

**Sex and Relationships for People with Learning Disabilities:
A Challenge for Parents and Professionals**

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Abstract

This paper considers some of the issues around sex and relationships for people with learning disabilities. It is essentially a discussion paper, highlighting previous research, and information about the rights of people with learning disabilities to have sex and relationships. It particularly focuses on concerns for parents and some implications for professional practice that have arisen from a research project that is trying to find out more about the issues. The main messages coming from parents within the research project is that there is a need for clear, concise information about sex and relationships for young people with learning disabilities and there is also a need for professionals to give parents more support.

Key words: Sex and relationships; people with learning disabilities; professionals; parents; rights

Introduction: The Sex and Relationships Research Project

The Sex and Relationships research project is a three-year piece of research being undertaken by CHANGE, a national organisation that fights for the rights of people with a learning disability, in partnership with the Centre for Disability Studies at Leeds University. 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 started in January 2007, with the remit of finding out more about the experiences and viewpoints of young people with learning disabilities, parents and professionals in this area. It is being carried out using the following methods: a series of drama workshops with young people with learning disabilities age 16-25 over a period of 18 months; a national survey of special schools and colleges; interviews with 20 parents of young people with a learning disability; and focus groups with teachers/ governors.

Some of the early thoughts of the research team are discussed below with specific examples from the 20 parent interviews that have been carried out. The research team would value comments and responses in relation to the discussion and, to point out essentially, that this is currently 'work in progress'.

Background Literature

Historically, before the introduction of Community Care policies in the UK in the 1990s, a large number of people with learning disabilities lived in institutions, and were often segregated (Welshman and Walmsley; 2006; Sinson, 1995; Potts and Fido, 1991). In such institutions, people with learning disabilities were not usually encouraged to have relationships (Valios, 2002), and the opportunities for any kind of sexual experiences were very limited, since there were very few

areas where people could have their own privacy (Collins and Cozens, 1999, Shakespeare et al, 1996). During the Eugenics movement, particularly in the late nineteenth and early twentieth century, it was argued that the procreation of people with learning disabilities should be discouraged to prevent what was seen as their 'defective' genetic material being passed on and endangering the human race (Blacker, 1950; Barker, 1983) and, as a consequence, many women with learning disabilities were sterilised (Howard and Hendley, 2004). Quite often, people with learning disabilities were seen as 'eternal children' (McCarthy, 1999) because they were considered innocent and asexual and, consequently, '...adults often assumed that sexuality was irrelevant because of the young people's level of cognitive and communication impairments.' (Morris, 2001, p. 15) People with learning disabilities have also been labelled as 'vulnerable' (eg., Association of Directors of Social Services, 2005; Department of Health, 2000; Lord Chancellor's Department, 1997), and at risk of being abused, all of which, historically, has given professionals and parents reason to be cautious in terms of encouraging them to have any form of intimacy.

Tackling sex and relationships for people with learning disabilities can be difficult for professionals and staff attitudes can greatly influence the experiences and rights, of people with learning disabilities in this area (Murray et al, 1999). Teachers of individuals with learning disabilities have been reluctant to become involved in sex education due to moral beliefs, attitudes, lack of confidence in their abilities to provide adequate sex education and the lack of availability of sex education materials (Howard-Barr et al., 2005; Murray & Minnes 1994; Smigielski & Steinmann, 1981). Diamond (1984) states that, 'While they [professionals] ...generally wish the sexual concerns to be ignored; they want them to sort of "go away", since they are ill at ease dealing with them, and don't really know how to handle the issues' (Diamond, 1984, p. 210) .

Although professionals may find it a difficult area to address, within the UK now, there is legislation that supports the rights of people with learning disabilities to have fulfilling relationships and sex lives if that is their choice. The Human Rights Act (1998, Article 8), for example, states that every human being has a right to respect for private and family life. The Disability Discrimination Act (1995) gives people with any kind of impairment, including learning disability, the right to equal treatment in terms of accessing goods and services, which includes services such as family planning clinics and advice centres. The Mental Capacity Act (2005) starts from the premise that a person must be assumed to have capacity to make decisions unless it is established that they lack capacity and it also states that a person is not to be treated as unable to make a decision merely because they might make an unwise decision. In this way, people with learning disabilities are granted the rights to make their own choices, in all areas of their lives (including relationships/sexuality) even if professionals/parents have concerns about those choices. There are provisions within the Mental Capacity Act for others to act in the 'best interest' of someone who has been shown to lack capacity, but there is more emphasis on assuming that, more often than not, people will have the rights and the opportunities to make their own choices and have responsibility for the consequences of those choices. In this way, therefore, the current UK legislation supports the rights of people with learning disabilities to have choices around intimate and sexual relationships.

