

Out of the shadows

“Our voices aren’t going to go quietly
into the dark anymore” (Self-advocate)

A report of the sexual health and wellbeing of
people with learning disabilities in Northern Ireland

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A report of the sexual health and wellbeing of
people with learning disabilities in Northern Ireland



LOTTERY FUNDED



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Guidelines for reading the report

Source of data

This report is based on data collected through interviews and self-completion questionnaires. This is backed up with information from focus groups and a conference workshop. Further details are available in the methodology section in Chapter one.

Structure and layout of the report

- Chapter one provides background information as well as the rationale, aims and objectives of the project. This chapter also focuses on the key principles that governed the methods used, with particular emphasis on those that were more pertinent to people with learning disabilities. Chapter two presents the findings from people with learning disabilities. Chapter three and four relates to findings from significant others in the lives of people with learning disabilities, that is, family carers and front-line staff. Chapter five focuses on relationships and sexuality education (RSE) for people with learning disabilities and includes the views of professionals and significant others. The final chapter presents some conclusions and recommendations.
- Each chapter begins with a quote from a person with learning disabilities or from a significant other. In general, quotes are presented as close as possible to that spoken by the participant, however, in certain cases some minor changes have been made to improve readability.
- Due to the large size of several focus groups, some quotes have been presented without biographical details as it was impossible to identify specific participants within the groups.
- To guarantee confidentiality, details that could identify participants or services have been withheld. Similarly, identifying details of interviewees quoted have also been changed.

Summaries are provided at the end of each chapter.

Terms used

The following terms are used throughout the report:

Family carer/carer:	Refers to anyone who cares for a person with learning disabilities. This might include a parent, brother, sister or guardian.
People with learning disabilities:	Learning disabilities is the preferred term used in the UK and by the Department of Health, Social Services and Public Safety in Northern Ireland (1995), therefore this term is employed throughout the report.
Person in their care:	Refers to the person with learning disabilities in the care of a family carer/carer.
Participant:	Refers to those who took part in the project.
Client/service user:	Refers to people with learning disabilities within a service.
Sample:	Refers to those participants in each grouping that took part in the project.
Interviewee:	Refers to those who took part in a one-to-one interview.
Respondent:	Refers to those who completed a questionnaire.
HSSB:	One of the four Health and Social Services Boards within Northern Ireland.
Per cent (%):	The percentage of respondents who answered a particular question.
N:	The total number of respondents that answered a particular question in the questionnaire.
RSE:	Relationships and sexuality education. We have used this term throughout the report. However, many people involved in the research more easily recognise the term sex education, so the two should be seen as interchangeable.

Data is presented in numbers in bar graphs and tables, and in percentages throughout the text.

Introduction and methodology

Twenty years ago we wouldn't have had a say. We would be sitting in wee corners in asylums with people making decisions for us, that wasn't right. We have come a long way and all I am going to say is that **our voices aren't going to go quietly into the dark anymore.**

(21-year-old young man)

Introduction

Background

In January 2000, **fpa** in Northern Ireland in partnership with the School of Social and Community Sciences at the University of Ulster began a pioneering Northern Ireland wide study into the sexual attitudes and lifestyles of young people under 25 years old. It was funded by the Research Grants programme of the Community Fund (now known as the Big Lottery Fund). The final report *Towards Better Sexual Health* was published in December 2002 (Schubotz, Simpson and Rolston, 2002) and since then has informed policy development and implementation of health and education strategies and service provision at both local and Northern Ireland wide level.

The *Towards Better Sexual Health* survey attempted to include young disabled people but the financial and methodological framework was not conducive for an effective inclusion of people with learning disabilities. In 2004, with funding again from the Research Grants programme of the Big Lottery Fund, **fpa**, in partnership with the School of Nursing at the University of Ulster, developed and implemented a research project which focussed specifically on the relationships and sexual wellbeing of people with learning disabilities in Northern Ireland. The research project became known as the SKY project (Sexual Knowledge and You) and a promotional leaflet was designed and disseminated widely to relevant organisations throughout Northern Ireland.

Rationale

There has been considerable social and legislative progress in tackling the barriers experienced by people with learning disabilities with regard to education, employment and housing issues. However, although in recent years the sexuality of people with learning disabilities has received increased attention from policy-makers (Department of Health and Home Office, 2000) and from self advocates (Williams and Shultz, 1982), various commentators have drawn attention to a large gap between the needs

of this group and the response of services (McCarthy and Thompson, 1995; Murray, MacDonald and Levinson, 2001).

At times in Northern Ireland sexuality can be a more sensitive issue than in the rest of the UK, and this can potentially militate against an open, honest acceptance and discussion of sex and sexuality. This conservatism is particularly evident with regard to people with learning disabilities who are often perceived as perpetual children who need to be protected from sexual knowledge. As a result, education and support around sexuality, sexual health and personal relationships has tended to be avoided or ignored. Consequently, opportunities for people with learning disabilities to develop adult friendships and relationships have been denied or restricted.

However, although there is still a reticence about addressing sex and sexuality, the experience of **fpa** in Northern Ireland and the University of Ulster working in the area of learning disabilities for the past three years, clearly indicates that more and more staff, carers and professionals recognise and accept the need for information, education and support for people with learning disabilities in relation to sex, sexuality and personal relationships. In addition, a number of Health and Social Service Boards (HSSBs) and voluntary organisations have recently produced policy statements on sexuality and relationships.

The majority of people with learning disabilities in Northern Ireland attend schools for students with specific educational needs and are restricted to work in 'protected environments' or on 'special projects', if they work at all (McConkey, Mulvany and Barron, 2006). Of those who live away from family carers, most reside in large residential settings and nursing homes, and to a greater extent than happens in England and Wales (McConkey and Barr, 2000). Although some attempts have been made to improve the equality of access for disabled people to spaces that are normally occupied by non-disabled people, the notion of 'special needs' and 'protection' still leaves people with disabilities largely segregated from many activities in society. As Anderson and Kitchin (1998) argued, lifestyles of non-disabled people are treated as the norm whereas the disabled people's lives are often portrayed as deviant. In doing so, these ideologies ensure that differences in the existing cultural lifestyles, attitudes and behaviours of disabled and non-disabled people remain intact. Such ideologies block the ability of people with learning disabilities to develop and establish relationships with those who are non-disabled thus effectively contributing to their segregation and social exclusion. In Northern Ireland, this social exclusion is further exacerbated by the ghettoing of young people in their own socio-political areas as a consequence of the conflict (Smyth et al, 2004).

Currently, the structure of care and the support mechanisms in place for people with learning disabilities often lead to a lack of autonomy and independence in decision-making. Reasons for that are manifold but include a concern that people with learning disabilities may not display what is perceived as appropriate or socially accepted behaviour in public (McConkey and Ryan, 2001; McConkey and Smyth, 2003); a belief that they are not capable of and therefore are unable to consent to sexual relationships; and the fear that people with learning disabilities are more vulnerable to abuse so therefore they need to be protected at all times. Consequently, the concepts

of 'special needs' and 'protection' tend to dominate and the legal and human rights of people with learning disabilities are not maximised.

Often, research provides the catalyst for change but in Northern Ireland there is a lack of research data on the personal relationships and sexual health needs of people with learning disabilities and especially research data that has specifically included the individual views, opinions and perceptions of this group. It is therefore hoped that this report will:

- Enable the voices of people with learning disabilities to be heard with regard to their needs, expectations and aspirations concerning personal relationships and sexual health.
- Ensure that the rights of people with learning disabilities with regard to sexual health become a priority for local politicians, decision and policy makers and service providers.
- Challenge the attitudes, fears and beliefs of parents, carers and professionals around sex and sexuality of people with learning disabilities.
- Contribute to the broader social inclusion, as opposed to the social exclusion, of this group.

Aim and objectives

The aim of the research was:

- To produce a profile of the feelings, attitudes and experiences of people with learning disabilities with regard to sex, sexuality and personal relationships; and to obtain comparable data with regard to their carers – formal and informal.

The objectives were to:

- Assess the information and emotional needs of people with learning disabilities around positive sexual health and to develop a tool to assist practitioners in this work.
- Gain insight into what extent, and from what sources people with learning disabilities receive relationships and sexuality education (RSE) and the improvements that they would like to see.
- Provide information about the attitudes of staff, teachers, family carers and health professionals towards the relationship and sexual health needs of people with learning disabilities in their care and how these inter-link.
- Inform the further development and implementation of policy and guidelines within education and health and social services, relating to the relationship and sexual health needs of people with learning disabilities.

Methodology

The project posed unique challenges in terms of arriving at appropriate methodologies. Specific details of samples and methods are provided in the relevant chapters and also more detailed reports are available on request. However, we were generally guided by the following principles.

Multiple perspectives

In all, over 500 people participated in our information gathering (a profile of the sample is presented in Appendix two). The project had to be centred on people with learning disabilities especially those aged 13–40. However, we could only gain a full understanding of all the issues, by engaging also with significant others in their lives.

Firstly, family carers are important, particularly in Northern Ireland where higher proportions of young adults (aged under 40 years) continue to live with their families (mostly parents) than in any other part of the UK. (Barron, McConkey and Mulvany, 2006).

Secondly, front-line staff working in day centres and supported accommodation are the service personnel with whom people with learning disabilities have most contact and with whom they are likely to forge friendly and trusted relationships.

Thirdly, professional staff such as social workers, nurses, teachers and psychiatrists are involved in assessing and advising on individuals referred to them, and/or support staff in the delivery of educational and therapeutic programmes. They are also involved in developing service policies and guidelines.

Figure 1 provides a summary of these different groupings and the methodologies used with each.

Figure 1: Informants



(NB: Two other possible groups were considered. The first included mainstream agencies involved in sexual health (other than **fpa**), but as we report later they are few in number in Northern Ireland and appear to have very limited involvement with our client group. The second group considered were the siblings of people with learning disabilities. Resources did not permit us to undertake this work but it is recommended for any future studies.)

Steering group

We established a steering group for the project at the outset. It was made up of professionals and support staff who work in services for people with learning disabilities, a parent, a research academic and two people with learning disabilities. Terms of reference for the group were drawn up and the group agreed to provide guidance on the implementation of the research according to its aims and objectives. Members also helped facilitate liaison with relevant organisations. Advice and direction from this group proved invaluable at all stages of the project.

Self-selection to participate

All participants had to positively opt-in to become involved with the project. This has obvious limitations regarding the representativeness of the samples we were able to access. We tried to off-set potential bias by ensuring that large numbers of participants had the *opportunity* to participate. We did this by contacting services, advocacy groups, education providers and parent organisations throughout Northern Ireland who were involved with a range of people with learning disabilities in terms of age and severity of disability. This was very time-consuming and at times apparently unproductive from a recruitment perspective, but it did heighten people's awareness of the project and possibly created an increased profile for the issue.

Qualitative and quantitative methods

The topic of sexuality and people with learning disabilities has received scant attention from researchers. Anecdotal evidence was available through conversations and meetings but little attempt had been made to record this in a systematic way.

For the purpose of this research, both qualitative and quantitative methodologies of data collection were adopted. Qualitative methods such as one-to-one interviews, workshops, observations and focus groups were used to gather rich, in-depth and comprehensive information. These were used with groups of people with learning disabilities, front-line staff and family carers. On occasions, these were part of a conference, a routine meeting or a specifically convened meeting organised by project staff.

To complement these, quantitative research methodologies, such as questionnaires, were used to enable us to sample the views of larger numbers of people than we could do through interviews. These helped us to gauge issues which were especially pertinent within the chosen groupings. Therefore, these two approaches helped to provide a more complete insight into the complexity of this topic.

Data from the questionnaires were analysed using Statistical Package for Social Sciences (SPSS). One-to-one interviews were transcribed verbatim. Detailed notes

were taken in focus groups, workshops and during observations. All qualitative data were then analysed using thematic content analysis.

Personal introduction to the project

Although an information leaflet about the project was produced, it quickly became apparent that project staff needed to engage with people face-to-face and through dialogue. This was necessary to allay people's misconceptions, fears and concerns but it also gave participants an opportunity to have their questions answered. This helped us to gain further insights into issues which are of concern to them. Even though this was time-consuming, these personal contacts were invaluable in building rapport and gaining credibility for the project. Through them, further contacts with individuals were also made possible – a snow-balling approach.

Development of data collection methods

The topic of sexuality and people with learning disabilities is still a new field of enquiry and only few methodologies are available. Therefore, we had to be prepared to develop our own tools and methods with the advice from the steering group. This meant conducting pilot studies prior to undertaking each phase of the information gathering. This provided an opportunity to refine the methods used to obtain our samples, the procedures used to gain information, and the content of the interviews or questionnaires. Again this prolonged the research phase but the result is a set of methodologies and procedures that can be used confidently by practitioners and researchers in the future.

Validation of findings

Our main strategies for the validation of findings were as follows:

- Independent cross-checking of the identification of themes in data analysis by the research team.
- Triangulation of issues across the different groups of informants.
- Confirmation of conclusions through the steering group for the project.
- Facilitation of special consultation seminars in which representatives from the different informant groupings participated.

Ethical considerations

Ethical approval

Ethical approval was obtained from the Ethics Committee of the University of Ulster as the Office for Research Ethics Committees (OREC) for Northern Ireland had not been established when the project commenced.

Informed consent from participants

Particular emphasis was placed on all participants being fully aware of the reasons for undertaking the research. They were provided with both a written and verbal synopsis of the research prior to data gathering and all had opportunities to have any questions answered. Assurances of confidentiality were provided regarding information they

gave. Following this, each participant signed a consent form if they were satisfied and happy to continue.

However, the most challenging aspect was making this information accessible to participants with learning disabilities. A consent form was devised in consultation with the steering group, with advice from speech and language therapists and advocacy organisations. It was piloted with 20 individuals before a final version was agreed (a copy is available on request). Again, project staff also explained the consent form to participants to ensure maximum understanding.

Interviews with people with learning disabilities

Limited access to people with learning disabilities

We were dependent on other people to help facilitate contact with people with learning disabilities, including adults. Service staff were reluctant to agree to this without the expressed permission of family carers and if family carers were not available, the permission of a social worker had to be obtained. This led to protracted delays and ultimately a poor response in the numbers of people with learning disabilities that could be invited to take part in the project. We can understand the reasoning for this, but equally it highlighted the lack of adult status accorded to these individuals. One solution we found was to work with advocacy groups as they had a tradition of consulting directly with the individual members while at the same time abiding by necessary safeguards.

Services who agreed that consent could be sought directly from the adult person with learning disabilities tended to ask those whom they thought would be most likely to agree to take part or who would enjoy participating in the project most, or who were most knowledgeable in the area. Others were chosen or nominated by staff because they had a particular interest in finding a partner. Occasionally, staff asked certain people mainly because they felt their parents would not object. Therefore, this has resulted in some bias among the group of people we had access to.

Initially recruitment resulted in more males than females. This could indicate that females are more protected and perceived as more vulnerable by service staff and carers. However, after we made additional efforts to recruit more females, a better gender balance was achieved.

Developing rapport and trust with people with learning disabilities

On most occasions, the interviewer met with participants prior to the interview. Where possible, they engaged in a social activity such as bowling or going to lunch. This allowed participants to become more comfortable with the interviewer and helped develop trust and rapport. At this stage they were told the purpose of the project, any questions were answered and informed consent was achieved. The value of this initial meeting became apparent in the one-to-one interviews. Participants were more relaxed, asked more questions and were more open and forthcoming throughout the interviews.

All participants who took part in one-to-one interviews and focus groups received a gift voucher as a token of thanks and appreciation for their time and energy.

Assessment tools

Development of accessible and manageable tools to assess the sexual knowledge, attitudes and feelings of people with learning disabilities proved a challenge. Few suitable assessment tools exist that assess the sexual knowledge of people with learning disabilities. The main tools include the *Socio-Sexual Knowledge and Attitudes Assessment Tool Revised SSKAAT-R* (Griffiths and Lunsky, 2003); and the *The sex knowledge, experience, and needs scale for people with intellectual disabilities SexKen-ID* (McCabe, Cummins and Deeks, 1999). These were consulted when preparing and developing our own assessment tools for people with learning disabilities, however several drawbacks were identified with regard to the specific needs of this project. For example, some line drawings and pictures were considered unclear, and specific to American culture, and this could have created ambiguity for our sample. The *SexKen-ID* was limited as it was mainly directed at those with mild learning disabilities. Questions were also structured and often close-ended which didn't allow scope to explore participants' own experiences or concerns.

Assessment tools were therefore designed to specifically meet the needs of this project. Line drawings, photographs and **fpa's** *Contraceptive display kit* were used. Generally, line drawings were compiled from various sources, but some drawings were especially commissioned by the project. It was felt that these were clearer and less ambiguous. They were piloted with 20 people with learning disabilities to determine suitability. (Assessment tools are available on request.)

Comfort levels

Discussing sexual issues can potentially result in feelings of embarrassment and discomfort. However, participants generally appeared at ease during interviews and contrary to what had been anticipated, few showed signs of embarrassment. Interviews were taken at a slow pace and participants were always forewarned and asked permission before starting a new topic area or being shown a line drawing. Only a small number of participants displayed some discomfort, and when this occurred the interviewer took a break, terminated the interview or redirected the participant's attention to a more relaxed topic.

Disclosure of abuse

In our contact with services we ascertained their policy on vulnerable adults. Prior to one-to-one interviews, participants were made aware that if there were any disclosures of abuse, this could lead to the involvement of relevant agencies. This occurred on one occasion – management were informed and they took responsibility for further investigation.

Follow up support

Following the information gathering, contact details for the project staff were given to all participants. This gave them the opportunity to contribute further to the project, ask retrospective questions, and to ask for help or information with regard to contacting other related services. In addition to this, several **fpa** educational booklets were given to people with learning disabilities which they themselves could read, or discuss with key workers, family members or teachers. On some occasions participants

refused these and said that they couldn't take them home because their family would disapprove. On other occasions, staff or teachers felt it was best that such booklets remained on the service premises.

Other participants gave their reactions to the SKY project after participating and many felt that the opportunity to talk about the area of sex, sexuality and relationships was very beneficial. Some staff also commented that their clients appeared more confident about discussing sexual matters. However, some participants left the interview feeling frustrated that there would be no further opportunities to discuss these issues or to get some support from relevant personnel. In response, albeit limited, **fpa** staff facilitated a one day information workshop for people with learning disabilities.

The success of this workshop and the fact that a lack of support was a common theme throughout the period of data collection encouraged **fpa** to submit a successful funding proposal to the Big Lottery Fund. In September 2006 a three year project commenced, which will provide workshops and one-to-one information sessions on sex, sexuality and relationships for people with learning disabilities and their family carers.

Dissemination of findings

Our goal was to share the insights gained from the research with the people who had the greatest stake in the topic – namely people with learning disabilities, family carers and practitioners. This was achieved verbally through conversations, meetings and presentations. The steering group guided us in identifying particularly salient issues.

As a result **fpa** has published an accessible summary of the main findings for people with learning disabilities. It is available from **fpa**. In 2007, **fpa** and the University of Ulster will design a CD–Rom which will detail the findings of the report.

People with learning disabilities

Introduction

We all have the same wants and needs.

(25-year-old young woman)

This chapter presents an analysis of the knowledge and views of people with learning disabilities with regard to sex, sexuality and relationships. Overall approximately 100 people with learning disabilities participated in the studies.

The chapter is divided into two sections. Section one presents data obtained from semi-structured interviews, and section two presents data obtained from three focus groups and a conference workshop.

Section one: interviews

Sample

A total of 62 people from the four Health and Social Services Boards (HSSBs) participated:

- 32 were male
- 30 were female
- 39 were under 26 years old
- 23 were aged 26 years and over.

A more detailed profile of the sample is included in Appendix two.

Method

Using the format of a semi-structured interview, data was collected on the following three key areas:

- knowledge
- personal experiences
- values and attitudes.

The interviews lasted between 1–2 hours and where possible, were carried out over two sessions. Following the rapport session and obtaining the person's consent (see Chapter one) the interview began by focussing on the participant's level of understanding of sexual health and wellbeing. This created a more relaxed relationship between the interviewer and the interviewee before questions were asked about

personal experiences of sexual behaviour, relationships and their values and attitudes. Where necessary, participants were given gentle prompts and questions were re-worded to aid understanding. The gender of the interviewer (female) generally did not pose a problem and several male participants said that they actually preferred a female interviewer.

- Interviews were mainly conducted on service premises.
- 20 interviews took place in the interviewee's home. These involved residential, supported and independent living settings.
- 18 interviews took place within a quiet classroom or office in 2 schools for people with specific educational needs.
- The remaining interviews took place at the interviewer's workplace, in a day centre or the interviewee's training and employment centre.

For most of the interviews, both the interviewer and a research assistant (both were female) were present. The interviewee was informed that they could also have someone else present with them in the interview if they wished, however only one person asked her mother to be present. This interview was conducted in the family home.

The interview assessment tool

The assessment tool devised proved very successful in practice and we felt that it had several areas of strength.

- The interview schedule was very comprehensive covering areas from gender understanding through to relationships, sexual intercourse, contraception and sexually transmitted infections.
- Most sections were supported by visual aids mainly consisting of line drawings and pictures. This helped communication and understanding. An example of the line drawings is shown opposite.



- The interview was divided into sequential sections that began with basic understanding of gender and growing up and then progressed to more personal and detailed sections examining areas of sexual health and personal relationships.
- A filter system was used so that if an individual did not know the response to the first few questions in a section, other questions were skipped and the interviewer moved on to the next section of the interview. This helped to make the interview more efficient and less time consuming.

All data presented in the text is in percentages which have been calculated to the base of 62 (the number of interviewees who took part in the project) unless otherwise stated. Bar graphs and tables are presented in terms of numbers of interviewees and illustrate responses from both males and females thereby allowing comparisons across gender.

Only correct responses from interviewees are presented. However, if it was judged that some interviewees were guessing the answer or were at risk of acquiescence (tending to always respond 'yes'), they were not credited with a correct answer. This judgement is based on agreement between two raters (the interviewer and research assistant) either during the session or from reviewing the audio tape of the session. When appropriate, significant statistical differences are noted.

Quotes from participants are presented to illustrate either the way they expressed their knowledge or else common misunderstandings and misconceptions.

