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Final Report: Talking about sex and relationships: The views of young people with learning disabilities

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Talking about sex and relationships:

the views of young people
with learning disabilities



Talking about sex and relationships: the views of young people with learning disabilities

**The final report of the sexuality project by CHANGE
2007-2010**

Contents

Acknowledgements	v
Accessible report	1
Introduction	22
Format of the report	22
Brief outline of the project	22
Background to the project	23
Summary of each section	26
Section 1: How we did the research	27
1.1 People with learning disabilities leading the research/ working in an accessible way	28
1.2 Running the drama group	29
1.3 Doing the interviews	34
1.4 Doing the survey	35
1.5 Doing the focus groups	35
1.6 Collecting resources	36
1.7 Telling others about the research	36
1.7.1 Conferences	36
1.7.2 Articles	37
1.7.3 Booklets	37
Section 2: What we found out	39
2.1 Young people with learning disabilities and their knowledge about sex and relationships	42
2.1.1 Friendships and relationships	42
2.1.2 Public/ private	48

2.1.3	Sex and masturbation	52
2.1.4	Puberty and pregnancy	56
2.2	Sex education	63
2.2.1	What is taught?	63
2.2.2	Who should teach sex education?	65
2.2.3	Mainstream/ special schools	67
2.2.4	Sex education- a human right?	69
2.3	Information	72
2.3.1	TV/ internet	72
2.3.2	Not enough information/ don't know where to get it	73
2.3.3	Resources used	76
2.4	Support	79
2.4.1	Closer working between parents and professionals	79
2.4.2	Worries of parents	80
2.4.3	Parents feeling unprepared	81
2.5	Wider issues	84
2.5.1	Attitudes	84
2.5.2	Issues for people from Black and Minority Ethnic (BME) communities	85
	Section 3: Conclusions and Recommendations	89
	References	97
	Appendices	101
	Appendix 1: Ethics	103
	Appendix 2: Laws and policies about relationships and sexuality for people with learning disabilities	106

Appendix 3: List of articles written	109
Appendix 4: National survey	111
Appendix 5: Parent interview questions	119
Appendix 6: Focus group questions	123
Appendix 7: List of resources	125
Appendix 8: Final thoughts by the Sexuality team	135

List of figures

Fig 1: Scene from the 'Michael and Hayley' play: Michael goes to buy condoms at a chemist shop. He is embarrassed. There is a queue of people behind him.	31
Fig 2: Scene from the 'Michael and Hayley play: Maria tells Hayley that she is getting bullied because she is a lesbian	32
Fig 3: Drama session: John pointing to pictures of different couples	43
Fig 4: Illustration drawn for the project showing saying 'No' without using your voice	52
Fig 5, 6: Drama session: Cut-out hands are placed on the drawings of a man and a woman by the young people to show where they like to be touched or where they would touch themselves	55
Fig 7: Drama session: 'Josephine' during the workshop with the young people	57
Fig 8: Drama session: Close up of Josephine's face	57
Fig 9: Drama session 'Josephine's' baby being born	58

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- The 20 parents who were interviewed
- Professor Colin Barnes (Centre for Disability Studies, Leeds University)
- Dr. Geoff Mercer (Centre for Disability Studies, Leeds University)
- Philipa Bragman (Director, CHANGE)
- The members of our Project Advisory Group
- The people who attended our conference
- Volunteers from Trainers for CHANGE (Formerly the Rainbow Group).

Talking about sex and relationships: the views of young people with learning disabilities

Accessible report

How the report was done



This report is about the Sex and Relationships project, which was funded by the Big Lottery Fund in 2007 to 2010.



The Sex and Relationships project was a 3-year project by CHANGE, a national organisation that fights for the rights of people with learning disabilities.



It was done with the Centre for Disability Studies at the University of Leeds.



The project found out about the views and experiences of young people with learning disabilities about sex and relationships.



We ran a drama group with young people with learning disabilities.