Although the rights of people with learning disabilities have improved with legislation, sometimes they are still on the receiving end of negative attitudes and lack of information. Shakespeare et al., (1996) suggests:

‘People with learning difficulties face some of the biggest restrictions in terms of availability of sex education. Whereas in other areas of life the trend is towards ‘normalization’, in other words, fitting people with learning difficulties into the roles and values of the rest of society (Wolfensburger, 1972), this does not seem to prevail in the area of sexuality.’ (Shakespeare et al., 1996, p. 25)

The Sex and Relationships project has been looking at the issues and experiences from the perspective of people with learning disabilities themselves, from parents and from professionals. The following section draws on some of the preliminary findings from interviewing 20 parents of young people with learning disabilities to highlight some of the challenges involved. It also suggests some implications for professional practice.

The Experience of Parents and Implications for Professional Practice

It has been found that parental attitudes can influence the experiences and rights, of people with learning disabilities around sex and relationship (Johnson et al 2002., Szollos and McCabe, 1995). Within the findings of the parent interviews in the Sex and Relationships research project, we found that many parents were positive about the possibility of their sons and daughters having relationships, but that their main areas of concern were around the lack of information and the lack of proactive support from professionals. Within the parent interviews, it was found that, quite often, parents kept their young people with learning disabilities close to home, under constant supervision. This way of life was seen as necessary due to the worries around the vulnerability of the young person. One parent said, ‘My big worry is that she would be taken advantage of.’ This reflects other research that suggests that some family carers want their children to have the same rights as everyone else but that they are concerned for their safety (Simpson et al., 2006). In terms of professional practice, therefore, there is a need to work in a supportive way with parents, and to be sensitive to their experiences and concerns about their sons’ and daughters’ level of vulnerability.

In general, in our study, parents felt that, in order to reduce the worry around young people with learning disabilities being vulnerable, it was very important for them to make sure that their sons and daughters had access to information. Several parents pointed out to us that, in general, their sons and daughters did not get their information from peers in the same way as other young people because they had lower levels of social skills and sometimes they lacked opportunities to socialise independently. Several parents commented that their son or daughter found out information from using the internet, watching television and particularly from watching soap operas. This was reiterated by McCabe (1999) who found that levels of knowledge around sex and relationships was lower for people with learning disabilities, than the general population, and that much more information was taken from the media, meaning they were less able to check the accuracy of the information or discuss their thoughts or feelings. Within our study, parents were worried that young people with learning disabilities might get misinformation from these media sources. However, one parent saw that the storylines of soap operas could be used as a good opportunity to open up a discussion:

‘Well, Hollyoaks is great because there are lots of issues in there and there’s everything from teenage pregnancies, different relationships, heterosexual relationships, bisexual relationships, a lot within that programme so there is always something to chat about afterwards...and there are even things like...alternative dressers and all that kind of thing. So it’s just an opportunity for them... well for H and myself to discuss things that we have maybe not come across in our everyday life.’

Most parents in our study felt that it was important to be proactive in giving their sons and daughters clear, consistent information. However, for most parents, access to information was severely lacking. Several parents commented that they did not know what their sons or daughters were being taught in schools in terms of sex education and, for some parents, the schools had not discussed the issue with them first.

In general, parents felt that they had to fight for information about sex and relationships for their young people, as it was not freely available. One parent said, ‘I’ve had no information at all; I’ve had to go and find it myself. I’ve never been given any information [about sex and relationships] as a parent.’ Another parent commented, ‘I have a daughter with learning disabilities and the practical thing was managing her own menstruation and the health aspects relating to that. I didn’t get any help. It was something I had to investigate myself...’ Another parent commented that she had to fight for information about sex and relationships for her daughter in the same way that she has had to fight for other things:

‘I went for help to the GP and I got a referral to the community nursing team and got this input, we got an ‘All About Me’ book. We worked through acceptable places to touch someone else, personal space issues. But it doesn’t come just through the fact that you’ve got a young person with learning disabilities, you’ve got to fight for it, you’ve got to fight for everything.’

