awareness, attitudes, information, communication skills, sexuality, and relationships & sexual health.

Action 13: To ensure that appropriate sexual health training which takes account of the needs of Section 75 groups is made available to teachers implementing RSE guidelines and youth workers involved in sexual health promotion

The plan also envisaged the establishment of a multi-agency Sexual Health Promotion Network (Action 23) to oversee the implementation of the Action Plan by the DHSSPS and HSC. This report and its recommendations might be referred to the Network to assist their review and refinement of the Strategy and their future planning for its implementation to other young people with specific needs.

One of the core values of the DHSSPS *Investing for Health Strategy* on which the Sexual Health Strategy is based is that of 'Building on Success': i.e. "future activities should, where possible, build on existing, evaluated, local, national or international good practice" (p. 3). It is in that spirit that the experiences gained through the *Growing Up* workshops are offered. A start has been made and new pathways identified.

It's not just a question of conquering a summit previously unknown, but of tracing, step by step, a new pathway to it.

Gustav Mahler

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Appendix

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