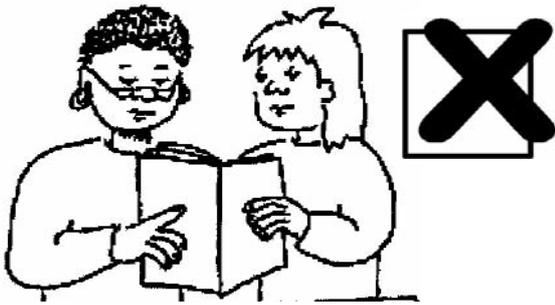
We also interviewed parents of young people with learning disabilities.



We also talked to groups of teachers.



There has not been much research done about this before.



People with learning disabilities have not done much research about this in the past.



People with learning disabilities were fully involved as researchers in the Sex and Relationships project.



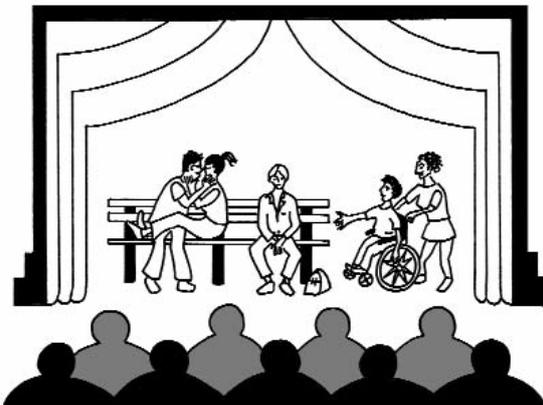
Using drama and pictures was a very important part of the project.



This is a good way for people who find talking, reading or writing hard, to show what they think.



Drama can be less embarrassing, because when people are acting they aren't talking about their own lives.



After working for 2 years the group of young people with learning disabilities performed a play that showed their views and experiences.



They showed parts of the play to professionals at conferences and workshops.

This is what we found out from our research



1. Knowledge about sex and relationships

Some young people knew a lot about sex and relationships and some knew very little.



Most young people in the drama group understood about friendships and relationships.



Most young people knew the difference between public and private places.



Some of the young people did not know much about puberty and pregnancy.



The parents and teachers said that some young people found it very frightening when their body changed.



Some young people found talking about sex and masturbation embarrassing.



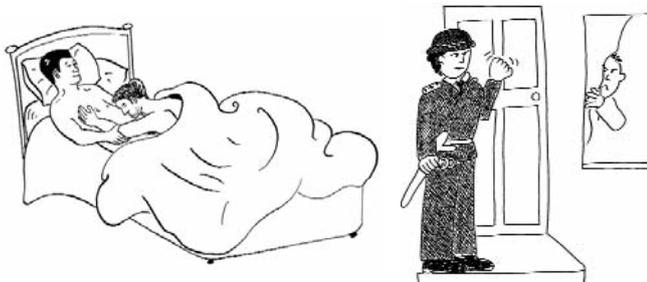
Most of the young people knew what condoms were for.



They could list places to get condoms from.



Most of the young people knew what the words 'gay' and 'lesbian' meant.



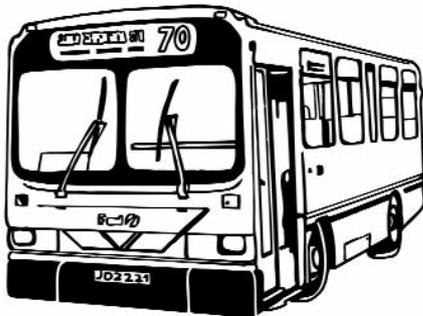
Three young people thought it was against the law for gay people to have sex.