This, therefore, has implications for professional practice in terms of being more proactive in providing information at an early stage rather than waiting for a problem to arise and to make information freely available so that parents do not have to fight for it. Several parents felt that their son or daughter should be getting information about sex and relationships at an early age, probably around age 9 or 10. But they also pointed out that it was equally important to be aware of a young person’s cognitive stage of development and for the information to be appropriate to their level of understanding. One parent suggested that young people could be taught in small groups of similar age or of similar cognitive levels of development. It was pointed out by several interviewees that young people with learning disabilities in mainstream schools can often miss out because the sex education that was taught was not at a level that they could understand and there was often not any individual support or segregated classes to go through the information more thoroughly or at a pace to suit their level of cognitive understanding. In this way, therefore, it is important for parents themselves (and other professionals) to know where to access information so that they can reinforce and explain information that has been given to their son or daughter at school.

Lack of information was a problem for most parents in our study. This resonates with other research that has found that parents often feel that they do not have

adequate knowledge in providing their child with information regarding sexuality (Ballan, 2001). Some parents in our study made suggestions around the kinds of things that would help in terms of information. One parent said, 'It would be nice to have a leaflet with some kind of help line number on it if there was a problem or someone you could phone up to speak to...' and another added, 'I do think [it would be good to have] up to date information, up to date plain speaking, good pictures and diagrams, and with a sense of humour to it as well.' Several parents suggested that it would be useful to have some kind of pack, with samples and information in it that could be taught at school and that they could use in the home with their son and daughter when the need arose. Parents were also very aware of the importance of providing information to their children in a visual format, rather than just through written words, as one parent suggests, 'whether it need be with props or with visuals, a way of getting information through, because obviously with a lot of people with learning disabilities, the spoken word isn't always that coherent for them.' Another important point made by several of the parents in our study was that information needed to be presented several times and to be repeated so that the young person could hear it again and again. They pointed out that some young people with learning disabilities forget information that is taught to them and others need information repeated several times before they can fully understand it. This suggests that it is important for professionals 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.

Among the parents who were interviewed in our study, most of them felt that they, as parents, were often left with the responsibility of teaching their children sex education. One parent said that, at the end of the day:

'no one is going to give her [my daughter] that information except for me, I would think. There's no other source for her. She wouldn't dream of going looking for it. My daughter has only just started making her own hair appointments so she isn't going to go to a family planning clinic.'

Many parents felt that professionals should play a bigger role in giving their sons/daughters information and that professionals should give parents more support. When asked, 'Who do you think should provide information to your son about sex and relationships?' many of the parents said that it shouldn't be down to one person. Several parents expressed the need for partnership working. Suggestions of the kinds of professionals who could be involved, included community nurses, as the following implies: '...I think there should be more work done in partnership. The community nursing team has all those resources, they are experienced professionals...They [community nurses] should be going into school as part of PSHE' (Personal Social & Health Education). Other parents thought that social workers and support workers should also play a part. The following quote shows that this parent felt that the information should be reiterated to young people by several professionals, without one person taking sole responsibility:

'It should be provided by parents like me, school and to a certain extent through the Social Services...So really wherever, as many places as possible, as many opportunities as possible... Social Workers. Support Workers. Anybody who is involved with these young people.'

The message for professionals, therefore, is to work together with other professionals in a joined-up approach and to work closely with parents.

In terms of giving young people with learning disabilities effective support and information in the area of sex and relationships, a number of parents felt that it would be useful to meet up with other parents. The parents felt that this would give them the confidence to tackle some of the issues and to find out from other parents how they have gone about addressing issues around sex education with their own sons and daughters. One parent commented:

‘Unless parents have mixed with other parents that are kind of confident and feel able to express and have been through that, which I don’t think happens enough still, because quite a lot of parents do it in isolation, then they don’t feel confident...’