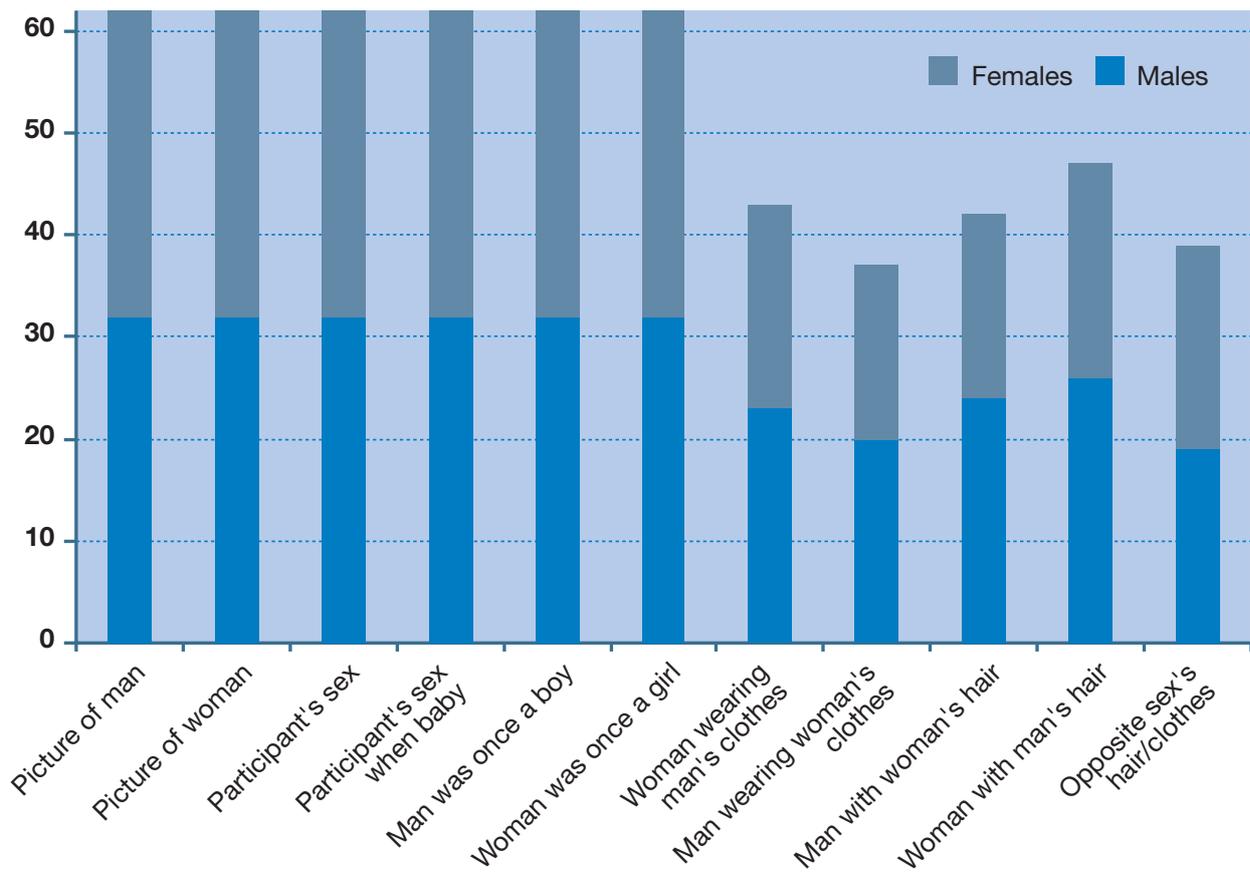
Knowledge

Fundamental aspects of sexual knowledge

Gender understanding

- Figure 2 illustrates that all participants recognised the genders of characters depicted in line drawings as well as their own genders.
- Most participants demonstrated gender constancy but some were confused in respect of male and female genders with non-stereotypical clothing and hair.

Figure 2: Indicators of gender understanding (in numbers)



Emotions

Interviewees were shown line drawings of facial expressions depicting a range of emotions.

- 98 per cent correctly identified the emotion of sadness
- 95 per cent correctly identified the feeling of being in love
- 94 per cent correctly identified the emotion of happiness.

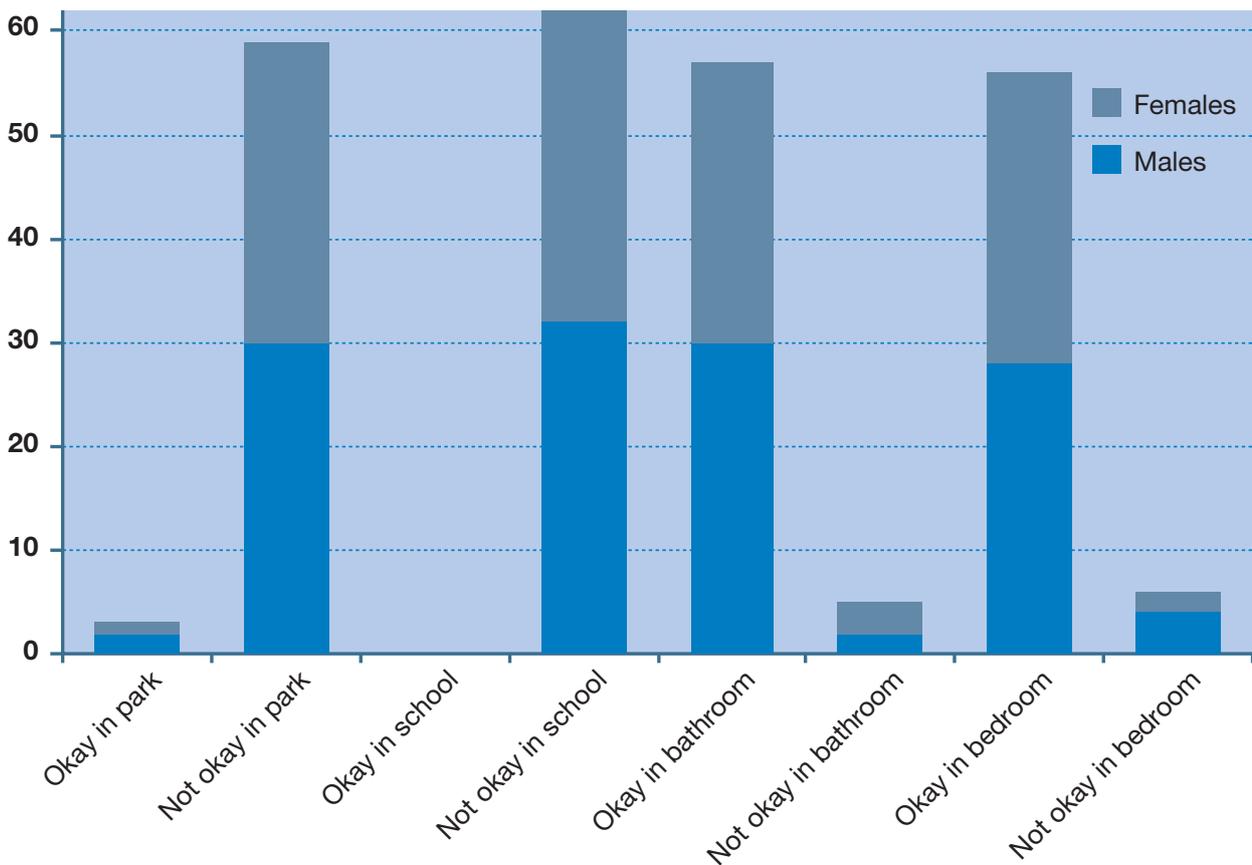
Interviewees had greater difficulty in recognising the facial expressions of anger (81 per cent) and fear (66 per cent).

Appropriate and inappropriate dress

When presented with line drawings showing a man and a woman in their underwear, all participants responded that the woman was wearing either underwear, a bikini, a bra and pants/knickers. Similarly all interviewees responded that the man was wearing trunks, boxers, underwear, knickers or pants.

Figure 3 shows that most participants responded in accordance with social norms when considering whether or not it was acceptable to wear this clothing in various public and private places.

Figure 3: Perceived appropriateness of underwear in public and private places (in numbers)



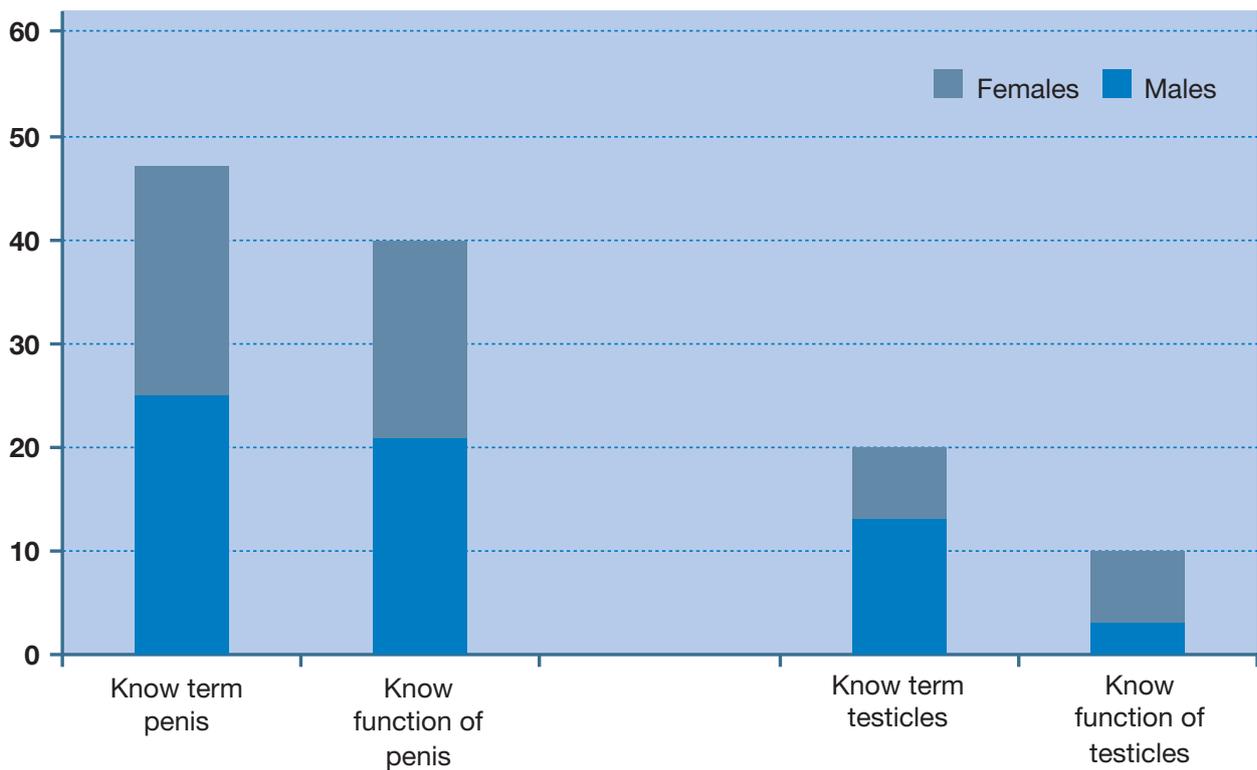
Personal growth and development

Male body parts

Interviewees were shown line drawings of the male body. As Figure 4 shows the majority were able to provide recognisable terms for the penis. Examples of misconceptions included the Adam's apple, vagina and testicles. However, interviewees' knowledge of the functions of the penis was less well developed. Many acknowledged that it is for 'going to the toilet' but displayed little or no knowledge of its sexual function.

There was less recognition of testicles and misconceptions included skin and intestine. Similarly there was little knowledge of the function of testicles and examples of misunderstanding included the testicles 'fills up kidneys' and 'keeps the penis together'.

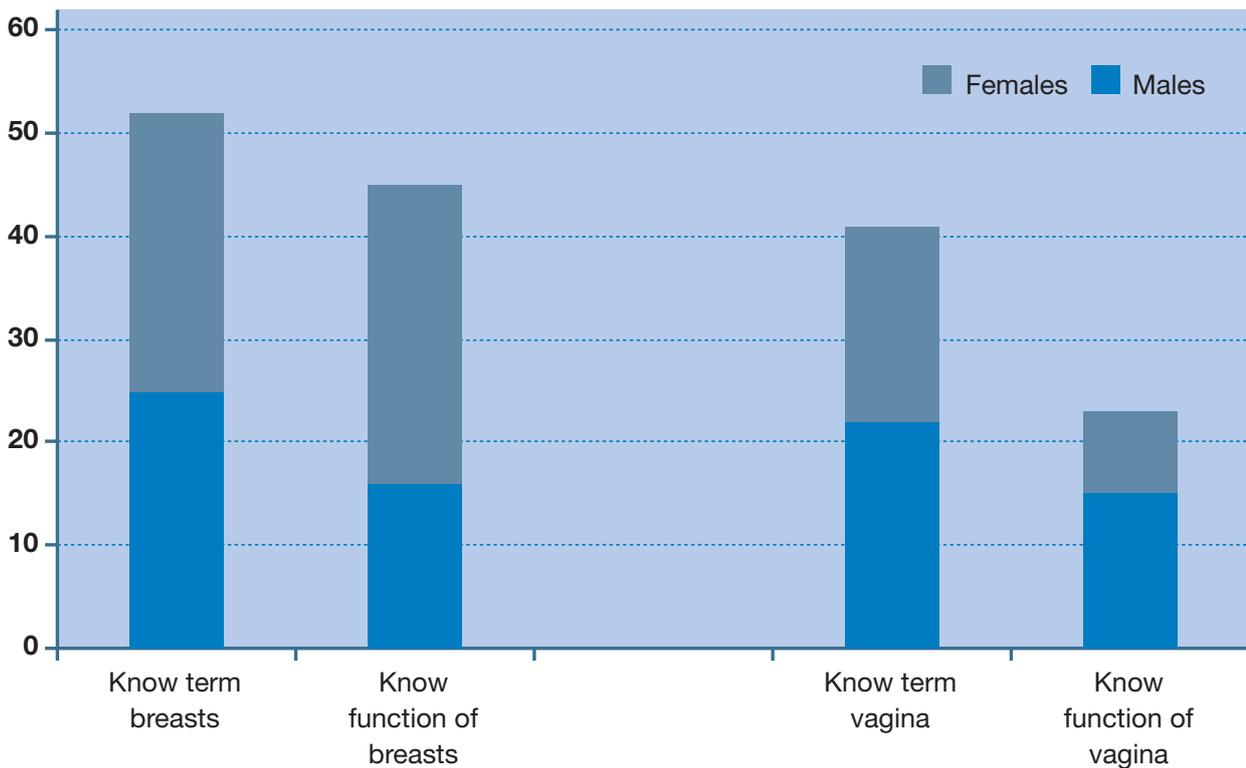
Figure 4: Knowledge of male body parts (in numbers)



Female body parts

Interviewees were shown line drawings of the female body. Figure 5 shows that their knowledge of the female anatomy was generally greater than that of the male anatomy. More females named breasts and knew their function but males were more knowledgeable than females of the vagina and its function. Misconceptions in respect of breasts included 'pompoms' and 'belly down below' and incorrect functions included 'to wear a bra' and to 'hold their tops up'. In relation to the vagina, some interviewees used incorrect terms such as cock, balls and penis and suggested that the vagina was there 'to wash' and to 'grow hair'.

Figure 5: Knowledge of female body parts (in numbers)

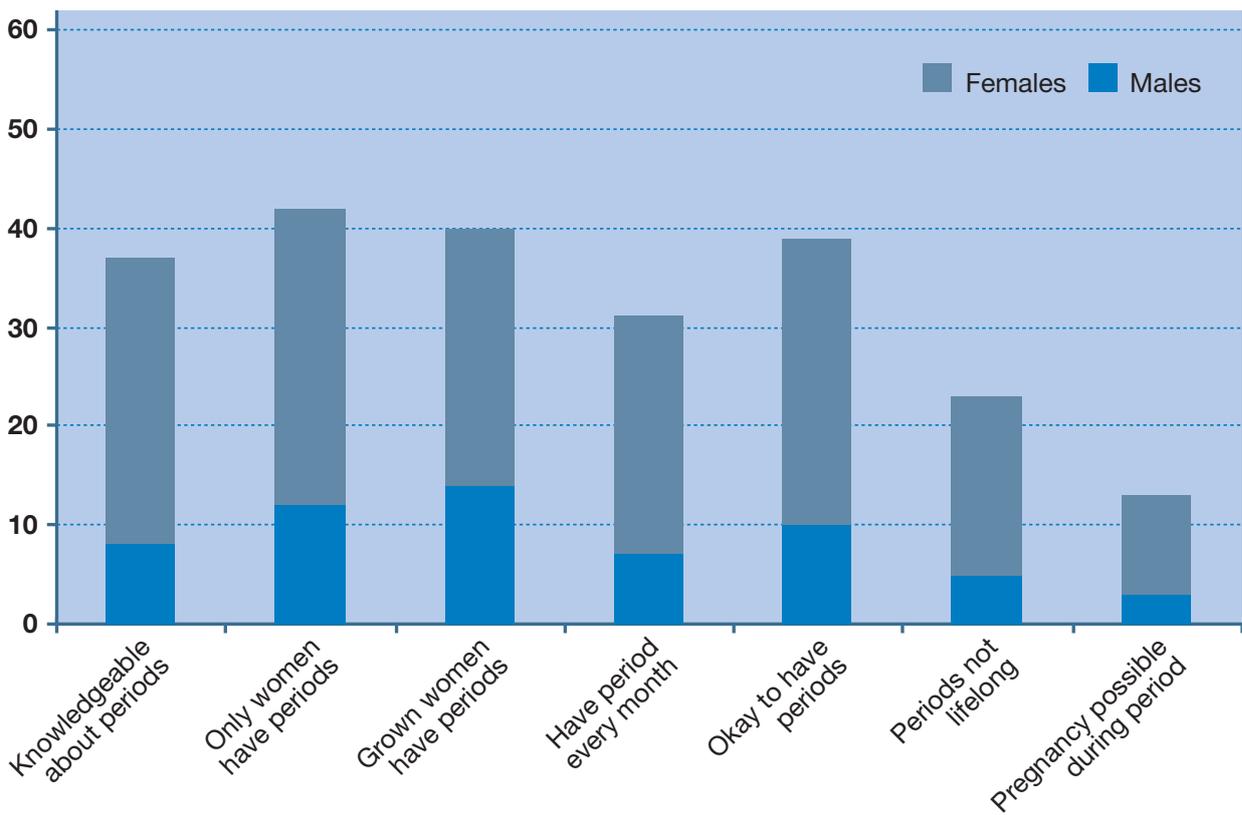


Menstruation

Participants were shown pictures relating to menstruation and as Figure 6 shows:

- 97 per cent of females were very knowledgeable about menstruation compared to 25 per cent of males. Misinterpretations included 'she is bleeding, she has a boil' and described as 'someone on toilet, with blood, don't know, is there a baby coming?'
- 63 per cent believed that it is okay for a woman to have periods because 'it is a natural thing', 'it means that it lets you know that your whole body is all working and then you're healthy' and 'if you don't have it, it means that there'll be something wrong with you'. However, female participants were more likely than males to report that it is okay to have periods and that they are a natural thing.
- 50 per cent knew that a woman normally has her period every month. Responses regarding frequency ranged from every day to every six months.
- 37 per cent stated that a woman has periods all her life.
- 21 per cent knew that a woman could get pregnant if she had sex during her period.

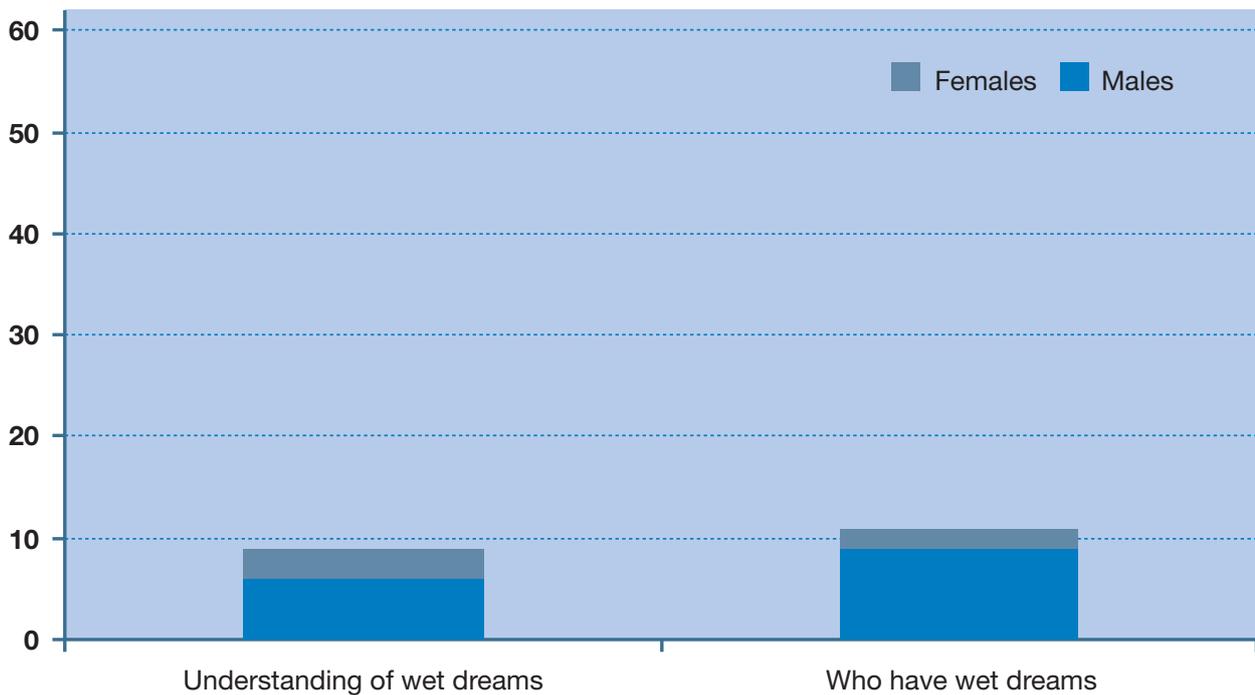
Figure 6: Knowledge of menstruation (in numbers)



Wet dreams

Interviewees were asked if they knew about wet dreams and what happened when they occurred. As Figure 7 illustrates, 74 per cent of participants had no knowledge, with females less knowledgeable than males.

Figure 7: Knowledge of wet dreams (in numbers)



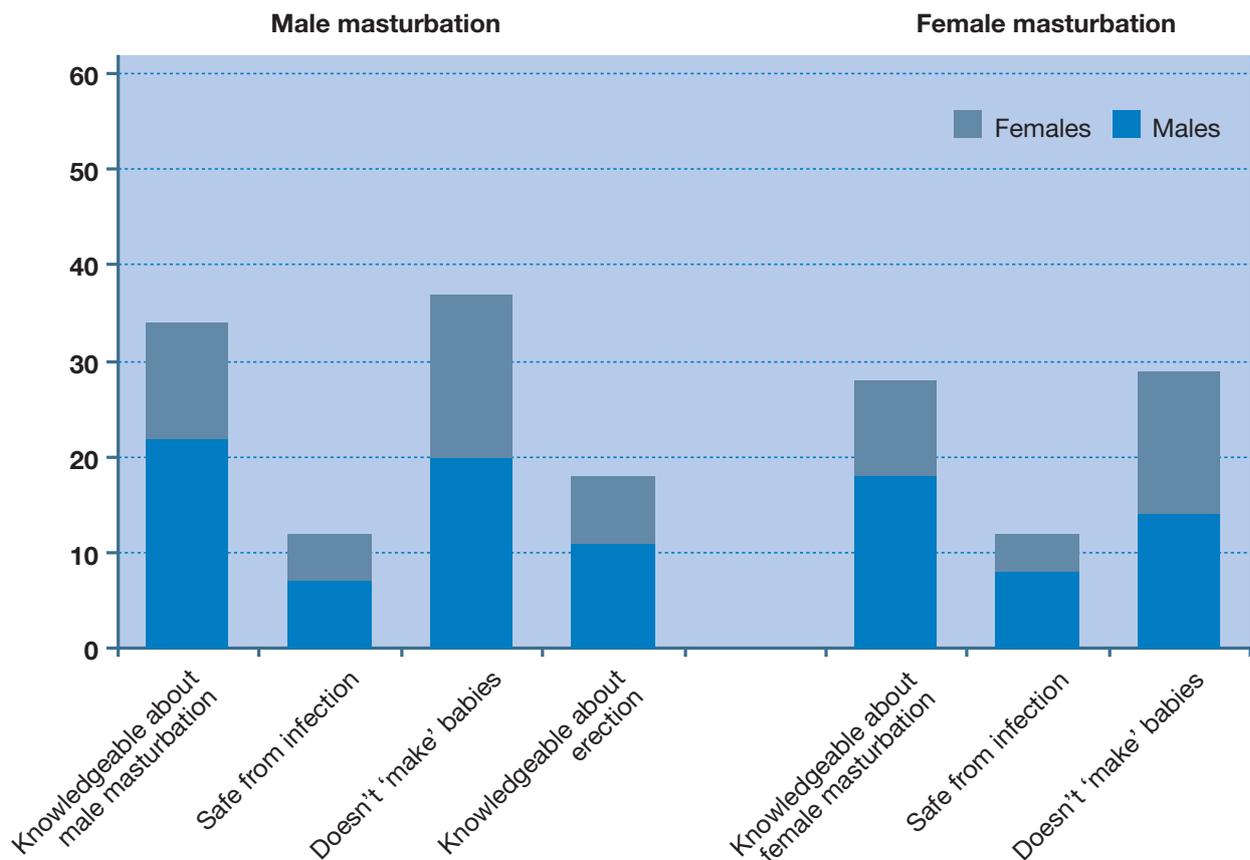
Masturbation

Interviewees were shown line drawings depicting male and female masturbation. Figure 8 shows that:

- 60 per cent knew that male masturbation cannot lead to pregnancy and 47 per cent knew that female masturbation does not result in pregnancy.
- 55 per cent displayed knowledge of male masturbation and 45 per cent of female masturbation.
- 29 per cent demonstrated knowledge of an erection (11 males, seven females).
- 19 per cent knew that male and female masturbation does not cause infections or cause a person to get sick.

