

## *Sex and Relationships for People with Learning Disabilities*

Ruth Garbutt



Dr. Ruth Garbutt was the researcher on this Sex and Relationships Project undertaken by CHANGE in partnership with the Centre for Disability Studies at Leeds University. Her research interests are around emancipatory/participatory research; creative methods in research; disability rights; professional practice; and sex/relationships for

disabled people. She presently works at Leeds University in the Staff and Departmental Development Unit.

### **Summary**

Sex and relationships, in relation to young people with learning disabilities, is a contentious topic. This article reports on a project that looked into this topic. It concludes that many young people with learning disabilities lack a good understanding of sex and relationships, and that information and sex education training for them is patchy. It makes recommendations for change, including the need for more support, training and better guidance for practitioners.

Historically, people with learning disabilities have been discriminated against in the area of sex and relationships. Sex and relationships for people with learning disabilities seem to be high on the agenda for practitioners but the results of an innovative, large-scale research project indicated that practitioners felt that there was a lack of information and advice for them.

The Sex and Relationships research project (referred to in the rest of this article as *The Project*) was a three-year piece of research that was undertaken by CHANGE, a national organisation that fights for the rights of people with a learning disability (<http://www.changepeople.co.uk>), in partnership with the Centre for Disability Studies at Leeds University (<http://www.leeds.ac.uk/disability-studies/>). It was funded by the Big Lottery. The Project came about because, in previous work, CHANGE found that many people with learning disabilities said that they were never told about sex and relationships when they were younger. The people with learning disabilities who were in contact with CHANGE said that if they had had better sex education, they might have made different choices as adults.

The Project ran from January 2007 to January 2010 with the remit of finding out more about the experiences and viewpoints of young people with learning disabilities, parents and practitioners in this area of sex and relationships. It was carried out using the following methods: a series of drama workshops with young people with learning disabilities age 16–25 years; a national survey of special schools and colleges; interviews with 20 parents of young people with a learning disability; and focus groups with teachers and governors.

The Project revealed that while some young people with learning disabilities had some knowledge of sex and relationships, they also had some misunderstandings, for example:

- Several of the young people thought gay sex was illegal.
- Several did not realise that the police investigate cases of sexual abuse.
- Others were unaware that sex could lead to pregnancy.
- Some had little or no understanding of contraception.
- Few knew that pregnancy would last nine months. Some of the parents in the study talked about the lack of information and understanding of the issues by their sons/ daughters. There were narratives of young people being frightened and confused by puberty – such as a boy who had plucked out his pubic hair with tweezers and girls who were unprepared for menstruation.

Many parents and practitioners in the study acknowledged that people with learning disabilities needed opportunities to have experiences of relationships and sexuality, if that was their choice, but parents, practitioners and people with learning disabilities in the study said that they generally needed better information and support on the issue. Existing research also indicated that parents and practitioners were often responsible for providing the training and education that individuals needed regarding relationships and sexual expression, yet, in many cases, neither felt prepared.

At the same time, parents were unable to explain the issues to their children – whose major source of knowledge seemed to be the television. The young people were picking up information from the TV soaps, but parents were understandably worried that they might be getting misinformation. A lack of opportunities for meeting other young people or travelling independently further restricted the young people's access to accurate information. The Project also highlighted that there were very few co-ordinated, consistent support services for people with learning disabilities in the area of sex and relationships, or for the front-line staff who are dealing with the issues.

The report from the research makes a series of recommendations:

1. There needs to be more information for young people with learning disabilities about relationships, including same-sex relationships, issues of public and private space, abuse, masturbation and contraception.
2. There should be more youth clubs and night clubs which cater for the needs of young people with learning disabilities.
3. Young people with learning disabilities should get

support to use transport more independently.

4. There needs to be better training for practitioners about delivering sex education or sexual health information to people with learning disabilities.
5. Practitioners need to work in a supportive way with parents, and be sensitive to their experiences and concerns about their sons' and daughters' level of vulnerability.
6. Practitioners need to be proactive in providing information rather than waiting for a problem to arise.
7. Practitioners need to be aware of the need to repeat information for the person with the learning disability and to give consistent information at an early age – at a level that they can understand and in a visual format.
8. Practitioners could organise groups where parents can meet together to share information and give each other support.
9. Negative attitudes towards people with learning disabilities around sex and relationships need to be challenged by awareness-raising and education.

Along with volunteers at CHANGE, the research team produced a number of illustrated booklets to help young people with learning disabilities to understand the issues and overcome some of their misunderstandings and fears. These can be purchased from the CHANGE website, <http://www.changepeople.co.uk/productDetails.php?id=2026>

They also produced a report entitled *Talking about Sex and Relationships: The Views of Young People with Learning Disabilities* which is downloadable from the CHANGE website: <http://www.changepeople.co.uk/showContent.php?id=70>

CHANGE is continuing to work to improve sex education for people with learning disabilities by delivering training and campaigning for equal rights.

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