Another parent pointed out that, in general, parents of young people with learning disabilities who go to mainstream schools tend not to meet each other in the same way that parents of young people in special schools might do:

‘If they go to a special school they tend to have a parents group, the parents go along even if it’s just to have a cup of coffee once a month and you talk. When the children are in mainstream there is no opportunity to meet up...I think it’s a very important part of having a son or daughter with learning disabilities or additional needs, talking to other parents.’

In order for parents to give good information to their children about sex and relationships, many felt that they needed more support from professionals. Professionals can play a role therefore in organising groups where parents can meet together.

The following summarises the key points for professionals that have arisen out of our research with parents so far:

1. Professionals 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.
2. Professionals need to be proactive in providing information rather than waiting for a problem to arise.
3. Professionals 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.
4. Professionals need to work together with other professionals in a joined-up approach and work closely with parents.
5. Professionals could organise groups where parents can meet together to share information and give each other support.

The Sex and Relationships research team have repeatedly been contacted by other professionals seeking advice on sex education resources and on handling certain situations around sex and relationships with service users, even though the research project itself is not a sex education programme, nor are the research team the experts. This shows that sex and relationships for people with

learning disabilities is high on the agenda for professionals but that there is a lack of information and advice for them. There seems to be no coordinated, consistent support for people with learning disabilities in this area, or for the front-line staff who are dealing with the issues. Parents and professionals are responsible for providing the training and education individuals need regarding relationships and sexual expression, yet, in general, within our research we have found that neither feels prepared.

Some Final Thoughts and Challenges

From the above discussion, it can be seen that sex and relationships for people with learning disabilities poses some issues for both professionals and parents. The challenge seems to be based on the need to protect people who are labelled as vulnerable, balanced with the rights of all human beings to have relationships and family lives. In all of this, it is important to listen to people with learning disabilities themselves, as Lesselliers (1999) says:

‘Professionals might like to honour the ‘right to sexuality’ of people with learning disabilities, but many do not know how to do this in practice. More often than not, parents and professionals are still endlessly discussing the extent and degree of permissiveness, responsibilities and consequences of sexual behaviour involving people with learning disabilities...in all these well intentioned discourses, what is unheard is that one important voice: that of people with learning difficulties...’ (Lesselliers, 1999, p. 137).

The Sex and Relationships research project is making sure that people with learning disabilities themselves are having their voice heard. A large part of the research involves a series of drama workshops with young people with learning disabilities to ascertain their own views and experiences. However, in order to achieve a full picture of the issues, we are making sure that parents and professionals give their views. As discussed earlier, historically, people with learning disabilities have been discriminated against in the area of sex and relationships. What is coming out of our research so far is that many parents and professionals acknowledge that people with learning disabilities need opportunities to have experiences of relationships and sexuality, if that is their choice. Parritt (2005), in an article written for ‘Disability Now’ magazine, argues that this is important and that the experience of sex and relationships for people with disabilities needs to become more positive: ‘Too much emphasis has been placed on issues such as risk assessment and sexually transmitted disease, without the balancing input of helping people to experience the joy, excitement and fulfillment of sexual expression in whatever ways they can.’ (Parritt, 2005).

Simpson et al. (2006) found that people with learning disabilities in Northern Ireland wanted to learn more about sexual health and relationships but her research concluded that, ultimately, the sexual needs of people with learning disabilities are fundamentally being ignored. The findings from our study are suggesting that parents and professionals, as well as people with learning disabilities, need better information and support. If sexuality and relationships is an area in which people with learning disabilities have previously been excluded, then the importance of the Sex and Relationships research project cannot be underestimated. It is a key anticipation of the project that the findings of the research will effect big changes around sex and relationships education and government policies for young people with learning disabilities. It is an

innovative, large-scale piece of research that hopefully will have implications for changing attitudes and ways of working with people with learning disabilities and will contribute to making relationships and sexuality a positive experience for them.

For further information about this research, please contact the Sexuality Team at CHANGE, Units 19/ 20, Unity Business Centre, 26 Roundhay Road, Leeds, LS7 1AB. Tel: 0113 2430202, e-mail: info@change-people.co.uk, website: www.changepeople.co.uk

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