There were clear negative connotations with regard to both female and male masturbation. Comments included 'it is dangerous for you' and 'she might get a transsexual disease'. Others linked it with sickness – 'thrush urine infection damage' and 'cancer.'

Figure 8: Knowledge of masturbation (in numbers)



Knowledge and understanding of intimacy

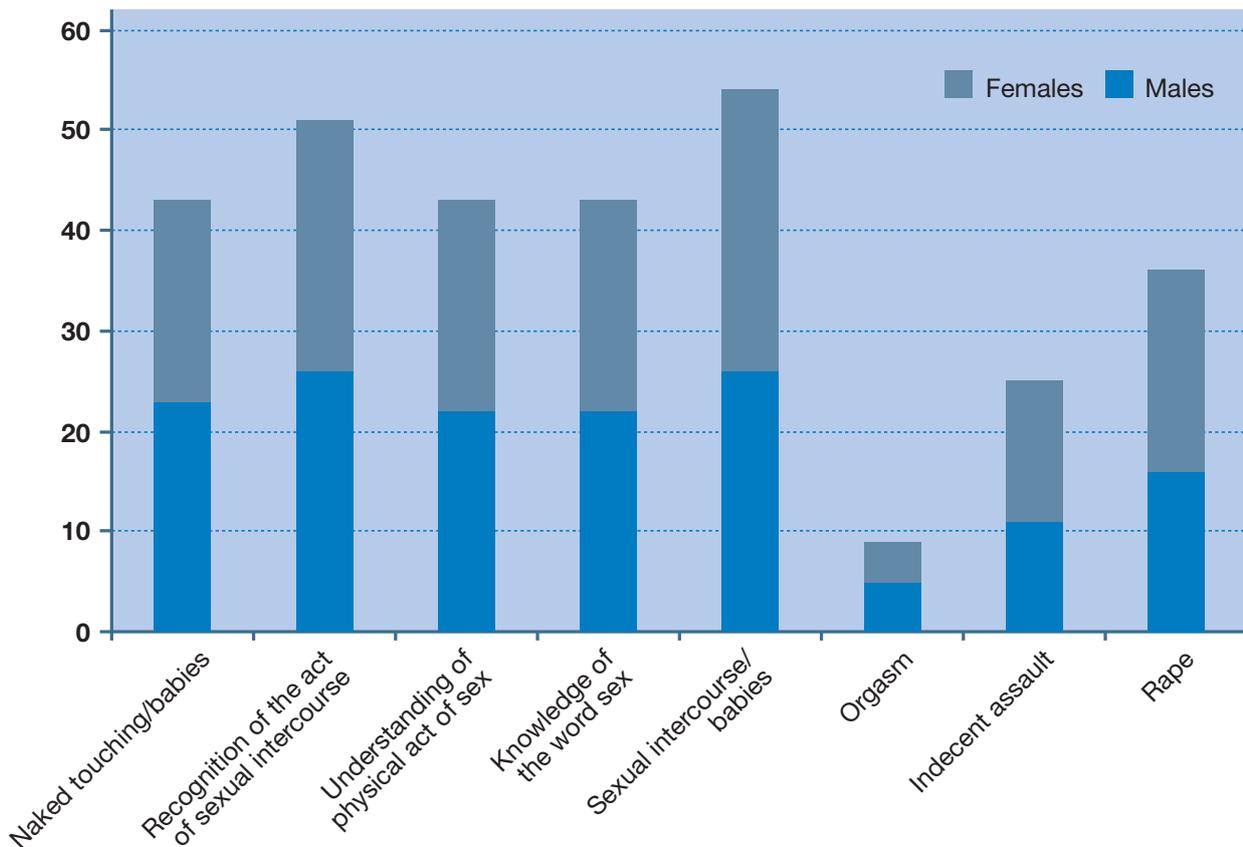
Naked touching and sexual intercourse

Interviewees were shown line drawings of a naked man and woman together. As Figure 9 shows:

- 87 per cent knew that a couple can 'make' babies from having sex.
- 82 per cent were able to recognise the act of sexual intercourse from a line drawing.
- 69 per cent used the word sex to describe sexual intercourse and were able to describe what actually happens during sex.
- 69 per cent knew that couples cannot 'make' babies from just naked touching.
- 58 per cent knew the meaning of the word rape. An example of confusion was rape being described as 'when you pass wind through your belly'.
- 40 per cent had good knowledge of the meaning of indecent assault. This was described as 'you can get done for it', 'rape' and 'attack or abuse'. An example of misconception was 'when you have too much salt in your food, bad heart'. There were significant age differences as participants under 26 years old were more likely to be more knowledgeable.
- 15 per cent knew the meaning of the word 'orgasm'. It was described as 'feels all tingly', 'gets a nice feeling in their body' and 'pleasure'.

There were no significant statistical differences between male and female interviewees' knowledge and understanding of intimacy.

Figure 9: Knowledge of intimacy (in numbers)



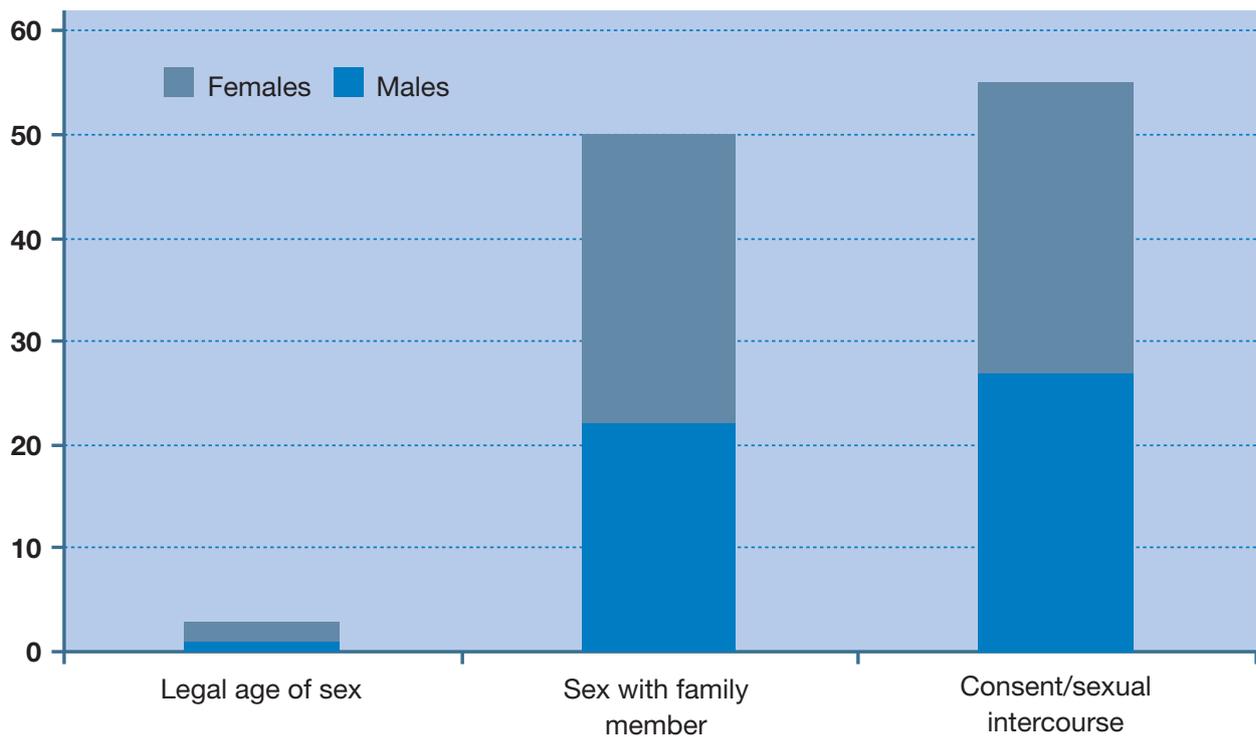
Sex and the law

Figure 10 shows that:

- 89 per cent knew that it was not okay to have sex with someone who doesn't want to. Some commented that this would be rape and that 'if the girl doesn't want to have sex, you can't force her to'.
- 81 per cent knew that it is illegal to have sex with a family member. They said 'it wouldn't be right' and 'you could get arrested for that'.
- Only 5 per cent of participants knew that the legal age of consensual sex in Northern Ireland is 17 years of age. One participant stated 'they don't allow that at all. I don't think the police would allow people to do it'.

Interviewees were asked about the law concerning relationships with people labelled under the appropriate acts in Northern Ireland (Mental Health (NI) Order 1986). However, for the majority, it proved difficult to explain this question and few appreciated the implications.

Figure 10: Knowledge of the law (in numbers)



Knowledge and understanding of reproduction and sexual health

Reproduction

Interviewees were shown line drawings of pregnant women. Most recognised that the woman was pregnant however an example of misconception was one person who thought that the woman in the picture was ‘a big fat lady, because (she’s) eating too much’. Another participant said that he had never heard of the words ‘pregnant or pregnancy’.

Figure 11: Knowledge of pregnancy (in numbers)

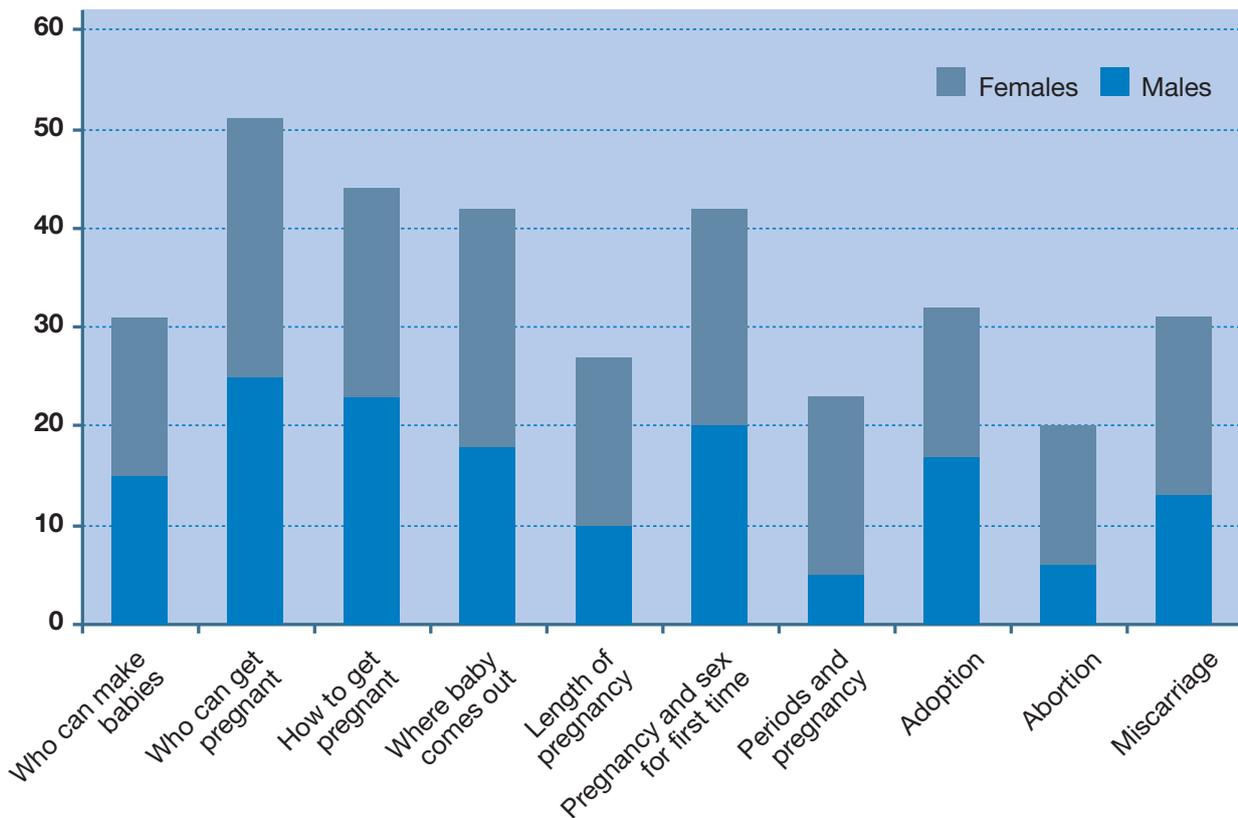


Figure 11 illustrates that:

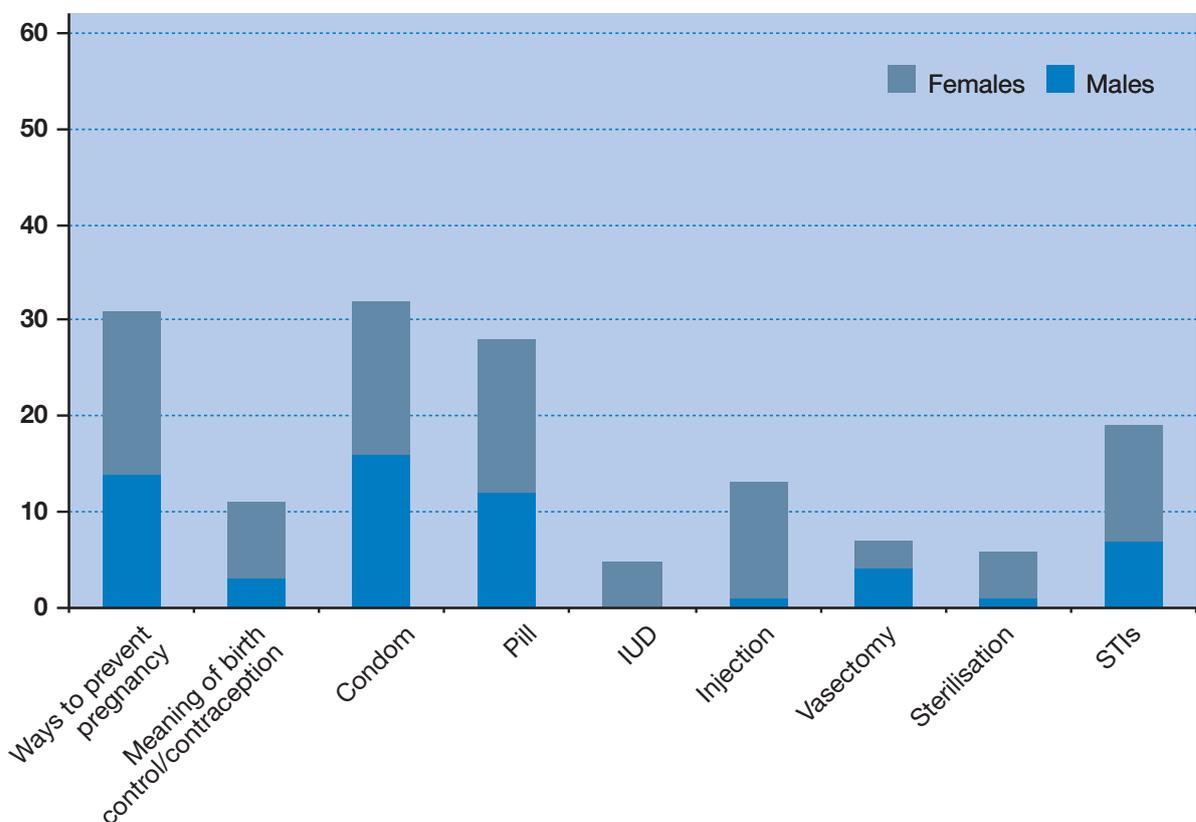
- From a choice of a baby, a man, a grown woman and an older woman, 84 per cent knew that the grown woman was the most likely person to get pregnant. One interviewee responded that ‘all of them can get pregnant’.
- 71 per cent knew that a woman needed to have sex with a man or needed a man to get pregnant.
- 68 per cent knew that a woman can get pregnant when she has sex for the first time.
- 52 per cent understood the meaning of the word adoption. Some examples of misunderstanding included ‘kidnapping people’ or when ‘two people split up or divorce’.
- 50 per cent of interviewees knew that men and women can ‘make’ babies together, however 10 per cent thought that two men could ‘make’ babies, 13 per cent thought that two women could ‘make’ babies together and 27 per cent thought that an elderly man and elderly woman could ‘make’ babies together.
- 50 per cent understood the meaning of the word ‘miscarriage’. Some interviewees were confused and thought it was when you were ‘in the car with somebody’ or ‘when you put the wee baby in the miscarriage’.
- 44 per cent knew that a pregnancy lasts for an average of nine months.
- 37 per cent knew that most women don’t have periods during pregnancy.
- One school requested that the question on abortion was omitted from the interview. Of the 56 interviewees asked about abortion, 36 per cent understood the

meaning of the word. Some interviewees were confused and said it was ‘people splitting up’ or when ‘two people broke up’.

Sexual Health

Interviewees’ level of knowledge on contraception and sexually transmitted infections was generally lower than areas of knowledge discussed above. Only 50 per cent knew of ways to prevent pregnancy – the condom and the contraceptive pill were the most common responses. Females tended to know more about contraception than males and there were significant gender differences with regard to the intrauterine device (IUD) and the contraceptive injection. One interviewee suggested that ‘going for a walk’ would help prevent pregnancy.

Figure 12: Knowledge of contraception and sexually transmitted infections (in numbers)



As Figure 12 illustrates:

- 79 per cent knew where to obtain contraception. The chemist, doctor/nurse and shop were most commonly identified.
- 31 per cent knew the meaning of sexually transmitted infections. Misconceptions included ‘hearing aid’, ‘a police officer’, and ‘people on drugs’. One interviewee responded that you can get sexually transmitted infections when ‘girls scratch themselves’. Some interviewees thought that diseases and infections can be caught if two women kissed, ‘cause they will get AIDS from each other’.
- 18 per cent knew the meaning of birth control/contraception. Some misconceptions included ‘giving birth to a baby’ and ‘tampons and stuff’.

- Only 11 per cent knew the meaning of vasectomy. Some misconceptions included ‘baby pulled out of tummy’ and ‘taking drugs’.
- Only 10 per cent knew the meaning of sterilisation. Some were confused and thought it was when ‘you go into your room and listen to your stereo’ and ‘it’s when you get pains in your eyes’.

Conclusions

Our primary goal was to devise and evaluate a tool that could be used with people who had learning disabilities ranging in age and ability. This was achieved in that all the people interviewed were able to understand what was expected of them and they were willing and interested in participating with little evidence of embarrassment. The questions covered the full range of knowledge in that everyone could answer at least one question but only a minority answered more complex topics. The tool was also useful in identifying their chosen vocabulary and any misconceptions they had around particular topics.

Although a representative sample could not be obtained for the study, the data suggests that many people with learning disabilities have marked gaps in their knowledge and are confused about sexual health, especially in the areas of masturbation, pregnancy, contraception and sexually transmitted infections.

Personal experiences

Relationships

I wouldn’t want to be lonely all the time.

(20-year-old young woman)

During the interviews many interviewees shared their own personal experiences of relationships and intimacy.

- 68 per cent (25 males, 17 females) aspired to get married some day.
- 60 per cent (24 males, 13 females) expressed a desire to have children some day.
- 56 per cent reported that they currently had a boyfriend or a girlfriend. Of those who did not, 12 males and four females stated that they had had a boyfriend or girlfriend in the past and nearly all of them aspired to have a boyfriend or girlfriend in the future. Issues with parents were mentioned as an obstacle to dating – ‘My mum probably wouldn’t want me going out with a 20-year-old’. (18-year-old young woman)

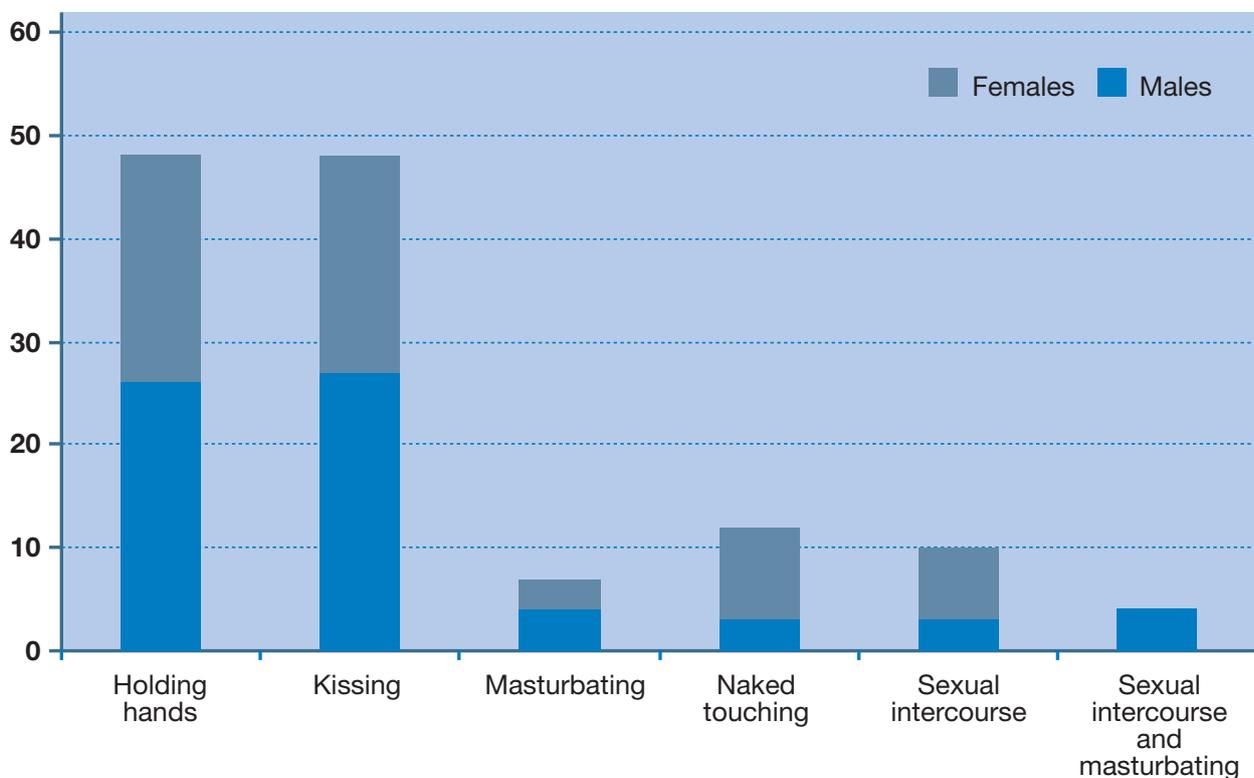
Sexual expression and intimacy

In this section, line drawings from previous sections illustrating intimate behaviours were revisited and participants were sensitively asked if they had engaged in any of these behaviours. It was apparent that several participants thought that they might have done something wrong and appeared embarrassed to admit that they had engaged in such behaviours. They therefore chose to deny having done so, despite reassurances from the interviewer. Conversely, others may have wanted to give the

impression of being sexually experienced as can happen with non-disabled young people (Schubotz, Simpson and Rolston, 2002). Consequently, the data presented here may have to be treated with some caution.

