

This factsheet summarises current research into the sexual health and wellbeing of people with learning disabilities living in Northern Ireland.

Key issues

- Compared to non-disabled peers, people with learning disabilities have a more limited and incomplete understanding of sexual health issues.
- Most carers acknowledge that people with learning disabilities have the right to sexual expression.
- Staff feel under pressure from managers and carers to supervise and limit the sexual expression of people with learning disabilities.

Introduction

In 2004, with funding from the Big Lottery Fund, **fpa** in Northern Ireland, in partnership with the School of Nursing at the University of Ulster, began a three year research project into the sexual health and wellbeing of people with learning disabilities living in Northern Ireland.

The aim was to produce a profile of the feelings, attitudes and experiences of people with learning disabilities in relation to sex, sexuality and personal relationships; and to obtain comparable data from their carers, formal and informal.

Objectives

- To assess all the needs of women and men with learning disabilities in relation to positive sexual health, and to develop a tool to assist practitioners in this work.
- To assess how much relationships and sexuality education (RSE) people with learning disabilities receive, to highlight the sources of this education, and to find out what improvements they would like to see.
- To provide information about the attitudes of staff, teachers, family carers and health professionals toward the relationship and sexual health needs of people with learning disabilities in their care.

- To inform the further development of policy and guidelines relating to the relationship and sexual health needs of people with learning disabilities.

Over 500 people participated in the project by completing questionnaires, taking part in one to one interviews and attending focus groups. They included people with learning disabilities, family carers, front-line staff and professionals.

The following summarises some of the main research findings and recommendations. These are presented in full in the research report entitled *Out of the Shadows*.¹

People with learning disabilities

In all, 62 people from the four Health and Social Services Board areas participated in the research, of whom 32 were male, 30 were female and 39 were under 26 years of age.

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

- knowledge;
- personal experiences;
- values and attitudes.

The interviews lasted between one and two hours and, where possible, were carried out over two sessions. The main findings included the following:

- Many people with learning disabilities are able and willing to talk about sexual health but often have limited opportunities to do so.
- Compared to non-disabled peers, their understanding of sexual health issues appears more limited and incomplete. Many were confused about issues such as masturbation, pregnancy, contraception and sexually transmitted infections. Some were aware of these issues but did not know how to check the accuracy of what they had been told by their peers or had picked up from the media.

- They reported limited experience of sexual expression and commented on the restrictions that carers and staff place on them. Some staff forbid them from having partners and think they should not be sexually active.
- They believe they should be free to decide whether or not to have intimate relationships or get married.

Family carers

Of all the carers who participated, 26 attended two focus groups, 63 completed a questionnaire and 22 took part in interviews. The main findings were as follows:

- The majority 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.
- Eighty six percent of those who completed the questionnaire were supportive of the right of people in their care to have a boyfriend/girlfriend.
- Most recognised the rights of people with learning disabilities to have relationships, but only 42% 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.
- Those who supported 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 issues.
- The majority of carers who completed the questionnaire also felt that staff should stop sexual practices such as masturbating or sexual intercourse but not kissing or holding hands.

Front-line staff

Five focus groups were held, involving 24 staff members from statutory and non-statutory organisations, and over 260 completed a questionnaire. The main findings were as follows:

- Staff felt under pressure from managers and carers to supervise and limit the sexual expression of people with learning disabilities. They appreciated that the consequences of this included lack of privacy and disrespect for the person with a learning disability, but felt they were powerless to do anything about it.
- They emphasised the need for clear policies and procedures on sexuality and relationships, policies that respect and respond to the person's needs and wishes and more openly acknowledge issues of confidentiality.
- Greater opportunities must be found for dialogue between staff, managers and carers so that possible misconceptions can be corrected and a culture of cooperation developed.

Recommendations

The recommendations were based on the following criteria:

- They could potentially make an immediate difference to the lives of people with a learning disability.
- They could be implemented through a change in practice rather than requiring extra resources.

- They would build on good practice that is already underway in Northern Ireland or elsewhere.
- They would command reasonable support across the different interest groups.
- They would be easily monitored so that progress in their implementation could be measured by agencies and advocacy groups.

They included the following:

- Teenagers and adults with learning disabilities should have access to information about sex, sexuality and relationships.
- Sexual health should feature in all person-centred planning and reviews.
- A nominated staff member should be available to respond to someone with learning disabilities who wants to know about or discuss personal matters.
- RSE initiatives in schools and day centres should include information and education on appropriate and inappropriate behaviours, and promote self-protection.
- Each Health and Social Care Trust should develop a training strategy that includes ongoing supervision and support.
- Carers should have additional support available to help them cope with the developing sexuality of the person in their care.
- Sexuality and relationships should feature in all training courses for professionals who are involved with people with learning disabilities.
- The importance of these issues to people with learning disabilities should be recognised at the highest level within Government.

Reference

1. Simpson A, Lafferty A, McConkey R. Out of the shadows: A report of the sexual health and wellbeing of people with learning disabilities in Northern Ireland. Belfast: fpa, 2006.

Resource list

These titles are available from **fpa direct**, Fax: 0845 123 2349, Email: fpadirect@fpa.org.uk or Telephone: 0845 122 8600. You may also visit www.fpa.org.uk

A comprehensive catalogue of books and resources about sexuality and relationships is also available. Please send an A5 SAE to **fpa**, 3rd floor Ascot House, Shaftesbury Square, Belfast BT2 7DB.

Talking together... about growing up

This is a workbook for parents of children with learning disabilities. It offers support to parents/carers of children with learning disabilities who are approaching or who are around the age of puberty. The easy to follow style is suitable for young people who may not be able to read. It will also help schools working in partnership with parents.

Talking together... about sex and relationships

This is a practical resource for schools and parents who work with young people with learning disabilities. It uses illustrated stories and activities for use in the classroom to explore a range of situations that young people with learning disabilities face as they grow up. It also has pages for parents/carers so that home and school can work in partnership.

Talking together... about contraception

This two book pack supports young people with learning disabilities who wish to access contraception. Book one contains a guide to the types of contraception available. Book two has been written for young people and has clear pictures, easy-to-read stories and picture posters.

FACTSHEET

Sexuality and learning disability: A resource for staff

Based on fpa's highly successful learning disability courses, this book features a range of creative approaches to working with people with learning disabilities. Topics covered include: current law and policy; developing awareness and understanding; and skills and teaching. It also features examples of work that can be carried out with people with learning disabilities, and a list of useful resources.

Other Northern Ireland factsheets:

Abortion

Family planning services in Northern Ireland

The legal position regarding contraceptive advice and provision to young people

Relationships and sexuality education in schools

Sexual behaviour and young people

Sexual orientation

Sexually transmitted infections

Teenage pregnancy

For further information, contact **fpa** at:

3rd Floor,
Ascot House,
24-31 Shaftesbury Square,
Belfast BT2 7DB
Tel: 0845 122 8687
Email: belfast@fpa.org.uk

or

3rd Floor,
67 Carlisle Road,
Londonderry BT48 6JL
Tel: (028) 7126 0016
Email: derry@fpa.org.uk

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