As illustrated in Figure 13, the majority of interviewees reportedly had held hands or kissed but there was a marked decline in relation to more intimate forms of sexual expression. Two interviewees stated that they refrained from sexual activities because of parental influences. One revealed that she had held hands and kissed both men and women, and one male interviewee disclosed that he had had sex with another man but referred to the experience as a 'big mistake' because he 'didn't want it to be like that'. An interviewee who had experienced sexual intercourse emphasised that 'both of us consented to it' thus demonstrating knowledge of the importance of consent.

Figure 13: Sexual expression and intimacy (in numbers)



In relation to sexual intercourse, 18 per cent of interviewees stated that they had never been taught about it.

The remaining interviewees reported that they had learnt about sex from various, and often multiple sources such as school (24), media (11), parents or other family members (11), front-line staff (9), professionals (5) and friends (2). Responses included:

- Mummy taught me not to do it.
- Maybe from dirty videos.
- Learnt most myself.
- Learn as I go along.

Didn't do it in school, they didn't teach us.

One stated that she was 'too young' and two reported that their mothers discouraged them from having a baby – 'Mummy won't let me' and 'I think my mum would hate me for a while if I got pregnant'.

Two females and one male reported that they had a child. These three interviewees no longer had responsibility for their children.

Use of contraception

More females (13) than males (7) had used or currently use contraception – 42 per cent reported that they had been taught about it. As Table 1 illustrates, the most frequent source was school followed by a training course. Although interviewees said that they were taught about contraception, this was not always reflected in their level of knowledge of contraceptives. One interviewee said that they had been taught in school about contraception but demonstrated no knowledge at all.

Table 1: Identified source of education about contraception (in numbers)

Taught about contraception	Frequency
School	12
Course (Nexus/Positive Futures/fpa)	7
Doctor	4
Staff (residential/day centre)	3
Family (mum/sister)	3
Clinical psychologist	2
Social worker	1

Conclusions

After rapport had been established between the interviewee and the interviewer, questions about sexual behaviours were embedded into the interview in a matter-of-fact way. Although, there was no means of validating interviewees' responses without breaking confidentiality, the low levels of sexual expression they reported does accord with data obtained in other studies and is markedly different from that of their non-disabled peers. In addition, the interviewees reported a lack of opportunities to learn about contraception.

Values and attitudes

The final set of questions explored interviewees' values and attitudes in relation to sexuality and behaviour.

Appropriate and inappropriate behaviour

Interviewees were shown line drawings of people exhibiting different behaviour such as that illustrated opposite.

The aim was to assess interviewees' attitudes to the drawings and their level of recognition of potentially abusive situations by indicating if the behaviour was 'okay' or 'not okay' or if they were unsure. Very few responded as unsure.

Table 2 summarises the number of participants who rated each behaviour as okay.



Table 2: Interviewees' acceptance of different touch behaviours (in numbers)

Behaviours	'It's okay' responses
Man and woman kissing on a sofa	56
Two men with arms around each other	27
Two men kissing	27
Two women kissing	25
Man trying to kiss a woman	10
Man with hand on young girl's bottom	9
Man groping a woman's breast	9
Man with his hand on young boy's knee	5
Man trying to grope another man	0

- The most acceptable behaviour was a man and woman kissing on a sofa. Those who did not think it was okay stated 'it's bad', 'they could be embarrassed' and 'it would be better to shake hands.'
- The least acceptable behaviours were those that might indicate possible assault/abuse, such as a man trying to grope another man, a man with his hand on a

young boy's knee, a man with his hand on a young girl's bottom and a man groping a woman's breast. There were no significant age or gender difference in responses.

- Interviewees generally felt that sexual behaviours involving two men are unacceptable. Comments included, 'it's terrible, disgusting', 'it's against the law' and 'yuck'. Those who thought it was okay stated 'if they're gay, that's fine, I've no objections to that particularly if they love each other' and 'they have their rights like us'.
- Two women kissing was a slightly less acceptable behaviour than two men. Some commented 'they must be in love' and 'it is not wrong, they can have a relationship like everyone else'. However, others felt that they 'shouldn't be doing that' because 'it is not good' and some thought that it was illegal.
- 97 per cent felt that it was not okay for a man to grope another reluctant man. The remaining interviewees were unsure.
- 90 per cent felt that it was not okay for a man to put his hand on a young boy's knee. The remaining interviewees felt it was okay because it was 'just to make friends with him' and 'to be nice'.
- 83 per cent felt that a man with his hand on a young girl's bottom or a man with his hand on a woman's breast was not okay. Of those who thought it was okay, their comments included 'the woman let him do it' and 'because they are two grown adults'.
- 81 per cent felt that it was not okay for a man to try to kiss a woman if she did not want him to do so. Those who disagreed stated that 'it's okay for him to try', 'it is okay on the cheek' and 'it could be his girlfriend'.

Masturbation

Of the 62 interviewees, 54 understood the meaning of masturbation. They were asked if they thought that masturbation was acceptable.

- 47 per cent felt that it was okay for males to masturbate and comments included 'it is something that boys do anyway'. Those who felt it was not okay commented 'it is not nice' and 'it is bad for a person, it is naughty'.
- 39 per cent felt that it was okay for females to masturbate and comments included 'she is having fantasies, maybe lonely'. Comments from the majority who felt that it is unacceptable included 'it is really dirty', 'it is disgusting' and 'weird'.
- There were significant gender differences where more males than females felt that female masturbation was more acceptable.

Sexual Intercourse

People with learning disabilities have sex just like everyone; they should have the right to have it and should be supported.

(22-year-old young man)

Of the 62 interviewees, 56 understood the meaning of sexual intercourse. They were asked about whether or not it was okay for people to do this.

As illustrated in Table 3:

- 75 per cent said that they thought it was okay for a boyfriend and girlfriend to have sex because ‘they’re in love’, ‘it’s natural’ and ‘they get pleasure out of it’. Others felt it wasn’t okay because ‘it is rude, nasty’, ‘could get a sore stomach’ and ‘could get pregnant easily’.
- 75 per cent felt that it was unacceptable for two people who are just friends or from the same club to have sex because they ‘could catch something’, ‘not married’ and ‘would be a tramp’. Of those who thought it was okay comments included ‘grown ups can do whatever they want’ and ‘because they are friends and they know each other’.
- Everyone felt that it was acceptable for a married couple to have sex because ‘they love each other’, ‘because they are husband and wife’ and ‘a good way of having children’.

Table 3: Interviewees’ acceptance of sexual intercourse (in numbers)

(N = 56)	‘It’s okay’ responses
Is it okay for:	
a boyfriend and girlfriend?	42
friends who know each other from the same club?	14
a couple who are married to each other?	56

Conclusions

The questions in this section were designed to give an insight in to interviewees’ attitudes to certain sexual behaviour, notably in terms of whether or not it was okay for people to engage in them. Most interviewees could relate to this and often were able to justify their chosen answer. In particular they seemed aware of potentially abusive behaviour.

The information gained through interviews however needed to be validated and we choose to do this by listening to the views of various groups of people with learning disabilities in group discussions.

Section two: group discussions

The following summary presents a general overview of the discussions that took place in the interviews and focus groups convened by the project and at a workshop which project staff organised at an All-Ireland Self-Advocacy Conference. These were often animated discussions with little apparent reluctance among the participants to express their views, especially in small group settings. Overall, it was agreed that the main factors that influenced the development of close friendships and relationships were family support, trust and social acceptance.

However, the following factors were identified as the main barriers to expressing sexuality and forming relationships.

Rights versus vulnerability

I think it has been ignored far too long. People with a learning disability have the same rights as everybody else plus they need to know lots about sexual awareness if possible, especially when you look at society, people with disabilities tend to be more vulnerable. There is a higher percentage of people getting abused when they are in a vulnerable situation and we need to know how to protect ourselves. And they need to know that it is okay that if they are in a healthy relationship, it is okay to feel like that too.

(25-year-old young woman)

Participants stated that they should have the autonomy to decide whether or not they wish to have intimate relationships or to get married. Nevertheless they acknowledged that they are perhaps more vulnerable and do fear some emotional, physical or financial abuse. Many had already experienced the reality of this and as the following demonstrates others were very aware.

There are people being born today with learning disabilities that know nothing about the subject of sex and awareness. I could go out to a night club or party anywhere with my friends and they could be led astray, and they could be raped and not know anything about it that they are being raped.

(21-year-old young man)

Family over-protectiveness

My parents are too protective, if I go out they are saying, 'Be home in half an hour', and there is not enough time to interact.

(24-year-old young man)

Participants reported that families often interfere by making decisions and for many people with learning disabilities this can mean that they feel unable to live their lives in the manner that they wish to do so. This prevents personal growth since the individual is afforded less opportunity to act for him/herself. This excessive control was deemed to come from parents' or carers' fears about the development of a friendship and the possibility of exploitation, and the belief that sex does not apply to their son or daughter. Participants therefore considered it helpful to have access to information and to discuss relationships with others outside the family.

The responsibilities of front-line staff in services

I would like more, to get out more places, I think the staff don't trust me or something, think that something might happen, I would like them to give me a chance, it would be nice to get a bit of independence.

(27-year-old man)

Participants reported that although there are several clubs for people with learning disabilities, they are also frequented by staff and this inhibits the development of personal relationships. They stated that some staff forbid them from having partners because they believe that they should not be sexually active. An issue of concern was

that privacy is necessary for those who are married and having sexual relationships. This can be difficult when living in shared accommodation or under staff surveillance.

Other people they identified as potential barriers were social workers and key-workers and one participant commented:

The people that I live with stop us from seeing each other because of the religion . . . they think that Catholics should mix with Catholics and Protestants with Protestants.

(25-year-old young woman)

Some noted that they face the dilemma of whether or not to trust others and that their own shyness, low self-esteem and nervousness may prevent them from forming friendships. A fear of pregnancy was expressed but it was stated that at the same time, information on contraception was scarce or inaccessible.

The message for the Government

Look at the Government and they will hardly do nothing about it. Yeah, more action, that is just how I feel about it.

(41-year-old man)

At the conclusion of the discussions participants were asked if there was anything they wanted the Government to hear. Essentially they felt that the Government wasn't doing enough in the area of sexuality, relationships and parenting for people with learning disabilities. Comments included the following.

- Consider transport costs for people with learning disabilities. Reduced transport costs could have a significant impact on maintaining friendships and relationships for those who live some distances from each other.
- Everyone has the right to have a relationship regardless of whether the other person has a disability or not.
- People with learning disabilities should be given the right to have children and to keep their children.
- The necessary support should be given to parents who have learning disabilities, where needed.

Summary of Findings

- Our research suggests that many people with learning disabilities are able and willing to engage in dialogues about sexual health. However, they often have limited or no opportunity to do so.
- Compared to non-disabled peers, their understanding appears more limited and incomplete. Although a representative sample could not be obtained for the project, the findings indicate that there are marked gaps in the knowledge of people with learning disabilities and many misunderstand and are confused about sexual health, particularly in the areas of masturbation, pregnancy, contraception and sexually transmitted infections.
- Some are aware of this and they are unsure how they can check the accuracy of what they have been told by their peers or may have picked up from the media.

- People with learning disabilities reported limited experience in sexual expression and comment on the restrictions which parents and staff place on them.
- The tools developed by the project could be used by practitioners wishing to respond to the needs and aspirations of people with learning disabilities in this aspect of their lives. However, further development may be required for these tools to be used with individuals who rely mostly on alternative and augmentative communication strategies, rather than speech.

Chapter 3

Family carers

Introduction

I had mentioned to a wee boy's mummy, they're all into the girls aren't they, and they love all the style ... and his mummy looked at me, you know like as if, what's she talking about? And I said, you know, is he not talking about the girls and all and about who he'd like to see? And she said to me, he never says anything like that to her! And she says, 'Honestly, I can't believe you said that to me, because it hasn't even crossed my mind!' And when I looked at the dance floor there was her son (aged 16) getting jiggy with this girl! I could even see the mummy then looking and it was like a wee switch in her eyes had went on!

(Mother of a 16-year-old boy)

Chapter three focuses on family carers of people with learning disabilities. It is important to obtain their views so that they and the person in their care receive the appropriate support and information on sexual health and wellbeing. We gathered information through focus groups, self-completion questionnaires and semi-structured interviews (see Figure 1 in Chapter one).

Throughout the project it proved difficult to obtain the views of carers of people with learning disabilities living with their families. These are mostly mothers and fathers but up to one-third of people in Northern Ireland are in the care of another relative – usually a sibling (McConkey, 2005). The views expressed are therefore probably not representative of all family carers as access was limited to those who either felt it was an important issue for their relative and/or that action was required rather than ignoring it.

Initially, eight statutory and voluntary agencies agreed to help gain access to family carers involved in their services. They in turn promoted the project to other agencies and it was also widely publicised at conferences.

Focus groups

I think it is very important that both carers/parents and family members with learning difficulties get help to come to understand how to approach this problem as a lot of the parents are old fashioned and could not talk to their child about any sexual problem.

(Sister of a 47-year-old man)

Sample

Focus group one

Nineteen parents attended (five fathers and 14 mothers). All had older teenagers or young adults with Down's syndrome who were attending a series of sessions as part of a 'Shout Project' – linked with the Down's Syndrome Association in Northern Ireland. Parents came from the four Health and Social Services Board (HSSB) areas including Derry, Portrush, Cookstown, Ballymena, Banbridge, as well as Belfast. However around ten parents actively contributed to the discussion.

Focus group two

Seven parents participated. All had teenagers or young adults, mostly with Down's syndrome, who were attending an activity centre. They lived mainly in the Greater Belfast area.

Method

The focus groups, which lasted between 60–90 minutes, were not audiotaped but written notes were taken during the discussions and the facilitator made reflective notes after they had ended.

The facilitators began the sessions by discussing the reasons why people with learning disabilities needed to know about sex and sexuality. As the dialogue continued prompt questions were used to further the discussion.

Main themes

The main themes which emerged from the two focus groups were as follows.

Independence versus protection

Parents felt that it was right for their children to receive relationships and sexuality education (RSE) as they recognised that their children experience the same feelings as other children. However, they argued that RSE must help to protect them as they are vulnerable and have a limited understanding of the dangers they may encounter. There was also recognition that RSE could help their children cope with different situations should they move out of the family home into supported accommodation.

Appropriate/inappropriate behaviour

Parents were concerned that young people might want to put into practice what they had learnt. The parents emphasised that young people needed to know the dangers and risks of certain behaviours including stranger-danger, socially accepted behaviours and avoiding pregnancy. However, parents pointed out that society needs to be educated about how to behave with people with learning disabilities. For example, there can be a tendency for adults to hug people with learning disabilities, but this can confuse them about the boundaries of acceptable behaviour, and cause them to misunderstand the contexts where certain behaviours are acceptable or unacceptable.

Parents are ill-equipped

When discussing RSE the common response among parents was feeling 'scared'. They felt they did not have the knowledge about how to talk to their children about RSE and were not sure how their children would react, therefore they needed guidance. However, they agreed that it can be difficult for any parent to discuss sexual issues with their children.

Loneliness

Parents were very vocal around the lack of friends for their young people and the lack of a peer reference group.

Questionnaire

People with learning problems are very vulnerable and need to be equipped to deal with many situations including predators.

(Mother of a 28-year-old woman)

Sample

A total of 63 carers completed the questionnaire representing an estimated response rate of 10 per cent. The majority were female (79 per cent), a parent (80 per cent) and in the 45–59 age group. Of the person in their care, 52 per cent were female, around one-third (36 per cent) were aged 13–18 years, one-third 19–29 years and 28 per cent aged 30 years and over. Carers rated around half their relatives (49 per cent) as having mild/moderate learning disabilities and 43 per cent as being severely disabled.

A profile of respondents is detailed in Appendix two.

Method

In order to sample the views of a wider range of family carers, a self-completion questionnaire was developed. Over 500 questionnaires were distributed to carers via a range of professionals working in the area of learning disabilities. (A freepost envelope was included.)

The questionnaire also included an invitation to take part in an interview which would give carers the opportunity to discuss in greater detail those issues concerning sexuality and relationships, which they identified to be important with regard to the person in their care. The carers were assured of confidentiality. The questionnaire was divided into three sections.

- personal feelings and attitudes
- staff roles as perceived by family carers
- RSE. (NB Data gathered on this topic is presented in Chapter five).

Data analysis

In the questionnaire, respondents were asked to rate their agreement with statements on a five point scale:

- 1 Completely agree.

- 2 Somewhat agree.
- 3 Not sure.
- 4 Somewhat disagree.
- 5 Completely disagree.

For simplicity in presenting the findings, these categories are amalgamated into agree, not sure and disagree.

Section one: Personal feelings and attitudes

Attention should be given to feelings and understanding of feelings. Masturbation should be explained and set in the context of privacy. Openness regarding questions should be encouraged.

(Mother of a 17-year-old young man)

Section one focuses on the views of carers around sexuality and relationships and sexual behaviours of people with learning disabilities.

The feelings and attitudes of carers towards sexuality and people with learning disabilities can be summarised as follows:

- 77 per cent agreed that people with learning disabilities have the right to sexual expression in the same way as others
- 68 per cent agreed that they can enjoy a good sex life
- 60 per cent were not sure if they usually have stronger than average sex drives (31 per cent disagreed)
- 50 per cent agreed that sex and sexual relationships are important in their lives (22 per cent were unsure).

Carers responded as follows about their feelings and attitudes towards personal relationships and people with learning disabilities:

- 86 per cent agreed that people with learning disabilities should be allowed to have a girlfriend or boyfriend
- 76 per cent agreed that people with learning disabilities were at risk of getting emotionally hurt if they develop too close a relationship with another person
- 71 per cent agreed that people with learning disabilities should be allowed to get married
- 61 per cent agreed that people with learning disabilities could be good parents (28 per cent were unsure)
- 58 per cent were not sure or disagreed that people with learning disabilities have the right to have children (42 per cent agreed).

Carers were asked to respond to statements regarding their feelings and attitudes to sexual behaviour and people with learning disabilities. They replied as follows:

- Although 23 per cent of respondents agreed that people with learning disabilities should **not** engage in any form of sexual activity, 61 per cent disagreed and felt that they should

- 68 per cent agreed that people with learning disabilities should be allowed to choose to have a boyfriend/girlfriend
- 68 per cent agreed that people with learning disabilities should be allowed privacy with their boyfriend or girlfriend
- 65 per cent agreed that they should be allowed to masturbate in private
- 64 per cent agreed that people with learning disabilities should be allowed to choose to have sexual intercourse and 78 per cent agreed that they should be allowed to choose to use different methods of contraception
- 59 per cent per cent disagreed that a couple with learning disabilities who were caught having mutually consenting sex should be kept apart in the future although 20 per cent agreed
- 42 per cent agreed that homosexuality between mutually consenting partners with learning disabilities is acceptable but 38 per cent disagreed
- 36 per cent agreed that people with learning disabilities should be allowed to choose to have an abortion but 40 per cent disagreed.

Section two: Staff roles as perceived by carers

Each person is an individual and should be treated as such. What applies to one is not necessarily right for another. There has to be close communication with the carer responsible.

(Father of a 20-year-old young man)

Section two focuses on the views of carers around the roles and responsibilities of service providers in relation to sexuality and relationships and people with learning disabilities accessing their services; their sexual behaviour, and the rights of carers to be consulted about their sexual curiosity and behaviour.

When asked how they perceived the roles and responsibilities of staff, in the general area of sex and sexuality and people with learning disabilities who are attending their service, they responded as follows:

- 94 per cent agreed that staff are completely responsible for a person with learning disabilities while s/he is in their care
- 89 per cent agreed that service providers should have a policy on sexuality and personal relationships and people with learning disabilities
- 82 per cent agreed that staff should answer questions about sex, sexuality and relationships if asked by a person in their care
- 81 per cent agreed that staff should always consult relatives on issues relating to sex, sexuality and relationships regardless of the age of the person with learning disabilities.

Carers were also asked their views on the roles and responsibilities of staff in relation to sexual behaviour and people with learning disabilities in their care. They responded as follows:

- 92 per cent agreed that there are certain behaviours that staff must not allow to happen
- 76 per cent disagreed that staff should stop service users from holding hands

- 66 per cent agreed that staff should stop service users from having sexual intercourse
- 63 per cent disagreed that staff should stop service users from kissing
- 58 per cent agreed that staff should stop service users from masturbating.

Finally, carers were asked for their views on the responsibilities of staff with regard to consulting carers about sex and sexuality issues relating to the person in their care. They responded as follows:

- 81 per cent agreed that staff must always consult carers on issues relating to sex, sexuality and relationships regardless of the age of the person with learning disabilities
- 66 per cent agreed that staff should contact carers if a person with learning disabilities asks them questions about sexual intercourse
- 63 per cent agreed that staff should contact carers if a person with learning disabilities asks them questions about contraception
- 63 per cent agreed that staff should contact carers if a person with learning disabilities asks them questions about masturbation
- 60 per cent agreed that staff should contact carers if a person with learning disabilities asks them questions about periods.

Conclusions

Although this group of carers is not representative, the findings do illustrate the differences in opinion likely to be found among a sample of carers. The reasons for this are not always apparent but probably reflect differences in the person in their care as well as their own personal views and attitudes. Unfortunately we were unable to pursue these possibilities in this study due to the limited sample size.

However, a more important lesson is the need to give carers opportunities to express their views and a similar questionnaire might be a useful tool that practitioners could use in workshops or training events with family carers to open up discussion of a range of issues. Equally, opportunities to listen to carers face-to-face provided greater insights into the dilemmas faced by them.

Interviews

They're just like the rest of us! They have a body but they have to get to know and learn about it and learn how to use it properly and be protected. They just function like you or me. I think people forget that adults with special needs are just people with sexuality and with emotions and with feelings and I think we don't give them credit for that and I think we, as mainstream, take a lot away from them.

(Mother of an 18-year-old young woman)

Sample

A total of 19 interviews were conducted with 22 carers. In three interviews a mother and father were both present. They lived in various areas of Northern Ireland including Belfast, Newry, Banbridge, Killeel, Limavady and Derry. The relationship of the carer to

the person with learning disabilities was as follows; mother (12); mother and father (3); sister (2); father (1); guardian/carer (1).

Method

Most of the interviews took place in the carer's home, but four were conducted in the carer's workplace and one at the University of Ulster. The interviews were semi-structured and lasted between 30–90 minutes. They were audiotaped, and transcribed for analysis. Topic areas (identified from previous interviews and the focus groups held with people with learning disabilities and front-line staff) were used to structure the interview. The topics included general attitudes to sexuality and relationships for people with learning disabilities, availability of relevant information and resources, support needs and views on RSE. (This data is presented in Chapter five). The carers were also encouraged to talk about other topics which they deemed important. This section discusses the main themes which emerged from the analysis.

All the interviewees were very comfortable and open to discussing sex, sexuality and relationships and most held supportive views concerning these with regard to the person in their care. Some carers also worked in the area of learning disabilities. Those carers who were uncomfortable with the issues did not participate in the interview process and therefore the sample we obtained is not representative of all carers. However, respondents did discuss their experience of other carers' reaction to this topic.

Knowledge of sex, sexuality and relationships

Most carers acknowledged that the person in their care had some knowledge around sex, sexuality and relationships. As the following quotes demonstrate some were not sure how much the person they cared for understood, and admitted that at times the knowledge they had resulted in them feeling confused.

I don't think he would understand what sex is or what it involves, although he would know the differences between a man and a woman's anatomy but he would not be aware of the detail.

(Sister of a 42-year-old man)

I feel that maybe a lot of the time they have questions, they don't know how to ask them or they don't know what it is that they want to know. I think they can't be clear there must be quite a bit of confusion in Sally's mind of what it's all about.

(Mother of a 21-year-old young woman)

We've been trying to teach her – you don't hug people outside your family, and you don't kiss people if you go out anywhere. Now, you go out up the town all the girls are walking out and holding hands and when they meet they're all kissing on the cheek and hugging each other, so she's getting very confused about what's appropriate and what's not.

(Mother of a 19-year-old young woman)

My son is 14 and he's going through body changes and he doesn't know what is happening . . . he started to get hair under his arm and he is trying to pull them out. I'm concerned.

(Mother of a 14-year-old boy)

People with learning disability are sexual beings

No matter what their disability or whatever, they still have all these feelings and they need to know how to cope with them, how to deal with them.

(Mother of a 13-year-old boy)

All carers recognised and accepted that the person in their care is a sexual being with emotions, feelings and needs. The first step for them was to recognise and accept this and understand that the person in their care may want to have relationships just like people who do not have learning disabilities.

Acknowledging their sexuality

The people that she would be meeting in the (day centre) would be more her peers . . . and it kinda did sorta plant the seed in my head that it may be that she might have some sort of romantic entanglement with them, so we've sorta gotta cross that bridge when we come to it.

(Mother of a 29-year-old woman)

I think it's vital because whether we like it or not we have to take on board that our daughters or sons have feelings and they have to be channelled in the right way.

(Mother of an 18-year-old young woman)

It just was my perception that he was never going to have these feelings, but obviously that's not the case.

(Mother of a 16-year-old boy)

The first time I noticed anything I had to have a wee bit of a cry and his daddy couldn't believe it.

(Mother of an 18-year-old young man)

The acceptance of the person in their care as a sexual being was for many of the carers embedded in the ethos of human rights, the right to have relationships and the right to access information, education and support to enable them to exercise that right.

Our rights are their rights!

I think very much that they have a right to develop and the right to have relationships if they so desire, maybe even to have families, providing that, I suppose, it depends on the illness (learning disability) really, but I think they all should be able to develop relationship skills or whatever.

(Father of an 18-year-old young man)

I know she has rights, she's entitled to a boyfriend and that's it. I'd love for her to have a partner, so I would.

(Mother of a 14-year-old girl)

For carers the acknowledgement of the right of the person in their care to express their sexuality could be challenged when that becomes a reality. However, most of the carers interviewed were very positive in their support of the person in their care taking actual steps to forming relationships.

The right to have relationships!

It doesn't worry me that he's talking about sex, I mean he's 16, you know what I mean. I suppose every wee lads going through it at that age.

(Mother of a 16-year-old boy)

They talk among themselves they're all very clued in. They might have Down's but they're not stupid.

(Mother of a 19-year-old young man)

I can see that John is a normal human being. He's as cute as a fox and he knows everything that's going on and he's got a girlfriend, he's had a girlfriend for a long time.

(Sister of a 47-year-old man)

I wouldn't have any objections to her having a sexual relationship. I suppose, as long as it was a consensual one and you made sure she wasn't being exploited or anything.

(Mother of a 20-year-old young woman)

People with learning disabilities need information and support

For somebody like him this is essential because he will as he gets older be wanting to experiment . . . he's got to be equipped with the information to do it.

(Mother of a 13-year-old boy)

To accept a person with learning disabilities as a sexual being dictates that they should have the right to accurate information and personal skills that will enable them to achieve positive sexual health. **fpa's** study (Schubotz, Simpson and Rolsten, 2002) found that just over 80 per cent of the young people surveyed, identified peers as their main source of information about sexual health and just under 59 per cent cited television/radio. Carers in this study did not mention peers but several did refer to the influence of television.

If they've got a TV set in their house the worms are right there in the corner. Every magazine too and Ann buys the magazines all the time. She looks at television, she goes to the movies, unless I put a blindfold on her, she's going to be seeing it.

(Mother of a 21-year-old young woman)

I think there's an awful lot on TV, even though I try to, I mean, you do try to censor what he sees.

(Mother of a 19-year-old young man)

I think she does have some idea but I think she's confused – she's very confused at the minute. And I think a lot of that is to do with the influence of television because she watches all the soap operas. And she is aware of teenage pregnancies, she's aware of homosexuality, but I don't know that she fully understands what it really means.

(Mother of a 19-year-old young woman)

The role of schools in educating young people with learning disabilities on sexual health was addressed by several carers and this is discussed in greater detail in Chapter five. The following discussion specifically focuses on the experience of carers as sex educators.

fpa's study (Schubotz, Simpson and Rolsten, 2002) found that approximately 53 per cent of respondents stated that mothers were their main source of useful information on sexual matters whereas only 18 per cent identified their father as an important source. Research (Department of Health and Social Services, 2000) does indicate that regardless of whether or not a young person has a disability, carers often do not discuss sexual health with the person in their care. Carers who opt out often do so because of embarrassment or feel that they are ill-equipped to address such issues as they don't have the appropriate language or knowledge base. The following comments demonstrate that some of the carers in this study have experienced similar feelings and consequently have not yet discussed some sexual health issues with the person in their care. It is important to emphasise that they are supportive of the person's right to the information and support but they simply don't know how and where to start.

Where to start?

As a family we haven't discussed it with him because we have no idea how to. I just dread having to go anywhere near it, you know?"

(Mother of a 13-year-old boy)

Oh God it's awful, what are we going to do here?

(Mother of a 13-year-old boy)

I think if anything happened . . . oh God! what way would you be dealing with it? To be quite honest with you I do not know, I think I would run, I really do think I would just run and leave him. I don't know what way I'd react to it or what way I would deal with it.

(Mother of an 18-year-old young man)

Others had thought about discussing sexual health but admitted that feelings of embarrassment were preventing them from doing so.

The blush factor

I would find it very hard to talk about sexual intercourse or masturbation to him because I'm too close to him and he would be embarrassed and I would be embarrassed.

(Mother of a 19-year-old young man)

When it came to the basics of sexuality I never would have been open with him.

(Mother of a 19-year-old young man)

Some said they were 'doing their best' but admitted to feeling confused about how to tackle certain issues.

We do our best!

I couldn't think of a clear way of explaining to her how to be in company with other people and not feel, you know, cause offence or be upset or whatever. I explained it to her in the end that there are areas of her body that are private and that nobody else should be touching . . . But at the same time we do, all of us do the very best that we can do given the circumstances that we're living in.

(Mother of a 19-year-old young woman)

I'm gonna have to look at things like does she go on the pill, does she go further than that and maybe get sterilised? I'm very confused about things like that, I don't really know.

(Mother of a 21-year-old young woman)

I would have no fears to talk to him and he would listen to me but I just didn't know how to approach it, either to wait and see.

(Sister of a 47-year-old man)

How much information do you give a young girl this age, how much can she handle and how much can she understand?

(Mother of an 18-year-old young woman)

However, some carers felt confident and comfortable in discussing sexual issues and asserted that they could speak very openly with the person in their care.

Dealing with it!

Not that I would be embarrassed or anything you know, everything here is quite open in the family . . . He (the father) would have no qualms about talking about sex to any of the boys.

(Mother of a 16-year-old boy)

There's very little that wouldn't be talked about in the house, quite openly, not inappropriately, but openly.

(Mother of a 14-year-old girl)

If you discuss that kind of thing with young people, when something comes up that does make them feel a bit uncomfortable they're more inclined maybe to come to you to see can you advise on how to sort it out, than they are to think, 'Well God, you couldn't talk to my mother about that'.

(Mother of a 29-year-old woman)

We would bring up sexuality, we would try and impress upon him appropriate and inappropriate touch and attitude towards girls.

(Mother of a 19-year-old young man)

Carers need support too

I think parents have to be involved but I think they need guidance. It's an area that they're very afraid to approach, because we're just afraid of opening up a can of worms and I think we just need guidance.

(Mother of an 18-year-old young man)

An overarching theme in most of the interviews was the lack of guidance and support available to carers.

Nowhere to go for help!

You asked me did I know of any support groups for parents and I can't say that I would know of any so if I wasn't getting this help, where would I turn to?

(Father of an 18-year-old young man)

We're just in the dark, we just don't know, we don't know where to go to get the information.

(Mother of an 18-year-old young man)

Well, there isn't really any support there for any of those sorts of issues at all. I would feel very isolated. I don't know who to turn to.

(Mother of a 13-year-old boy)

I would like to maybe talk to somebody that maybe has went through this and maybe where they could give me a wee bit of advice. I mean obviously I can only go on what my gut instinct is to tell him.

(Mother of a 16-year-old boy)

One carer was in total despair and felt that while she wants to help her son in learning about his sexuality, she wasn't even getting the support she needs for his general health and welfare.

I don't know anything really. I don't know nothing even about benefits for Simon or anything like that.

(Mother of an 18-year-old young man)

What we really need

Several carers highlighted the inadequate information that is available to them and others had actively tried to seek help and guidance to improve the services and support available to the person in their care.

Sometimes you find that the resources that you would get for younger children aren't detailed enough . . . you might get stuff that's aimed at primary school children but it's not really what you're looking for, you want it to be real but not at the level that some of these resources would be.

(Mother of a 14-year-old girl)

Everybody's busy and they're not going to run to a meeting once a week on that sort of issue but what you do need is information on how to deal with things.

(Mother of a 14-year-old boy)

I have suggested to the youth club that I would like to see this (sex education), I don't mean anything heavy.

(Mother of a 16-year-old boy)

I spoke to the consultant paediatrician, who assumed that the school would eventually address the issue.

(Mother of a 14-year-old boy)

I thought they (the school) would have, that's why I said to a teacher about it, to start talking about it.

(Mother of a 14-year-old boy)

However, some carers reported encountering barriers when looking for help. One mother wasn't sure how to explain the issue of menstruation to her daughter. During a support group meeting for parents and carers of people with learning disabilities she suggested to the group that perhaps someone could provide help with this and other RSE matters. Others in the group were 'appalled', expressing 'shock' and 'horror' and stating 'there will be no relationships!'

Another mother whose child had moved to a school for students with specific educational needs has asked every year:

When are you gonna do these sexual issues, when is it coming into the curriculum?
Now children in mainstream get that in P6 and P7.

(Mother of a 14-year-old boy)

She reported that the teacher got dreadfully embarrassed and said he would pass it on to the head teacher. Then they said that they would invite in a nurse.

Independence versus protection

I thought that I was very open, I thought that I was very liberal, I thought that I was very forward thinking in my attitude to him and all of a sudden I have realised that he is vulnerable and he's walking into an area where he can't physically cope with a lot of the stresses, but one of the stresses he also can't cope with is the new relationships that are going on. Because he's never actually walked into an area and formed relationships without the protection of either teachers or his family.

(Mother of a 19-year-old young man)

Even for carers who were supportive of the rights of people with learning disabilities to access information and support to enable them to enjoy and express their sexuality

the dilemma over how to protect them at the same time was omnipresent. On the one hand they are scared for and protective of the person in their care as they perceive them to be more vulnerable than someone who does not have a disability. But on the other hand, as far as possible, they want them to live an independent and complete life.

I'm scared for her, like, I am scared for her.

(Mother of a 14-year-old girl)

You just don't know when you're going to get some sort of a predator that would think of taking advantage and I'm trying to leave her as aware as I possibly can without scaring her witless.

(Mother of a 29-year-old woman)

I would feel because she's such a pretty wee girl she'd be very, very vulnerable . . . I always have a terrible worry of the wrong person getting to her.

(Mother of a 21-year-old woman)

They're more vulnerable in lots of ways and one of them probably is sexuality . . . the girls who have been introduced to them can manipulate them and they can't protect themselves at all in this environment . . . it's that level of protection.

(Mother of a 19-year-old young man)

It's very easy to sit and say, I would love her to have a relationship and get married and in an ideal world that would be what her future would be but at the same time, I think I would be terrified for her.

(Mother of a 19-year-old young woman)

The dilemma is aptly illustrated by one carer who commented:

Some parents are very loathe to let go, and believe me the hard thing is to let go, that's the very hard thing, the easiest thing is to keep them at home and protect them and make sure he's well looked after.

(Mother of a 19-year-old young man)

The carers were also very aware that some other carers take a more conservative attitude towards the sexuality of the person in their care.

I think they should step back and stop looking at what they themselves feel maybe is a big issue and make it a big issue when it really shouldn't be.

(Mother of a 13-year-old boy)

If you go and say we're having a wee meeting about sex, they're not going to go 'cause they're going to be embarrassed, you can't do that . . . I think the only way we're going to overcome that is to start talking about it.

(Mother of a 14-year-old girl)

Nevertheless, the interviewees were very honest about how much control people with learning disabilities really have in making decisions about their personal relationships. They admitted that regardless of how much they encouraged the person in their care to make their own decisions, it is the carer who has the ultimate control over how much independence the person with learning disabilities is given.

No matter how much you try to involve them in decision making, at the end of the day parents make the decisions.

(Mother of a 19-year-old young man)

Fulfilling aspirations

We really don't want to see her going through life and not have a relationship, because you want that for all your children . . . I think that would be heartbreaking to see her not ever experiencing that.

(Mother of a 14-year-old girl)

Most carers, regardless of whether or not the person in their care has a disability, want that person to be happy. Many recognise that the ability to form and maintain personal relationships is an important element of happiness. The carers interviewed in this study specifically identified the following as important to the happiness of the person in their care.

No more loneliness

He's really dying to have some sort of relationship, he's really ready for a relationship and I feel he's very lonely.

(Mother of a 16-year-old boy)

There is a loneliness in their lives.

(Mother of an 18-year-old young woman)

Companionship

It's really only for the company because he, I think that he does feel that he needs a girlfriend.

(Mother of a 16-year-old boy)

Self-esteem

It just makes him feel good, that there's somebody there that wants to be his girlfriend.

(Mother of a 16-year-old boy)

To be the same as everybody else

We would love that for her, now whether she ever has children, we don't know, but we would love to see her in a relationship just like we love to see our other children having relationships. We very much want her to experience the same things that her big sisters have.

(Mother of a 14-year-old girl)

However, some of the interviewees did express some reservations.

Oh God, I wouldn't want to see him with a family . . . They're only just fit to look after themselves and do a fantastic job the way they are.

(Sister of a 47-year-old man)

Summary of findings

- Overall, the majority of carers who participated in the study acknowledged that people with learning disabilities have the right to sexual expression but only half of those who completed the questionnaire agreed that sex and sexual relationships are important in the lives of people with learning disabilities.
- Most held positive attitudes with regard to sexuality and people with learning disabilities and 86 per cent of those who completed the questionnaire were supportive of the right of a person with learning disabilities to have a boyfriend/girlfriend.
- All carers interviewed felt that the person in their care had some knowledge of sexual health but recognised that often the information is confused.
- Most recognised the rights of people with learning disabilities to have relationships but only 42 per cent of those who completed the questionnaire agreed that homosexuality between mutually consenting partners is acceptable.
- All of those interviewed were critical of the lack of appropriate information and resources for carers to support them in educating the person in their care about sexuality and relationships.
- All the carers who participated in the focus groups and interviews and who were supportive of the rights of people with learning disabilities to have relationships also emphasised the need for them to be protected and kept safe. They felt apprehensive about the person in their care forming relationships but all wanted them to be happy and to have the same experiences and rights as everyone else.
- The majority of carers who completed the questionnaire felt that service providers should have a policy on sexuality and relationships and should consult them if the person with learning disabilities asked questions about sexual health.
- The majority of carers who completed the questionnaire also felt that staff should stop sexual practices among people with learning disabilities, such as masturbating or sexual intercourse but not kissing or holding hands.
- While most carers were supportive of the rights of the person in their care to form relationships, there was evident tension around them exercising those rights, for example carers wanted staff to report incidents of sexual behaviours to them.

Chapter 4

Front-line staff

Introduction

You would hope that in the future there would be some sort of development in policies. Staff members would feel supported in taking the opportunity to support people to make choices in this area of their life. They are more likely to be constructive, proactive supportively if they felt that the end result isn't going to be the agency landing down on them like a ton of bricks.

(Front-line staff member)

This section focuses primarily on service personnel who mainly work as support workers and care assistants, either within supported accommodation or day services. They are the staff who have most frequent contact with people who have learning disabilities. It is important that we have insight into their attitudes and perceptions regarding sexuality and relationships as this will identify areas of support that they may require from their managers and service leaders.

The information was obtained through a two stage process of focus groups and a self-completion questionnaire.

Focus groups

We talk about policy and procedures but we don't even know what they are.

(Front-line staff member)

The aims of the focus groups were to:

- Examine staff views and attitudes towards the sexual health and wellbeing of people with learning disabilities.
- Assess their general knowledge around the area of sexuality, the policies and procedures both specific to their organisation and at Health and Social Services Board (HSSB) level and whether or not these procedures are put into practice.
- Identify areas of support that they may require from their managers and service leaders.

It was expected that all of the above would also inform the design of the self-completion questionnaire.

Sample

Five focus groups were held involving 24 staff members (23 female and one male). Two were held in Derry (Western HSSB), two in Belfast (Eastern HSSB) and one in Newry (Southern HSSB). The aim was to involve staff working in a range of roles and settings. Therefore, the groups were made up of care assistants, day care and residential support workers, employment officers, advocacy workers, deputy managers and managers of day centre and residential units, staff nurses, community nurses and social workers.

Staff were recruited from statutory and non-statutory organisations through the project's steering group members and networks developed with various organisations, as the project developed.

Method

The focus groups were co-facilitated by the researcher and the research assistant; three were held in different service settings, and two took place at the University of Ulster. The groups focused on how staff members dealt with situations within their workplace in relation to sexuality and relationships. They discussed their anxieties around the issue and also the problems and difficulties they face and how they feel these problems could be overcome. To aid discussion the facilitators presented the following four scenarios which were designed to encourage staff to discuss how they would react in a given situation, the reasons for this and the challenges this would present for them.

David and Sarah are both clients within your service and both have a mild learning disability. You are on holiday with both David and Sarah and other service users. David and Sarah have been good friends for a long time and David has asked you if it would be possible for Sarah to sleep in his bed tonight. What do you do? How do you respond?

Two clients, both aged 18, use your service and both have a moderate learning disability. They have recently announced to everyone that they are now girlfriend and boyfriend. They spend a lot of time together, watching television, eating and reading together but you have recently noticed that they are also going to the bathroom together. What would you do?

Mark is 32 years old and has a moderate learning disability. You and another colleague take some of the clients shopping. When you arrive back at the centre/home you discover that Mark has purchased a pornographic magazine and you realise that he is using it to masturbate in his bedroom. What do you do?

Clare and Ryan have been boyfriend and girlfriend for almost a year. They are inseparable and are very kind towards each other and extremely good company for each other. Ryan has recently asked you if you could buy him some of those things that would stop him having babies with Clare. How do you respond?

The focus groups generally lasted between 60–90 minutes and the discussions were audiotaped, transcribed and analysed.

Results

In general, staff did not feel comfortable or confident in dealing with the type of situations portrayed in the scenarios. They felt that their reactions vary between individuals and would be influenced by:

- How well the staff knew the client including knowledge of their client's personal relationships.
- The degree of the person's disability.
- The person's level of understanding of sexual issues.
- The person's capacity to consent.
- The person's age (for legal reasons).

During the discussions it became evident that there were other important influences on their decision-making and reactions. These were grouped into the following three main themes:

1. policy and procedures
2. autonomy of staff
3. staff perception of family carers.

Policy and procedures

Because of where I work there are so many rules and regulations, I can't allow that (the scenarios) to happen.

(Front-line staff member)

Staff felt entirely governed by the rules and regulations of their place of work. They felt restricted in making decisions about sexual relationships and behaviour among clients. Other factors to emerge were:

- Staff fear losing their jobs if the rules aren't abided by.
- Staff views differed according to their level of training and their organisation's policy.
- There is variation in knowledge of policy among staff.
- Staff were keen to have policies to guide them although they felt that policies in themselves did not provide a complete solution.

Other staff reported that although they were familiar with their organisation's policy they felt that it did not support them to work effectively with people with learning disabilities on issues concerning sexuality and relationships. Some commented:

The policies are not well written.

(Front-line staff member)

I am trying to work through the policy but it is a minefield.

(Front-line staff member)

Autonomy of staff

I'm sitting here and I feel like a complete hypocrite, because there is so much I would love to be able to do but my hands are tied. If they came to me and asked me (for help) I couldn't do it because my job and my neck would be on the line.

(Front-line staff member)

Staff tended to be supportive of the rights of people with learning disabilities in general when discussing the scenarios but when it came to the individuals in their care, they saw themselves as being completely responsible for the person and therefore were more cautious.

They went on to describe the requirement placed on them to report all instances of sexual enquiry and behaviour. They appreciated that this resulted in a lack of confidentiality for people with learning disabilities as often this involved contacting parents and the multi-disciplinary team. This created tensions for staff.

I know we do it but it's not right to discuss somebody's relationships in that way. My reaction is, if they are over 18 they should have the right to make their own decisions.

(Front-line staff member)

I'm just stunned that they can't have a confidential conversation about sex. I really am shocked . . . It's very scary that every last detail of their lives can be discussed by a whole team of people. I had no idea that's what it was like.

(Front-line staff member)

Overall staff felt a need to 'cover their own backs' resulting in them adopting a protective if not prohibiting role. They considered themselves to have no authority to make independent decisions and needed to consult with colleagues and line managers.

Staff perceptions of family carers

I think it's true to say that parents are one of the main barriers with people with learning disabilities in expressing sexuality.

(Front-line staff member)

In discussing the scenarios staff were asked to consider the likely views of parents and how they as staff would engage with them, if at all. The general view was that staff constantly felt answerable to parents, whom they perceived as over-protective and having negative views about sexual/personal behaviours.

Many staff noted that how they would respond to a particular issue or incident was determined by how they thought the carer would want them to respond. However, some staff felt that decisions about sexual behaviour or relationships should not be decided on the basis of the carer's beliefs.

Staff also reported that their clients behave differently in front of their carers than they do with staff. They agreed that education for carers would be beneficial as it would help them understand their son or daughter's rights and needs. The views of staff on relationships and sexuality education (RSE) are included in Chapter five.

Questionnaire

I would hope that this will lead to more informed help and support for people with learning disabilities. They should be supported and guided in all the areas. It is very important for their feelings and questions to be valued, and that they have a voice in decisions taken about relationships and how they can express their needs in appropriate ways.

(Female worker at a day centre, 45–59 years)

Based on responses from the focus groups and information gleaned from past studies, a structured questionnaire was developed to further explore staff attitudes to issues around sexuality. The aim of the questionnaire was to obtain data from a larger and potentially more representative sample of staff as well as helping to identify:

- possible predictors of staff attitudes
- commonly held perceptions and attitudes
- areas of disagreement
- their training and support needs.

The questionnaire would also allow contrasts to be drawn between staff who had undertaken a training course in sexuality and relationships and those who had not. This would help to identify potential for change as well as the need for further training.

Sample

Over 260 staff completed the questionnaire. They were recruited through service managers and staff across the four HSSBs who distributed questionnaires to staff working in their service. This included non-statutory and statutory services. Some staff did not give their personal details or answer all the questions therefore the statistical data presented in this discussion are based on those who did. The number of missing responses can be calculated from the numbers cited.

- The majority of respondents were female (79 per cent) and under 45 years old (68 per cent).
- 72 per cent had a second level educational qualification.
- 19 per cent had a university degree or post-graduate qualification.
- 9 per cent had no formal education qualification.
- 52 per cent were employed in some form of day centre provision and the remainder in residential and supported living services.
- 43 per cent had worked in learning disability services for five years or less and the same percentage worked for ten years or more.
- The majority (57 per cent) were employed as support workers/care assistants; 33 per cent as senior support workers (level 3); and 10 per cent as managers or deputy managers.

A more detailed profile of the sample is presented in Appendix two.

Method

Staff were given the questionnaire with a covering letter. They could complete the questionnaire anonymously and returned it directly to the University using a freepost address.

Data analysis

In the questionnaire, respondents were asked to rate their agreement with statements on a five point scale:

- 1 Completely agree.
- 2 Somewhat agree.
- 3 Neutral.
- 4 Somewhat disagree.
- 5 Completely disagree.

For simplicity in presenting the findings, these categories are amalgamated into agree, neutral and disagree.

The following were the main issues addressed in the questionnaire along with responses received.

Sexuality training, policy and guidelines

Training

Of the respondents:

- 40 per cent had participated in some form of sexuality training, mainly a one-day (59) or a two-day course (24).
- Those who had been working in services for six years or over (59 per cent) were more likely to have participated in training courses, compared with 16 per cent of those who had been working in services for five years or less.
- Those aged 45 years and over were more likely to have attended training (59 per cent), than those who were aged 30–44 years (40 per cent), and those under 30 years (19 per cent).

Policy

Of the respondents:

- 63 per cent stated they knew the service policy on sexuality, 25 per cent were unsure of it and 3 per cent stated they did not know it.
- Those who attended training were more aware of the policy (91 per cent) than those who had not attended training (55 per cent).
- Those aged 45 years and over were more likely to know of the policy (81 per cent) compared with those aged 30 years and under (50 per cent).

Guidelines

Of the respondents:

- 44 per cent stated they knew the service guidelines on sexuality, 29 per cent were unsure of them and 5 per cent did not know of them.

- Those who attended training courses were more aware of the guidelines (72 per cent) than those who had not been trained (44 per cent).
- Staff in residential services were more aware of the guidelines (66 per cent) than those in day services (48 per cent).
- Staff aged 45 years and over knew of the guidelines (73 per cent) compared with those aged 30 years and under (33 per cent), who did not.

Issues in sexuality

Respondents were asked to rate their agreement or disagreement with a series of statements relating to sexuality and relationships and people with learning disabilities. These were grouped into key themes that were raised by staff in the focus groups.

Sexuality and people with learning disabilities

Table 4 summarises respondents' attitudes to sexuality and people with learning disabilities. Although the overwhelming majority of staff felt that sexuality is important in the lives of their clients, they held mixed views around the potential for them to be hurt and their rights to sexual expression and 49 per cent felt comfortable if they encountered sexual expression among their clients. Staff therefore appeared to struggle with the implications of acknowledging the sexuality of people using their service.

Table 4: Views of front-line staff on sexuality and people with learning disabilities (in percentages)

Item	Agree	Neutral	Disagree
Sexuality is not very important in the lives of people with learning disabilities.	8	4	88
I am uncomfortable if I encounter people with learning disabilities engaging in any form of sexual expression.	28	23	49
People with learning disabilities are at risk of getting hurt if they develop too close a relationship with another person.	41	17	42
People with learning disabilities are not able to have the right to sexual expression in the same ways as others.	40	12	48

Procedures

Table 5 represents the views of staff on the procedures in their services with regard to sexual enquiry and behaviour of clients using their service. As Table 5 shows the majority of front-line staff are in agreement that they must document or report instances of sexual enquiry or behaviour. This suggests that staff are required to fulfil supervisory and reporting functions with respect to sexuality with limited scope for flexibility and respecting a client's privacy.

Table 5: Views of front-line staff on service procedures (in percentages)

Item	Agree	Neutral	Disagree
There are certain sexual behaviours that my service must not allow to happen.	85	7	8
We have to document all verbal queries from clients on sexual intercourse.	73	13	14
We have to document all verbal queries from clients on contraception.	71	14	15
We have to document all verbal queries from clients on periods.	57	17	26
We have to document all verbal queries from clients on masturbation.	66	15	19
I must always consult with colleagues about perceived sexual behaviour of clients.	79	9	12
We should not support people with learning disabilities to make choices about sexual behaviour without referring to senior staff.	60	10	30

Autonomy of staff

Table 6 represents the views of staff on the level of discretion they feel they can exercise with respect to sexual issues and their clients. Nearly three-quarters felt that they had to ‘cover themselves’ but opinion was more diverse on other items relating to compliance with policy.

Table 6: Views of front-line staff on staff autonomy (in percentages)

Item	Agree	Neutral	Disagree
I have to cover my back in areas of sexuality.	74	13	13
Not everyone in my service adheres to the policy.	21	35	44
Sometimes, I wish I didn’t always have to abide by the policy of my service.	28	21	51
At times, I feel like a hypocrite on sexuality. I would love to be able to do something, but I feel that my hands are tied.	40	32	28

Carers

Staff responded to three statements relating to carers. As Table 7 shows, the majority of staff took the views of carers into consideration irrespective of the age of the person with learning disabilities. In addition, around one-half believed that carers did not want their daughter or son to engage in any sexual activity, although one-third of respondents held neutral views. These beliefs create a further tension for staff as they

try to balance the person with learning disabilities' needs and wishes with those of their families.

Table 7: Views of front-line staff on carers (in percentages)

Item	Agree	Neutral	Disagree
I must always consider the views of parents regardless of the age of the client.	63	10	27
Parents do not want their daughter to engage in any sexual activity.	53	33	14
Parents do not want their son to engage in any sexual activity.	49	35	16

Impact of training

In 2004 the Eastern HSSB issued policy guidelines on sexuality and organised a series of one-day training courses for staff in some HSSB Trust areas. The aim of the training was to familiarise staff with the content of the policy and to sensitise them to issues relating to sexuality. Around three months later the same self-completion questionnaire discussed above was disseminated to those who had attended the training and 103 responses were received. As the questionnaire was completed anonymously, the responses could not be compared on an individual basis. However, comparisons can be drawn between groups of staff from the same HSSB area who had attended training and those who had not (119).

There were only two significant variables that distinguished staff who had attended training from those who had not. Attenders were more likely to:

- have worked for the service for six years or longer (61 per cent)
- hold an NVQ at level 2 or above (67 per cent).

There were no differences in terms of the type of service, level of post held, or in other personal characteristics such as gender and age.

The analysis of the questionnaires revealed the following.

Knowledge of policy and guidelines

Staff who attended the training were significantly more likely to know about the policy (92 per cent were aware with only 7 per cent unsure) compared with those who did not attend (42 per cent aware and 37 per cent unsure). Similar differences existed around the awareness of guidelines but these were not so marked. Of those who had attended training courses, 72 per cent were aware of the guidelines and 24 per cent were unsure. Of those who had not attended training 51 per cent were aware and 45 per cent were unsure.

Attitudes

The impact of training on the range of statements about sexuality identified only two items in which there was a statistically significant difference. Attenders were more likely

to agree that ‘sometimes they wished they didn’t always have to abide by the policy of the service’ (35 per cent of attenders compared with 18 per cent of non-attenders) and to disagree with the statement ‘I don’t feel it is my job to help people with learning disabilities with their sexuality and in their relationships’ (80 per cent of attenders compared with 74 per cent of non-attenders).

Training needs

All staff completing the questionnaire, whether as attenders of a training course or not, were asked to indicate what further training, if any, they would like to have in the area of sexuality and relationships. Approximately one-quarter of respondents (77 per cent) answered this question, which suggests that either they had no wish to take any further training or they were unsure of the training they needed. Of those who replied, the complexity of the issue was demonstrated by the broad range of training topics identified, including the law; informed consent and how to respond to situations. However, some staff simply stated ‘anything’ and ‘everything’.

Summary of findings

- Staff feel under pressure from managers and parents to supervise and limit the sexual expression of people with learning disabilities. They appreciate that the consequences of this include lack of privacy and disrespect for the person with a learning disability but feel they are powerless to do anything about it.
- They emphasise the need for clear policies and procedures on sexuality and relationships. However, these need to respect and respond to the needs and wishes of people with learning disabilities and to give greater recognition to issues of confidentiality.
- Greater opportunities need to be found for dialogues to occur between people with learning disabilities, staff, managers and carers so that possible misconceptions can be corrected and a culture of co-operation developed.
- Staff who received training were more likely to be familiar with the policies and guidelines of their organisation.
- Staff who received training were more likely to be empathic to the sexual health and relationship needs of their clients.

Relationships and sexuality education

Introduction

Several approaches were taken to explore what proactive relationships and sexuality education (RSE) work is currently taking place within services throughout Northern Ireland, particularly for adults with learning disabilities. These included the following:

- Adverts were distributed through extensive emailing lists to staff in statutory, non-statutory and private services for people with learning disabilities.
- Letters were sent directly to senior management of day centres, and residential and supported living services.
- The steering group were consulted which produced possible leads.
- Discussions were held with people with learning disabilities, professionals, front-line staff and carers who participated in the project, about their experiences of RSE (if any).
- Direct contact was made with services that had a history of carrying out RSE work.
- Participation of project staff in workshops and seminars related to the topic.

Despite all these efforts, we found very little current, proactive RSE work taking place in services for adults with learning disabilities in Northern Ireland. However, throughout the study it was evident that RSE was an important issue for people with learning disabilities, family carers, professionals and front-line staff, so this chapter will therefore examine the issue from their perspective – notably the need for, and the content of RSE. We end by examining the RSE work taking place within school settings. (NB: At times the term ‘sex education’ was used in the data collection as this was a more familiar term to many of those who participated in the studies. However, throughout this chapter we have used the term RSE).

The views of people with learning disabilities

We are no different to anyone else ‘cause when I was at school, I only had very little sex education and you know, it should be taught in schools as well.

(21-year-old young man)

People with learning disabilities who participated in the interviews (Chapter two) had all attended either a school for students with a specific educational need or a school which had facilities for people with learning disabilities. Of these, 29 per cent were of school age and thus still attending school.

Their experience of RSE was vague or non-existent. Of the 62 interviewed, 79 per cent reported that they would like to learn more and 35 per cent stated that they wanted to learn ‘everything!’ Several interviewees expressed the opinion that they should have the same rights as everyone else and several of those who were not of school age reported that they wanted to go on a course.

Most female interviewees reported that they preferred to talk with another female as it would be embarrassing for them to talk to a man, whereas males did not have a preference. Several interviewees said that they would be comfortable discussing sexual issues with staff but others preferred a stranger as ‘staff would be too personal.’ Some who were still at school said they would be uncomfortable with teachers.

The views of family carers

School/service providers can only teach them so much. It is up to the carer to make sure that he or she is ready for a relationship.

(Mother of an 18-year-old young woman)

The questionnaire for carers (which was discussed in Chapter three) included questions on RSE as did the one-to-one interviews. Their responses to RSE were as follows.

Questionnaire data

Of the 63 respondents:

- 77 per cent wanted the person in their care to receive age appropriate RSE
- 68 per cent wanted to be involved in providing RSE to the person in their care
- 16 per cent agreed that RSE encourages sexual experimentation
- 84 per cent believed it helped people with learning disabilities to prepare for adult life
- 71 per cent agreed it would help them to make more informed decisions about their lives.

The latter view was strongly endorsed by carers (72 per cent) who believed that the person in their care had the ability to form sexual relationships compared with 29 per cent of those whose relatives are judged not to have this ability.

When asked who should teach RSE, the majority indicated that it is a shared responsibility and responded as follows:

- 81 per cent said it should be shared equally between family and school/service providers
- 12 per cent said it should only be taught by the carer or family members
- 7 per cent said it should only be dealt with by schools/service providers.

Comments included:

Professional back up is always welcome. Parents can be uncertain as to how to address specific topics.

(Mother of a 21-year-old young woman)

Carers were asked which topics they thought should be included in RSE. As Table 8 shows, the majority agreed that all topics should be covered.

Table 8: Carers' views on RSE topics (in percentages)

Item	Agree	Not sure	Disagree
Appropriate and inappropriate behaviours	88	4	8
Sexually transmitted infections	89	4	7
Emotions	87	7	6
Gender understanding	83	12	5
Pregnancy	88	4	8
Body parts and functions (including sexual organs)	83	10	7
Appropriate and inappropriate clothing	80	15	5
Contraception	87	4	9
Menstruation	78	14	8
Wet dreams	75	13	12
Sexual intercourse	79	14	7
Masturbation	72	23	5

Carers' experiences of discussing sexual issues

Carers were asked if they had ever discussed sexual health with the person in their care. In total, 36 (59 per cent) stated that they had and 25 (41 per cent) replied no.

However, only ten carers (15 per cent) reported doing this frequently, with 24 (38 per cent) stating they sometimes did, and three (5 per cent) rarely. Not surprisingly, carers who believed their relative had the ability to have a sexual relationship or to marry were more likely to have discussed sexual health.

Half of those who replied that they did not discuss such issues stated that it was because of the inability of the person in their care to understand the information.

Because I feel he would not understand and I still see him as a child.

(Mother of an 18-year-old young man)

Other reasons included s/he is too young, disinterested or resistant to joining in the discussion. Carers also acknowledged that they themselves opted out because they were too embarrassed, uncertain as to how to do it, feared misunderstandings and didn't have enough time. Some said it was unnecessary as the school was doing it.

Topics most likely to be discussed by carers were pregnancy and childbirth (36), followed by menstruation, sexual intercourse, contraception and appropriate/inappropriate behaviour. Menstruation and body parts were discussed with moderate frequency while those less frequently raised included emotions, homosexuality, sexually transmitted infections and marriage.

A school or service provider had asked 21 carers (33 per cent) for an opinion on RSE. This tended to happen more with parents than other carers.

Ten carers noted that they had had the opportunity to receive education to help them to discuss sexual health with their relatives and this tended to be from schools. A total of 27 (43 per cent) stated an interest in having such opportunities.

I have never really thought of this subject before. I would be interested in some sort of help regarding sex education as I don't know how to approach it.

(Mother of an 18-year-old young woman)

Information from interviews

The interviews with 22 family carers provided an opportunity to explore some of the issues relating to RSE in more detail.

Who should be responsible for RSE?

I think it should be a co-ordinated approach . . . My ideal scenario would be that there is some sort of programme in place, I know what the programme is, and then I back that up with information at home.

(Mother of a 14-year-old boy)

Carers had mixed views as to who should have responsibility for discussing sexuality and relationship issues with the person in their care, but the majority felt that it was a shared responsibility between carers and the school or service setting.

A minority believed that it was the primary responsibility of the carer.

I would have to say it is the carer because they spend most time with the child or the adult so I think it's primarily down to the carer to make sure everything's going on.

(Father of an 18-year-old young man)

In contrast one parent refuted this.

I don't know how to do it so the school is going to have to do it for me.

(Mother of a 13-year-old boy)

Nevertheless, regardless of whose responsibility it is, carers were clear that they wanted to be involved and informed as to what was being taught to the person in their care. As one carer stated:

I would rather know because I don't want any shocks or surprises.

(Mother of a 13-year-old boy)

RSE in schools

There is some sort of sexual related work through the school, I think regarding periods but not sexual. I think it's basic.

(Mother of a 14-year-old girl)

Carers were asked if they were familiar with the RSE programme in the school where the person in their care was attending or had attended. Generally, carers knowledge was vague or they thought the programme was basic.

I don't think they went into it in any depth but they would have looked for consent for her to take part.

(Mother of a 30-year-old woman)

One carer thought the school:

Seemed to have a pretty good RSE programme.

(Father of an 18-year-old young man)

How RSE should be delivered

With a child with disabilities you have to be upfront about it, you have to really explain it a lot more and talk a lot more about it.

(Mother of a 13-year-old boy)

All carers wanted the person in their care to receive RSE. Generally they felt that it is a life long process that should begin at a young age and continue into their adult years.

To leave it until the person is an adult is too late.

(Mother of a 20-year-old young woman)

Several stressed that it is not only about educating them about their bodies but also about how to deal with their emotions and giving them the skills for managing relationships and becoming more socially involved.

We hammer into them you shouldn't do this and you shouldn't do that and they have these strong feelings but they don't know what these feelings are.

(Mother of an 18-year-old young man)

They also had clear ideas of who should teach it, and how it should be taught.

You want somebody who is straight to the point . . . to get it over right and make sure they understand.

(Mother of a 16-old-year boy)

For adults with learning disabilities they need clear, very simple, big visual aids.

(Mother of an 18-year-old young woman)

In summary, carers who took part in our research felt it is important for the person in their care to receive RSE and that it is a shared responsibility. However, front-line staff and professionals working in services felt that this was not how carers typically responded. They perceived a great reluctance among carers for the adult in their care to receive RSE.

The views of front-line staff

This is an area no one in my workplace seems to know much about. I feel it's a very complex area and it doesn't appear fair that staff can have sexual relationships but the other adults at work (that is, clients) must be discouraged from doing so. It would be very beneficial if someone would come to one of our staff meetings to discuss views on sexuality and how best to support our clients with this subject.

(Senior/key worker, day centre, 30–44 years)

In the focus groups held with staff, they generally appreciated the need for RSE and most expressed some willingness to contribute to it. Equally they saw the need for training for themselves and also family carers. However, they pointed out that at times carers do not always want them to discuss sexual issues with the person in their care and that training opportunities are not always available to staff who have recently joined services and those in more junior positions.

In the questionnaire for staff, respondents were asked to rate a series of questions relating to the provision of RSE and training. As Table 9 indicates, most staff were in agreement that RSE was important and appeared willing to be involved in this. A surprisingly high number rated themselves as confident in answering questions but this is within the supervisory context they had noted earlier.

On all the topics below, staff opinion was broadly similar across types of services and for staff at different levels. In addition, staff characteristics such as gender, age, and length of time in employment were not significant predictors of their responses.

Table 9: Staff views on RSE topics (in percentages)

Item	Agree	Neutral	Disagree
Only senior staff should receive training in sexuality.	6	3	91
I would be interested in receiving training to train other staff	60	19	21
RSE is not very important for people with learning disabilities.	12	2	86
I don't feel it is my job to help people with learning disabilities with their sexuality and in their relationships.	16	11	73
I would not want to be involved in giving RSE to the people I work with.	18	20	62
I feel confident answering questions about sexuality asked by people with learning disabilities.	66	17	17

The views of professionals

With the community opportunities going up I think the risks go up and more sex education is needed.

(Service based professional)

It became apparent in our discussions with services that professional staff such as social workers, nurses and therapists, had taken on most of the responsibility for whatever RSE was provided, usually in response to incidents that had arisen. We explored their general knowledge about, and attitudes towards, sexual health and RSE for people with learning disabilities, through individual interviews. We also examined professional practices in their everyday work, levels of training and expertise in RSE, and proposed changes for the future.

Sample

In total, 24 professionals, most of whom were female (15), participated in a one-to-one, in-depth interview. Diversity of perspective as well as job relevance to the subject area, dictated those professionals approached to take part in the study. Professionals involved in management, policy development and decision making within learning disabilities services were considered most relevant.

The majority of the participants were learning disability nurses (8) and social workers (5) while the remainder included psychiatrists, vice-principals of schools for students with specific educational needs, one psychologist, one occupational therapist, and community care, residential, hospital and day centre managers. All participants were based within the Eastern, Western, and Southern Health and Social Services Board (HSSB) areas. With two exceptions all participants were employed by statutory services.

Professionals were broadly categorised as clinician or service based on the basis of their job role. This provided added detail to the quotes while protecting the anonymity of the professional. Clinicians included learning disability nurses, social workers, psychiatrists, a psychologist, and an occupational therapist. Service employees included school vice-principals and managers. Their views are incorporated in quotes which are included in the discussion.

Suitable professionals, nominated by members of the project's steering group and other networks, were sent a written invitation to take part. While two interviews were conducted at the researcher's workplace, the remainder took place in interview rooms or offices within the interviewees' workplace. They generally lasted between 30–60 minutes and were audiotaped, transcribed, and analysed using thematic content analysis.

The interviews were semi-structured in nature. Several of the interview topics were determined by data from previous interviews and focus groups with people with learning disabilities and front-line staff. The following themes emerged.

Perceived relevance of RSE to job role

As professionals, we have a duty to give them the same opportunities of course, but also to protect them and to offer them as much protection and education for their cognitive level. I work with adults and children and I go right down to profound and severe. I think, what we as professionals need to be very aware of, that it's not just sexuality, but it's also about emotional education too.

(Clinician)

Professionals reported that issues relating to sexuality and relationships are becoming increasingly relevant to their work, since referrals have increased due to greater community presence of people with learning disabilities, mis-referral of people with learning disabilities, and developments in human rights legislation.

Those who were employed in consultancy or a management role reported less current and direct involvement in RSE therefore their responses were mainly based on their experience in previous posts. Of those professionals who worked directly with clients, RSE involvement included undertaking assessments, programme delivery and evaluation, participation in dedicated strategy groups, and interventions in response to specific incidents. However, at times their involvement in RSE was minimal.

Perceived relevance of RSE to people with learning disabilities

It's something that's offered to everybody else so why not people with learning disabilities? They have the same rights as everybody else to have access to information about everything in their life.

(Clinician)

All professionals were of the opinion that RSE is important for people with learning disabilities. They recognised it as a human rights issue and advocated that it is an integral part of a holistic view of people with learning disabilities. However, they did point out that because people with learning disabilities are more vulnerable and therefore at greater risk of encountering abusive situations, professionals have a dual responsibility towards them – education and protection. However, in terms of priority, protection tended to supersede that of education.

Delivery of RSE to people with learning disabilities

I don't think it's as simple as saying everybody can have sex education, but I think there should be sex education at different levels as appropriate for the client's needs and with symbols for understanding.

(Service based professional)

There was agreement that RSE is a life long process and should be age/ability appropriate. For example, it was suggested that early work ought to focus on emotional education and the development of an emotional vocabulary as this paves the way for later work on sexuality.

The professionals advocated a multi-disciplinary approach which included carers. Some professionals felt that unlike schools where RSE is a compulsory element of the curriculum, it should not necessarily be mandatory in service settings for adults with learning disabilities. And in regard to schools, they emphasised that large classes are inappropriate. It needs to be tailored to individuals.

Reactive versus proactive work

There's very little going on, any work that is going on is taken on by certain professionals who feel themselves that there is a need. Very often it's in response to some incident rather than any sort of planned educational programme.

(Service based professional)

The majority of professionals described their work as mainly, if not entirely, reactive in nature. They stressed that economic constraints and lack of human and material resources reduced the scope for proactive RSE initiatives outside the school setting and in particular in adult services. One professional suggested that a structured and up-to-date educational package should be developed. Some suggested that there was a tendency for professionals occupying senior positions to believe that RSE issues are 'better left alone' and the absence of clear service policy and guidelines and lack of training opportunities contributed to the overall inertia.

Protection versus personal development

I suppose to start off it's more around protection and then working on that and trying to, you know, if there is self-esteem or confidence issues there then yes, we can work on that, but it's more around protection.

(Clinician)

Many professionals agreed that both protection and personal development are important but given their professional responsibilities and the predominantly reactive nature of RSE, protection is inevitably the priority.

However, some professionals did acknowledge that whereas protection should be a priority for clients of all cognitive levels, the promotion of independence and autonomy should also be a priority for those with higher ability. Professionals also face a dilemma whereby a balance must be struck between the priorities of carers and those of the person with learning disabilities. This creates a tension with regards to whose needs take priority.

Professionals' perceptions of attitudes of carers

The younger carers of today have come on leaps and bounds. They are now well aware that their young son or daughter is, and can be sexually active, and have the same sexual feelings as they themselves.

(Service based professional)

Some carers would have that view that this just doesn't exist for my child. And they will use the word child even though you could be sitting there with a 35-year-old man.

(Clinician)

Professionals reported both positive and negative attitudes of carers to RSE. On the positive side some carers are pleased that issues concerning sexuality and relationships are being dealt with but others fear that knowledge will translate into action. Several reported that some carers are unable to perceive the person in their

care as an adult and assume that the learning disability precludes sexual awareness and desire. Some reported that negative attitudes are related to religious beliefs.

Some professionals had experienced carers who were caring for a daughter suggesting she should be sterilised to protect against pregnancy. Others wanted their child to be labelled 'vulnerable' regardless of whether or not this is applicable. The intention is that the activities of the person in their care will be restricted and his/her sexual needs therefore dismissed or ignored.

Informing carers about RSE

I always will work in partnership with their families and engage their carers – nearly always the mother and I'll say to them, 'Listen, I will be talking to your son or daughter about this. How do you feel about it?' And they would say, 'Well, I do like it', or 'I don't like it.' And I would say, 'Well, it's part of my remit in terms of protection work for them, because they are an adult so I have to give them the right and that information.' If their son or daughter does give me the go ahead that they want that information, then I ask them 'Do they want their family to know, do they want them involved?'

(Clinician)

If the client is under 18 years old the carer's consent is always sought. For clients over 18 years old, it is more complex. The decision as to whether or not to seek consent or not from carers is determined by factors such as age, level of disability, sexual knowledge and whether or not the person is in a relationship. However, professionals considered it important to always be sensitive to their family's cultural and religious beliefs.

Policy and practice in RSE

Staff will come and say, 'Look, will you speak to such and such', because obviously they don't feel comfortable. But I don't think it's being uncomfortable with RSE, it is just they don't feel confident enough with the area – they probably need more training and practice and more doing it.

(Service based professional)

The need for training was emphasised by many professionals, particularly on the law, parenting assessments and resource development. It was reported that in day centres staff do not always feel that they are adequately equipped to carry forward training programmes and therefore such programmes become a low priority and are only held in response to a particularly problematic incident. It was also suggested that the experiential nature of training in this area of work often left staff with unresolved personal issues.

A small number of professionals were responsible for ensuring the delivery of RSE training to staff. However, it was reported that the training must be supported through supervision.

In some cases, training had been received ten years previously and therefore was now outdated. In other cases no specific training had been received and any RSE/policy knowledge was gained through working within the learning disability field or alongside psychologists.

Many recognized that it was important for services to have RSE policies in place but some questioned their effectiveness given the lack of training opportunities.

Barriers to providing RSE

They're (carers) all out for their sons or daughters. They've had to fight for different services and they're going to continue, but there is that almighty fear that talking about sex will encourage them to go out and do it . . . because they believe, well they don't even think about things like that, so why would I even introduce it into their brains. That's why I've always gone along the line of keeping safe, and being aware and going for smears.

(Clinician)

The general protective attitude towards and fear for their child, meant that carers were often perceived by professionals as a major barrier to RSE. But some professionals also had concerns regarding how the information will be interpreted and used by the person with learning disabilities once s/he leaves the confines of the services and consequently this prevented them from providing full information. This was compounded by a fear of litigation.

They also suggested that inadequate guidelines and training on the guidelines may present a barrier to practice and that a lack of organisational commitment inhibits professionals from engaging in RSE. However, external factors were also identified as barriers. As one professional commented:

I think Northern Ireland's not a very open society . . . so I think society's attitudes really are probably the biggest barrier . . . sexuality's not a part of life or if it is, it's a very abnormal part. I think that's by far the biggest barrier.

(Clinician)

Another similarly commented:

I don't think the whole community has totally accepted learning disabilities . . . that recognition that they are very different and they are not one of us and they wouldn't have sexual feelings and how would Johnny know about erections and penises, sure he wouldn't know that!

(Service based professional)

It was also acknowledged that people with learning disabilities have their own barriers to accessing RSE, including embarrassment, lack of knowledge/inability to understand, poor self-perception and poor communication skills.

Recommendations for the future

I would like to see the guidelines reviewed and updated. I would like to see the in-depth training take place for the staff who are willing to go down that road. I think there should be some sort of a support group for those staff, somebody who will just be there to bounce ideas off.

(Service based professional)

All professionals recognised that changes must take place both within the RSE programme and at organisational and societal levels if RSE is to be effective and relevant. From an organisational perspective it was considered imperative to review policies and guidelines and provide appropriate training and ongoing supervision to ensure that they become a reality. One professional suggested that an RSE specialist should be appointed for each organisation.

However, professionals suggested that to bring about real change RSE must become a strategic priority issue and the Government must lead on this.

RSE in schools in Northern Ireland

We didn't do it in school. They didn't teach us. I just learnt from SKY TV and TV programmes.

(27-year-old man)

As mentioned earlier, little proactive RSE work is currently being carried out within adult services for people with learning disabilities. As a result, in our research we were forced to focus on ongoing RSE work within schools in order to learn more about its form and content. Several methods were employed.

Firstly, a brief set of questions relating to RSE were sent to approximately 35 schools for students with specific educational needs throughout Northern Ireland and a total of 18 were returned.

Secondly, discussions (formal and informal) took place with those who were responsible for RSE within six schools for people with specific educational needs. These included four schools for those with severe learning disabilities and two for those with moderate learning disabilities. On three occasions, these discussions took place with the vice principal.

Thirdly, five separate observations took place within three schools for students with specific educational needs. These observations involved classes for young people aged 10–17 years with varying levels of disability. Although several schools reported that they had an RSE programme within the school, when questioned further, it became evident that it wasn't currently running and they appeared reluctant to discuss the topic of RSE further with the project team.

The findings are as follows:

- 17 out of the 18 have an RSE programme currently in operation and the remaining school stated that it was 'somewhere in between'.
- 16 out of the 18 have a written policy regarding content, delivery and organisation of RSE, and a designated member of staff with responsibility for co-ordinating it across the curriculum. In several schools, this was the vice-principal.
- Generally, they taught gender understanding, emotions, body parts, appropriate and inappropriate touch, and puberty. However, sexual intercourse was not taught in five schools and six schools reported that they didn't teach pregnancy and contraception. Sexually transmitted infections were not taught in seven of the schools. Wet dreams and masturbation were the topics least likely to be taught.

- 17 taught RSE as part of personal, social and health education (PSHE) and/or in other subject areas. As illustrated in Table 10, these include health education, pastoral care, general science or religious education.

Table 10: Subject areas where RSE was taught

Subject area	No. of schools
Personal, social and health education	17
As part of another/many other subjects	17
Health education	9
Pastoral care	8
General science	7
Religious education	3

Interviews and observations

The main themes to emerge from observations of RSE classes alongside formal and informal discussions with teachers prior to and following the RSE class were as follows:

Inconsistent delivery of RSE

Variation existed in the delivery of RSE in schools. Some schools were delivering excellent RSE programmes covering a wide range of topics, however, other schools claimed that they were delivering a comprehensive RSE programme, but on further questioning it became evident that certain topics were being omitted. These included sexual intercourse and related areas such as pregnancy, contraception and sexually transmitted infections.

RSE was generally taught to young men and women together, however the class was sometimes separated to teach gender specific areas such as menstruation. RSE was a subject that appeared mainly directed at school leavers in order 'to prepare them for being out in the community'. Some felt that RSE is a subject that needs to be tailored to individual needs but resources prevented this. Several teachers used the term 'discreetly' to describe how they delivered RSE while another teacher emphasised that it was 'on a one-to-one, needs to know basis'.

The students engaged well in the RSE classes observed and felt comfortable in asking questions. All appeared to enjoy the classes and few displayed embarrassment. Efforts were made by teachers to involve all the students in the class and checks were made for understanding. However, some classes were quite large (around 14) and the students may have benefited from smaller groups. All teachers commented that the delivery of RSE is a very gradual process which needs to be repeatedly reinforced. One teacher admitted that although RSE was taught, the main emphasis was placed on being safe and protected.

In one school, a teacher reported that different views existed as to whether RSE actually promotes behaviour that the pupils might never get an opportunity to engage in, as well as ‘opening a can of worms’.

Working with family carers

Teachers confirmed that parents are kept fully informed of RSE work. Generally they found that carers are slightly worried that their child is receiving information on sexuality and sexual health but most are glad that it is at least being addressed by someone. One teacher mentioned that although carers have the right to withdraw their child from RSE classes, few did so. One exception that had occurred was when masturbation was being discussed.

In one school, the teacher noted that carers felt that it wasn’t necessary to teach pupils about sexual intercourse, therefore this was not taught unless otherwise requested. They recounted how there had been an incident involving a 17-year-old girl, so school staff asked her carers if they wanted them to do some one-to-one work with her on sexual intercourse. The mother was appalled. This teacher felt that carers and people with learning disabilities ‘have enough on their plate’ and that ‘students don’t really need to be taught about sexual intercourse’ because ‘you don’t want to confuse their feelings’.

Communication and reliance on external organisations

Several schools relied on **fpa** staff, clinical psychologists, nurses and other health care professionals to deliver most of the RSE, rather than a teacher. Some teachers felt that these professionals are better equipped and knowledgeable for teaching more in-depth areas of RSE, areas that they themselves wouldn’t feel confident to teach.

However, there appears to be a lack of communication between teachers and health care professionals and with other teachers. In one case, when an external organisation did teach RSE, the teacher was not present in the class and therefore, was unaware of what was being taught. The teacher then found it difficult to re-enforce this information. Another similar example of breakdown in communication occurred when a class was being taught about contraception and sexually transmitted infections. The teacher was asked if the students had already been taught about sexual intercourse and she simply responded that she didn’t know.

Training

As some teachers felt ill-equipped to deliver RSE, it is no surprise that they stated a need for training in the area. Two teachers stated that although they taught RSE, they had never received any training on the subject. This was due to lack of opportunity and funding. One teacher said that she needed guidance and felt that ‘a working document that indicated or set out what knowledge should be taught that is appropriate in accordance with the age of the pupil’ would be useful. Few mentioned having a curriculum document available to them.

Resources

Teachers were consistent in reporting the lack of suitable RSE resources and the lack of funding available to invest in any that did exist. Many relied on materials they had created themselves.

Summary of findings

From all these sources of information we can conclude:

- There is little formal RSE available to people with learning disabilities in Northern Ireland despite their desire to know more about sexual health, the acknowledgement of its importance by some carers and the appreciation of the need for it by front-line staff and professionals.
- The preoccupation with the protection of vulnerable people has stymied progress in this area as has an over-emphasis on responding to the wishes of family carers irrespective of the needs and wishes of the person with learning disabilities. Wider social and religious attitudes have also been inhibitors.
- There was some agreement around the style and level of RSE required. It should start early and be tailored to individual needs. Family carers should be informed and involved. Extensive use should be made of visual aids. It needs to be integrated with other educational and support programmes. It should include strategies for self-protection.
- Staff and carers need training in the design and delivery of RSE for people with learning disabilities. There is currently an over-reliance on 'outside' personnel which provides little ongoing support to people after the RSE sessions have ended.
- Recommendations for the future include the appointment of an RSE co-ordinator within learning disability services, the normalisation and prioritisation of RSE within health and social services and the production of policy directives and guidelines to ensure action is taken.

Conclusions and recommendations

This chapter completes the report by describing the main conclusions to arise from the information gained from all the stake-holders during the project – people with learning disabilities, family carers, front-line staff and professionals. From these, we move on to identify key recommendations that are designed to ensure action is taken by all the key players and not least, by people with learning disabilities themselves.

Conclusions

The conclusions are presented in terms of the four main stake-holder groups. This section also includes:

- An overarching analysis of the complexities inherent in the issues of sexuality and relationships with regard to people with learning disabilities.
- Conclusions with regard to relationships and sexuality education (RSE).
- A summary of responses that were common across the various stake-holders.

These conclusions were validated at a meeting of the steering group which took place on 1 September 2006.

Although we accept that people's attitudes, needs and wishes have to be assessed individually, it is possible and necessary to draw general conclusions. However, we would argue that this can only progress when there is a cultural shift in attitudes and beliefs around these issues among all stake-holders. We hope that these conclusions will contribute to that progress.

Although the conclusions are particular to Northern Ireland, they do echo many of the themes present in British and North American research on these issues.

Stake-holders

People with learning disabilities

Sexuality and relationships are a primary concern to self-advocates

In our meetings and dialogue with various individuals and advocacy groups, they stressed their wish for sexuality and relationships to be addressed more actively than they are at present. They were concerned about the lack of educational opportunities available to them and the limitations that family carers and staff placed on them. They felt 'over-protected' and thought their capacity to consent was not respected. They appear to have few opportunities for sexual expression. Many talk in terms of having or wanting a boyfriend/girlfriend.

Discrimination is evident

Despite recent legislation that promotes equal opportunities for people with disabilities, this is not happening in the area of sexuality and relationships. There is a lack of educational opportunities available in schools and colleges. People with learning disabilities do not have the same opportunities to form friendships and relationships. Many lead lonely lives and often have little privacy. Reform of the Mental Health Act is needed to accord with people's rights.

Disempowered people

Although Government policy emphasises the empowerment of people with learning disabilities, the opposite appears to be true in the area of sexual health. Any queries about sex or sexual health have to be documented by service staff, and family carers informed. Any close relationship between two consenting adults is at risk of being terminated or closely supervised to prevent sexual activity occurring. Most adults with learning disabilities have little choice or control over their activities and relationships whether they live at home with family carers or in supported accommodation.

People are confused and ignorant about sexuality

Compared to their age peers, many people with learning disabilities have limited understanding and experience of sexual health, notably sexual intercourse, pregnancy, contraception and sexually transmitted infections. Although staff and family carers are fearful of sexual abuse occurring, they seem reluctant to offer specific guidance in self-protection and prefer to rely instead on prohibition and supervision. Arguably this puts people with learning disabilities at greater risk of abuse.

Family carers

Many family carers prefer to ignore the issues of sexuality and relationships

We experienced great difficulty in engaging with family carers on these issues. Our impression was that families preferred to ignore the topic. Some perceived their relative as uninterested in sexual health issues or they were reluctant to pursue any interest their relative may have, possibly because of embarrassment or a fear as to what it might lead to. Few carers could see their relatives coping with pregnancy and children and wanted to ensure this never happened.

Who to turn to?

We gained the impression that family carers rarely raise the issue of sexuality with professionals or front-line staff unless there has been a specific problem. Equally, professionals appear reluctant to address the issue with carers. The consequence is that no dialogue takes place and both parties feel isolated and unsure of each other's views and concerns.

Carer involvement

Although there are carers who have taken active steps to educate their relatives they also appreciate the benefit to be gained from professionals and front-line staff providing RSE. However, carers felt they would need to be fully informed when this happens

so that they can reinforce the learning at home. They would also welcome training opportunities being made available to them although this does not appear to happen at present.

Front-line staff

Supervise and limit sexual expression

Front-line staff working in day centres or supported accommodation feel under pressure from managers and family carers to supervise and limit the sexual expression of people with learning disabilities. Staff appreciate the lack of privacy and disrespect this entails but they feel they are powerless to do anything about it, in case it reflects badly on them.

Clear policy and guidelines

Staff emphasise the need to have clear policies and guidelines on sexuality and relationships which include procedures on how these issues should be handled within services, but often they feel these are lacking. These guidelines need to emphasise respect for the person with learning disabilities' needs and wishes, and to give greater recognition to issues of confidentiality. Supportive leadership from managers is essential.

RSE is needed

Staff appreciate the need for RSE and most express some willingness to contribute to it. Equally, they see the need for training for themselves and also family carers. However, these opportunities may not be made available to staff who have recently joined services, those in part-time posts and those in more junior positions. Any training needs to be located within a co-ordinated approach within and across services, to respond to the needs of service-users.

Working together

There appeared to be limited opportunities for dialogue to occur between staff, managers and carers. Consequently, misconceptions occurred and a culture of co-operation was not common. This could be resolved by ensuring that dialogue between all interested parties begins in the primary years of schooling and is reviewed regularly as part of person-centred planning.

Professionals

Whose job is it?

A wide range of professionals can be involved in dealing with sexual issues that arise in family and service settings. None are especially prepared to undertake this work but through personal interest, training and experience certain people can and have gained a particular expertise. This needs to be encouraged within professional teams and the availability of this role publicised to service personnel and families. Equally, service personnel would gain from contact with colleagues in other disciplines and places, for example through a network.

Proactive rather than reactive

All professionals agreed that much of their present work is directed towards reacting to problems that have arisen. This can be time-consuming and ultimately frustrating as options for change are limited. They prefer to be more proactive through engagement with RSE, social skills and relationship training, and by identifying individuals 'at risk'. Their current workloads prevent this from happening.

Leadership is lacking

As with service staff, professionals often feel they are working in a vacuum as regards policy and service guidelines. Service directors and managers appear reluctant to provide a strong lead on this issue but this may be compounded by a lack of professional advocacy on this matter within services. Common initiatives are required across education, health and social services.

Complexities

A recurring theme in the information gathering was the complexity of the issues raised by sexuality and relationships. These included:

- The variety of people included in the group 'learning disabled'. This includes age, level of disability, additional disabilities, living arrangements and past experiences. They form a heterogeneous group for whom it is difficult to prescribe common approaches.
- Northern Ireland society tends to be conservative with a high level of religious adherence. Political and community leaders along with family carers and service personnel may adopt defined positions with regard to sexual behaviour. Asking people to compromise or change deep-seated beliefs is not easy. There is no tradition of discussing religious and ethical differences in Northern Irish society in an open, informed and respectful manner.
- Education and social services currently prioritise the protection of vulnerable people. While this should be balanced by opportunities for personal growth and development this is not easily done and at present the balance is tilted towards protection. People with learning disabilities may be seen as a threat to others and it is a priority to minimise this.
- Staff working in services are mostly low paid and many have no formal vocational qualifications. Advising people on sexual health and relationships requires a high level of skill and expertise. This is lacking within services and cannot be quickly rectified.
- There is little tradition of service staff and family carers working together on issues around sexuality.
- The advocacy of people with learning disabilities is in its infancy. Assumptions about their lack of competence in decision-making and risk-taking have undermined their attempts to make their views known through either individual or group advocacy.

These go some way towards explaining the intricacies involved in addressing the issue of sexuality and people with learning disabilities, and the multi-faceted nature of the task.

Relationships and sexuality education

Our conclusions regarding RSE in Northern Ireland for people with learning disabilities are summarised as follows:

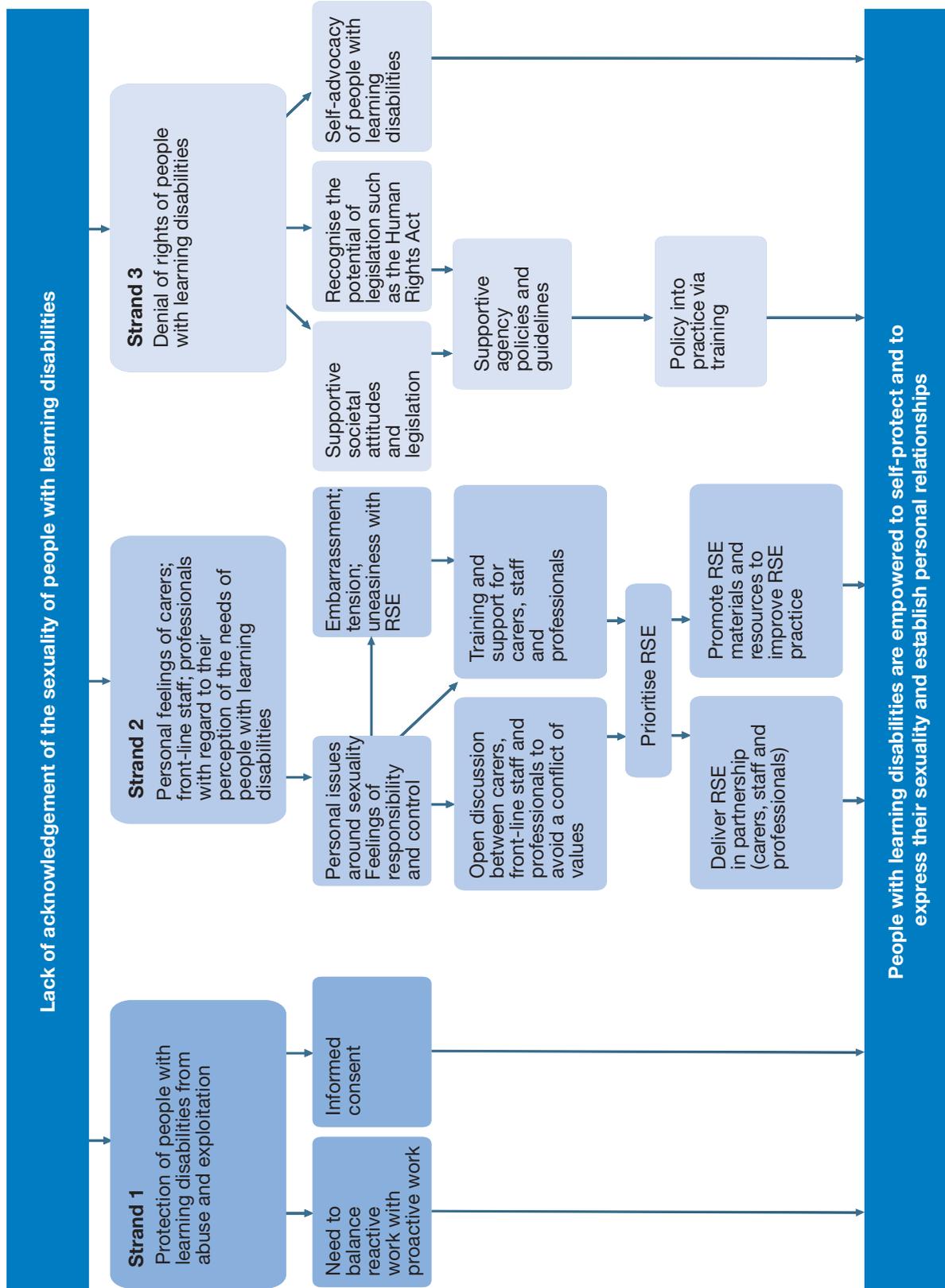
- There is little RSE being delivered in schools and still less in further education, day centres and supported accommodation. Often its delivery is determined by the commitment of a particular staff member.
- What is said/reported to be delivered is often difficult to see in practice.
- When RSE does take place, the emphasis tends to be on protection rather than on personal growth and development, and the more intimate aspects of sexuality. However, there is much variation in practice.
- RSE tends to take place with people with learning disabilities on a reactive basis, particularly when adults with learning disabilities are involved.
- There is no explicit policy on the provision of RSE within health and social services. Clear service directives are required to ensure that RSE is provided. This needs to be linked to training opportunities for staff. Mechanisms need to be established for monitoring its implementation and evaluating its impact.

Common responses

Finally, the following responses were common across the various stake-holders:

- **Fear and risks:** Sexuality and relationships were defined more in terms of fears and risks rather than creating positive opportunities for people.
- **Inertia:** Significant others in the lives of people with learning disabilities seemed content to do nothing and maintain the status quo, rather than take action.
- **Lip service:** Services often give lip service to the issue of sexuality and relationships without taking active steps to address it or to do so in an adequate manner. A similar approach is used with user control and choice.
- **Lack of knowledge:** Family carers and service staff appeared unaware of what could be done or what was happening elsewhere in terms of information, education and support for the person in their care.
- **Lack of dialogue:** There were few instances of any attempts among the various stake-holders to work together on the issues of sexuality and relationships. Stake-holders are isolated from one another.

Figure 14: Sexuality and people with learning disabilities



Summary

In Figure 14 we have attempted to summarise the reasons for a lack of acknowledgement of the sexuality of people with learning disabilities. We identify three main strands that recurred across the groups consulted. These generate various tensions and a consequent reluctance to act. For many people, doing nothing seems a safer option.

However, this framework also allows us to detail the steps that need to be taken to transform this impasse into one that will result in people with learning disabilities being empowered to self-protect; to express their sexuality and to establish personal relationships.

The next section describes the potential practice and strategic recommendations needed to bring this about. Key steps are summarised in Figure 14.

Recommendations

The recommendations listed in this section are selective rather than comprehensive. Although we recognise that much needs to be done to address the conclusions noted previously, we have chosen to focus on recommendations that we felt met the following criteria:

- They could potentially make an immediate difference to the lives of people with learning disabilities.
- They could be implemented through a change in practice rather than requiring extra resources (even though these will be required in time if new policies and practices are to be fully implemented).
- They would build on good practice that is already underway in Northern Ireland or elsewhere in the UK.
- They could command reasonable support across the different interest groups.
- They would be easily monitored so that progress in their implementation can be measured by agencies and advocacy groups.

The detail of the recommendations has evolved through consultation sessions held with the project steering group augmented by a range of personnel drawn from all sectors and interest groups. The full impact of the recommendations will be felt if they are implemented in their entirety as each one supports the others. We have grouped them into practice and strategic recommendations. They are however mutually dependent.

Practice recommendations

Teenagers and adults with learning disabilities need to have access to information about sex, sexuality and relationships

Each Health and Social Services Board (HSSB) should produce an accessible information leaflet for people with learning disabilities and their family carers that would list sources of information and support on sexuality and relationships. This could include details of relevant booklets, contact details of statutory and voluntary agencies,

telephone helplines and websites. The leaflet should be distributed widely through schools, day centres, services and general practices.

Sexual health should feature in all person-centred planning and reviews

When family carers request, or service professionals undertake, any form of person-centred review – for example in transition planning, after health checks, or in day activity programmes – the practitioner (for example, the keyworker) should raise the issue of sexuality and sexual health issues with both the person with learning disabilities and with their family carer. The resulting person-centred plans should document the actions to be taken (or reasons for why no action was taken).

Resources

Front-line staff and professionals repeatedly mentioned a scarcity of resources but there are excellent resources available for conveying sexual information to people with learning disabilities. Clearly these resources are not generally known or made use of. It is therefore recommended that each HSSB commits to jointly producing a regional catalogue of appropriate resources which is updated on an annual basis.

RSE for people with learning disabilities

The provision of RSE in schools and day centres is inconsistent. It is recommended that in each school, centre or service, one member of staff is given responsibility for identifying suitable local and regional resources, accessing training opportunities for staff and when appropriate enlisting the help of outside personnel to assist with the delivery of RSE. A range of approaches will be required including those centred on individuals as well as those based on groups. The assessment tool developed in this research will assist practitioners in ascertaining a profile of an individual's present level of knowledge and awareness around which educational inputs can be planned.

It is also recommended that a staff member is nominated as a person who can be approached when someone with learning disabilities wants to know about or to discuss personal matters. This could be a senior member of staff within schools, colleges or centres who has experience of pastoral care. Keyworkers might also fulfil a similar role in supported accommodation.

Self-protection

The vulnerability of people with learning disabilities to abuse was a primary concern of carers and many practitioners. However reliance on protective strategies may not prove sufficient and greater attention must be paid to enabling people with learning disabilities to protect themselves, either from abuse or having accusations of abuse levelled against them. At a minimum this requires them to appreciate the difference between appropriate and inappropriate sexual behaviour and to have the vocabulary to describe unwanted sexual encounters. Denying people such opportunities, arguably increases their vulnerability. It is therefore recommended that all RSE initiatives in, for example, schools and day centres, include information and education on appropriate and inappropriate behaviours, and promote self-protection.

Training for front-line staff and professionals

A major issue for front-line staff and professionals was the lack of available training on sexuality and relationships. Some were particularly concerned that even where services have policies and guidelines in place there was inadequate training to enable them to ensure that these are put into practice. An additional concern for many was the absence of support for them when dealing with sexuality and relationships issues with clients. It is therefore recommended that each HSSB develop a training strategy which includes ongoing supervision and support.

Information and support for family carers

Some family carers had taken active steps to educate the person in their care on sexuality and relationship issues but others have struggled because of their feelings of embarrassment or fear. Some have preferred to ignore it as an issue. It was also evident that with the exception of incidents which required reactive strategies there was often little dialogue between carers, front-line staff or professionals.

It is therefore recommended that each service or organisation should provide a joint awareness raising or training event on the topic of sexuality for their staff and family carers on at least an annual basis. The nature and form of the training could vary depending on local circumstances and need but these will provide a forum for the issue to be brought into the open and concerns addressed in an open and systematic way. The leadership for these events could come from any of the interested parties identified in the research, for example, a user's committee within a day centre, a carers' group, a professional or service manager.

Some family carers could also benefit from additional support to help them cope with the developing sexuality of the person in their care. This could be in the form of one-to-one support or within a group setting. It is therefore recommended that each HSSB explores options as to how this need might be met.

Peer education

The potential of people with learning disabilities to act as a peer educator on basic sexual health issues should be explored. The advantages are that the peer educator acquires skills and confidence which can transfer to other people with learning disabilities while simultaneously giving out useful information. The peer educators could also contribute to the training of staff, professionals and family carers.

However, successful peer education initiatives require effective management and support and it is recommended that each peer educator would have a support worker alongside him/her.

Local area networks

Within a locality, for example a District Council or an HSSB area, a network of interested people should be identified which could meet periodically to share information and plan joint events with the intention of ensuring some continuity across service sectors and mutual support. These would also offer life-long learning opportunities to people with learning disabilities. Local networks could be affiliated to a regional network or evolve from one that starts at this level.

Opportunities for friendships and sexual expression

Although some organisations operate befriending initiatives, a recurrent theme among people with learning disabilities that we consulted was the lack of opportunities they had for making friends and dating. This would suggest that service organisations and family carers need to give this matter much greater attention than they may have done in the past. However, it is likely that advocacy and voluntary organisations will continue to play a crucial role in filling this void and it is recommended that they should learn from initiatives happening in other parts of the UK to consider the feasibility of establishing similar initiatives in Northern Ireland. One initiative that was specifically mentioned by several participants was a dating agency specifically for people with learning disabilities such as ‘Stars in the Sky’ which was recently launched in London. As well as matching people, the agency provides a screening and chaperoning service.

Availability of relationship counselling and sexual health advice

We anticipate increasing demand for these services. Service organisations therefore need to include these within their staff development and skills’ programmes while also reminding and encouraging mainstream agencies in these areas to fulfil their responsibilities under the Disability Discrimination Act in providing these services. Again their involvement in local area networks would assist such developments.

Strategic recommendations

The recommendations in this section are addressed more to policy makers and service directors. However, all groups have a crucial role in lobbying to ensure that action is taken. This can be more effective when done in a co-ordinated way across different interest groups especially with the involvement of advocacy groups.

Legislation

Current legislation in Northern Ireland, which regulates the sexual activity of persons with ‘mental impairments’ is outdated, and arguably contravenes the Human Rights Act. It is hoped that recommendations emerging from the Bamford Review of Mental Health and Learning Disability will be speedily implemented, especially with respect to capacity legislation.

Leadership

The importance of the issue of sexuality to people with learning disabilities needs to be recognised at the highest level within the Government, for example in ministerial speeches and policy directives from Government departments and statutory agencies. Monitoring arrangements are also necessary to assist with implementation. We would urge the school inspectorate and the newly appointed Regulation and Quality Improvement Authority to include this aspect in all future inspections they undertake of schools and services.

Guidance

We commend the development of service policies around sexuality that is ongoing in Northern Ireland, especially those that are inter-agency. However a common complaint

that we heard from service staff was the absence of practice guidelines that give specific advice on how to deal with the day-to-day issues that arose for them in their work. Equally, practice guidelines would better inform the people using the services about the conduct they are expected to show when in service settings. All statutory agencies, but especially in health and social services, need to give this immediate attention.

Professional training

Sexuality and relationships should feature in all training courses for professionals who are involved with people with learning disabilities, most notably nurses and social workers. In addition, competency-based standards and training materials should be produced that increase its profile within NVQs in social care.

Social attitudes

A supportive social climate is essential if we are to achieve a more inclusive society. In Northern Ireland there has been a gradual acceptance by a significant section of the population of a diverse range of relationships including couples choosing to live together rather than marrying, same sex relationships and civil partnerships. This acceptance needs to be extended towards people with learning disabilities with regard to their sexuality. Opinion formers within society, such as local politicians, need to be well briefed on the issues and the media has an important role to play in reshaping attitudes. It is recommended that statutory and voluntary agencies produce briefing papers for local politicians using the evidence from this study and work with the print and broadcast media to portray and promote positive stories about people with learning disabilities with regard to their sexuality and relationships.

Partnership efforts

These recommendations are not the sole preserve of any one grouping. It is not a question of waiting for 'them' to do something about the issue rather our hope is that the initiatives will come from a range of groups and better still, through them working in partnerships with one another. In our project we came across excellent examples of leadership being shown by advocates, carers, staff and professionals. We feel that small-scale local initiatives, coupled with broader strategic plans, could quickly resolve the inertia and dilemmas that currently pervade issues of sexuality and relationships for people with learning disabilities. They deserve better.

Appendix one

Steering group members

Lizzie Dickson	Team Leader, Learning Disability Team, John Mitchel Place, Newry and Mourne Trust
Louise Duffy	Network Co-ordinator, Disability Network, Lisburn
Jenny Fitzsimons	Senior Practitioner, Downshire Hospital, Down and Lisburn Trust
Pauline Fitzsimons	Support and Development Worker, Mencap, Eastern area and Parent
Ian Hayes	Self-advocate
Joanne McDonald	Equality Officer, Mencap and Self-advocate
Ann McGarry	Senior Social Worker, Muckamore Abbey Hospital, Muckamore
Siobhan McNally	Community Nurse Care Manager, Foyle Trust
Dirk Schubotz	Young Life and Times Director, ARC, Queen's University, Belfast
Stephen Woods	Network Co-ordinator, Disability Network, Lisburn (formerly as Support and Development Worker, Mencap, Eastern Area)

Appendix two

Profile of participants

People with learning disabilities, carers, professionals and front-line staff participated in the study. This section will present a profile of those participants. The number of participants in the interviews and focus groups are small therefore the profile only includes percentages for those groups who completed questionnaires.

People with learning disabilities

A total of 17 statutory, voluntary and community agencies throughout Northern Ireland helped to gain access to participants. They were recruited as shown in Table 11:

Table 11: Recruitment source of participants (in numbers)

Recruitment Source	No. of participants
Schools	18
Day-care services	14
Residential services	10
Advocacy groups	7
Supported living services	7
Employment and training services	3
Professionals	3
Total	62

Data were obtained from semi-structured interviews and focus groups.

Interviews

A total of 62 semi-structured interviews took place between February and November 2005.

Gender

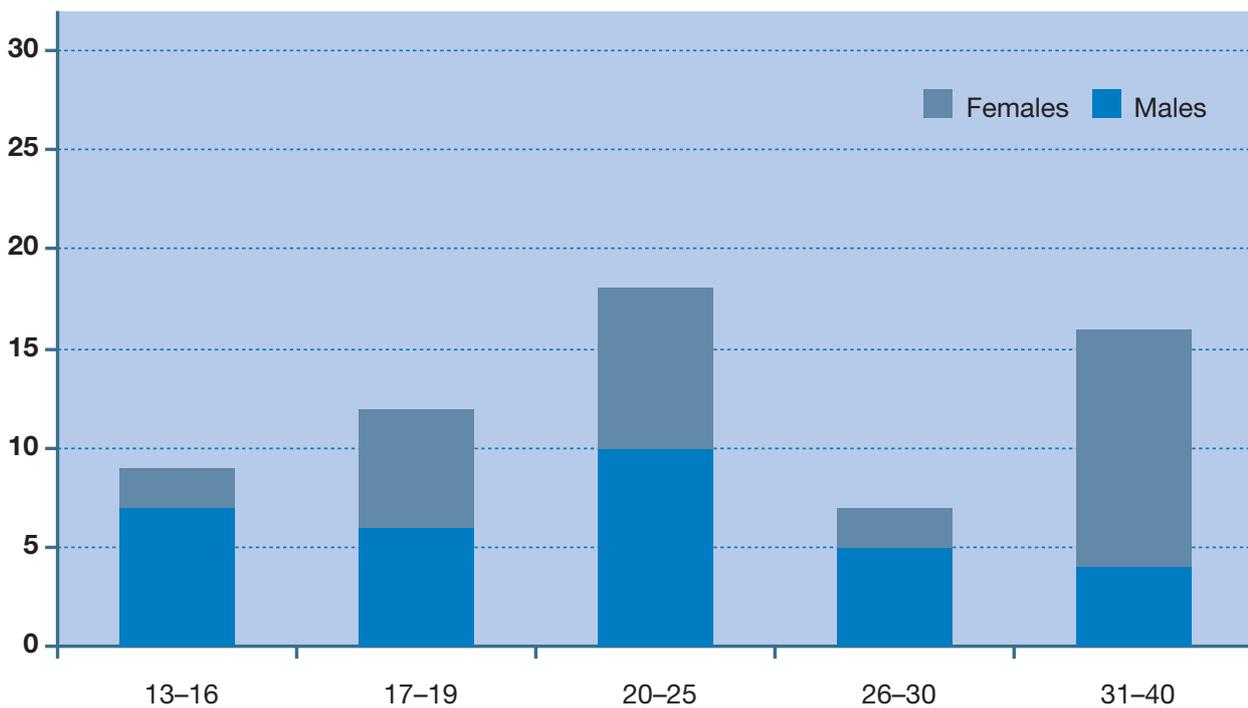
- 32 were male
- 30 were female.

Age

As Figure 14 shows:

- 39 were under 26 years old
- 23 were aged 26 years or over.

Figure 15: Male and female participants by age group (in numbers)



Demographic background

The interviews were conducted throughout Northern Ireland which has four Health and Social Services Boards (HSSBs). The aim was to interview people with learning disabilities in all four Board areas.

In total:

- 29 lived in the Eastern HSSB area
- 13 lived in the Southern HSSB area
- 11 lived in the Northern HSSB area
- 9 lived in the Western HSSB area

The Eastern HSSB is over-represented in the sample but it is the largest HSSB in Northern Ireland, and it was easier to access people with learning disabilities via this board as it has the highest percentage of people with learning disabilities in Northern Ireland (McConkey, Spollen and Jamison, 2003).

Living arrangements

Table 12 illustrates the living arrangements of the participants with the majority (37) living at home with a family carer. Of those who did not live with a family carer, most had frequent contact with family carers through visits and phone calls. Only two interviewees indicated that they were not in contact with a family carer.

Table 12: Living arrangements of participants (in numbers)

Living situation	Frequency
Living with family/carer	37
Residential housing	12
Supported living	10
Independent	3
Total	62

Religious affiliation

- 32 said they were Roman Catholics
- 26 said they were members of a Protestant denomination.

The religious affiliation for four interviewees was unknown.

Degree of disability

The schools attended by the interviewees were used as an indicator with regard to their level of disability.

- 29 attended/are attending a school for people with severe learning disabilities
- 18 attended a mainstream school with facilities for people with learning disabilities
- 10 attended a school for those with moderate learning disabilities
- 1 attended a school for those with behavioural problems.

The remaining four participants could not remember the name of their last school.

Focus and discussion groups

A total of 12 people with learning disabilities participated in three focus groups. All the participants had previously taken part in the pilot. A discussion group also took place during a conference which included people with learning disabilities and this is discussed in greater detail in Chapter two.

The following information only relates to the focus groups as it was not possible to record individual information at the conference workshop.

Gender

- 7 were female
- 5 were male.

Age

The participants' ages ranged from 19–41 years. Half were under 26 years old. The mean age was 28 years.

Demographic background

Participants lived throughout Northern Ireland:

- 4 lived in the Western HSSB area
- 3 lived in the Southern HSSB area

- 3 lived in the Northern HSSB area
- 2 lived in the Eastern HSSB area.

Living arrangements

- 5 lived with their parents
- 3 lived in supported living accommodation
- 2 lived in a residential setting
- 1 lived with her sister.

One interviewee stated that he lived with his parents part-time and within a supported living scheme for the remainder of the time.

Religious affiliation

- 7 said they were Catholic
- 3 said they were members of a Protestant denomination.

The religious affiliation for two participants was unknown.

Degree of disability

The schools attended by the participants were used as an indicator of their level of disability.

- 4 had attended a school for people with moderate learning disabilities
- 3 had attended a school for people with severe learning disabilities
- 3 had attended a mainstream school.

The remaining two participants could not remember the name of their last school.

Recruitment source

- 9 were recruited through advocacy groups linked with Mencap
- 3 were recruited through a supported living service.

Family carers

Data were obtained through self-completion questionnaires, one-to-one interviews and focus groups.

Questionnaire

Over 500 questionnaires were distributed through a variety of professionals and services. These included day centres, a special needs school, parent groups, advocacy services, residential services and other voluntary organisations for people with learning disabilities. All questionnaires were returned using a freepost envelope. A total of 63 carers completed the questionnaire.

Gender

- 49 (78 per cent) were female
- 13 (21 per cent) were male.

One carer did not respond to this question.

Age

- 33 (52 per cent) were aged between 45–59 years old
- 19 (31 per cent) were under 44 years old
- 10 (16 per cent) were aged over 60 years of age.

One carer did not respond to this question.

Demographic background

Carers were located throughout Northern Ireland.

- 27 (43 per cent) lived in the Eastern HSSB area
- 18 (29 per cent) lived in the Southern HSSB area
- 12 (19 per cent) lived in the Western HSSB area
- 2 (3 per cent) lived in the Northern HSSB area.

Four carers did not respond to this question.

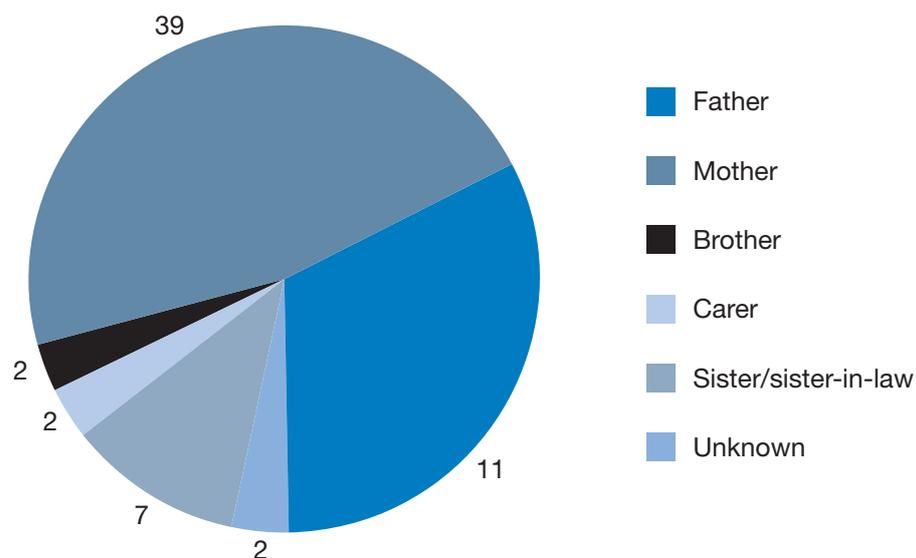
Relationship of the carer to the person in their care

As Figure 16 shows, the majority (79 per cent) of respondents were parents.

- 39 (62 per cent) were mothers
- 11 (17 per cent) were fathers
- 7 (12 per cent) were sisters/sister-in-law
- 2 (3 per cent) were brothers
- 2 (3 per cent) described themselves as a 'carer' (both were female).

Two carers did not respond to this question.

Figure 16: Relationship of the carer to the person in their care (in numbers)



Religious affiliation

- 37 (59 per cent) said they were Catholics
- 20 (31 per cent) said they were members of a Protestant denomination

- 1 (2 per cent) said they were a Christian
- 1 (2 per cent) said they had no religion.

Four carers did not respond to this question.

Interviews

A total of 19 interviews were conducted with 22 carers. The interviews were mainly conducted in the home of the participant but four were conducted in the interviewees' workplace and one took place at the University of Ulster.

Gender

- 18 were female
- 4 were male.

Demographic background

Of the 22 carers:

- 11 lived in the Eastern HSSB area
- 4 lived in the Southern HSSB area
- 7 lived in the Western HSSB area
- 1 lived in the Northern HSSB area.

Relationship to the person with learning disabilities

- 12 were mothers
- 2 were sisters
- 1 was a father
- 1 was a female guardian/carer.

Three interviews were conducted with both a mother and father present.

Focus groups

Two focus groups involving a total of 26 carers were held. All were parents –19 attended the first focus group and seven attended the second.

Gender

- 19 were mothers.
- 7 were fathers.

Background

The participants in focus group one all had children who were older teenagers or young adults with Down's syndrome. They lived in Derry, Portrush, Cookstown, Ballymena, Banbridge and Belfast, therefore the four HSSBs were represented.

Carers in focus group two lived mainly around the greater Belfast area and consisted of a group of parents whose son or daughter was involved with an activities centre.

Professionals

Data from professionals working in the area of learning disabilities were obtained from one-to-one interviews. A total of 24 professionals participated.

Gender

- 15 were female
- 9 were male.

Profession

- 8 were learning disability nurses
- 5 were social workers.

Other interviewees included psychiatrists, vice-principals of schools for students with specific educational needs, a psychologist, an occupational therapist, and community care, residential, hospital and day centre managers from across three of the HSSBs.

Front-line staff

Data were obtained from questionnaires and three focus groups.

Questionnaire

A total of 264 front-line staff completed the questionnaire. As a significant number failed to complete some of the sections on personal data the percentages presented refer to those who did complete the relevant questions.

Gender

- 185 (79 per cent) were female
- 48 (21 per cent) were male.

A total of 31 respondents did not answer this question.

Age

- 103 (42 per cent) were aged between 30–44 years
- 74 (31 per cent) were aged between 45–59 years
- 49 (25 per cent) were under 30 years of age
- 5 (2 per cent) were 60 years and over.

A total of 33 respondents did not answer this question.

Employment setting

- 132 (52 per cent) were employed in some form of day centre provision
- 121 (48 per cent) were employed in residential and supported living services.

A total of 11 respondents did not answer this question.

Experience of working with people with learning disabilities

- 48 (19 per cent) had worked in learning disability services for less than two years
- 62 (24 per cent) had worked in learning disability services for 3–5 years
- 38 (15 per cent) had worked in learning disability services for 6–9 years

- 110 (42 per cent) had worked in learning disability services for 10 or more years.

Six respondents did not answer this question.

Job title

- 130 (57 per cent) were employed as support workers/care assistants
- 75 (33 per cent) as senior support workers (Level 3)
- 23 (10 per cent) as managers or deputy managers.

A total of 36 respondents did not answer this question.

Qualifications held

- 48 (19 per cent) had a university degree or postgraduate qualification
- 103 (42 per cent) had undertaken further education, such as a diploma or NVQ
- 74 (30 per cent) had GCSEs/A Levels
- 22 (9 per cent) had no formal education qualifications.

A total of 17 respondents did not answer this question.

Focus groups

Five focus groups were conducted with a total of 24 staff members.

Gender

Only one male participated in the focus groups.

Occupation

Participants included care assistants, day care and residential support workers, employment officers, advocacy workers, deputy managers and managers of day centre and residential units, staff nurses, community nurses and social workers. Staff were recruited through steering group members and networks developed with other organisations.

Demographic background

Two focus groups were held in Derry, two in Belfast and one in Newry. The four HSSBs were represented by the participants.

Appendix three

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Out of the shadows

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(Self-advocate)

A report of the sexual health and wellbeing of people with learning disabilities in Northern Ireland

Audrey Simpson, Attracta Lafferty and Roy McConkey

In 2004, **fpa**, in partnership with the School of Nursing at the University of Ulster, developed and implemented research (the SKY project) which focussed specifically on the relationships and sexual wellbeing of people with learning disabilities in Northern Ireland. *Out of the shadows* is the report of that research.

Written and presented in a clear and user-friendly style this report will prove invaluable for a range of front-line staff and professionals whose work involves people with learning disabilities, and also family carers. It should also be essential reading for civil servants, policy makers and academics.

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