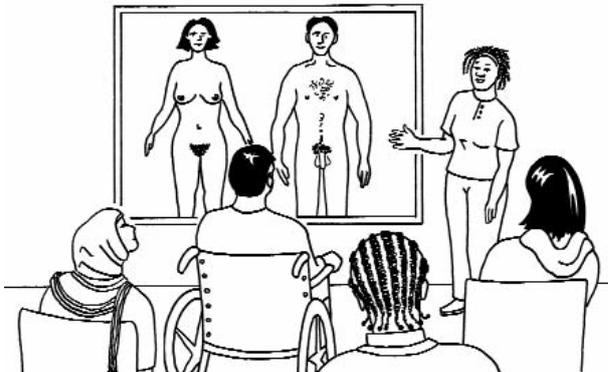
The young people said there were not many places for them to meet. The teachers and parents agreed with this.



Teachers and parents said that they were worried about young people being unsafe.



Some young people told us that it was difficult to use transport on their own.



2. Sex education

Everybody we talked to felt sex education for young people with learning disabilities needed to be better.



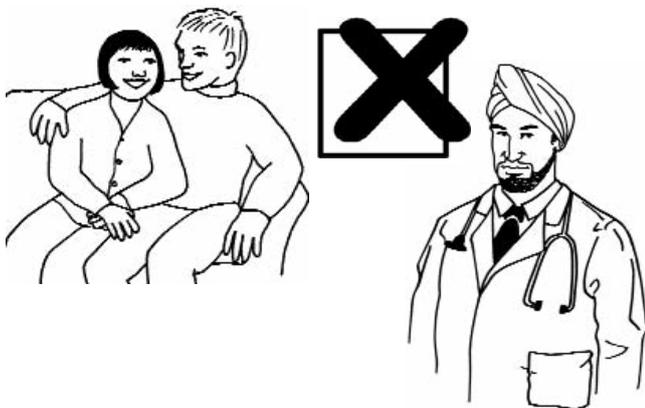
We found that sex education often only talks about what sex is.



People said it would be good to talk about having sex in a relationship, or to feel good.



People said sex education should be taught in small groups, and taught more than once.



Parents said that they wouldn't go to a doctor for information about sex education.



The young people said they would go to a doctor for information about sex education.



Teachers felt responsible for sex education.



Parents often didn't know where to get information about sex and relationships.



Some parents didn't know if they should talk about sex to their sons and daughters.



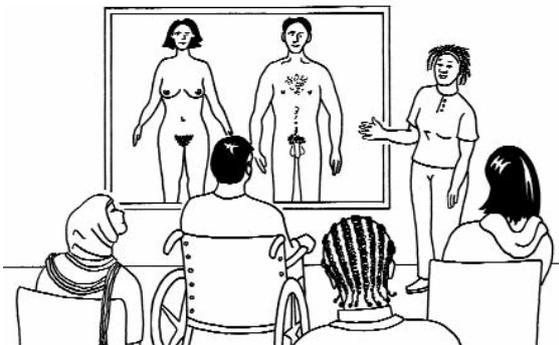
Teachers said that in mainstream schools sex education doesn't always make sense to young people with learning disabilities.



Teachers said that sometimes if there is a problem one pupil will be given sex education by themselves.



Many parents and most young people think they should have the right to sex education.



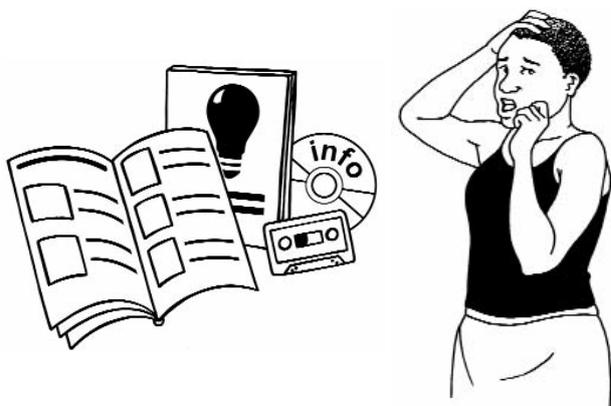
3. Information

We found that some young people got information from the TV and internet.





Parents and teachers worried that young people would not get the right information.



The young people told us it was difficult to get accessible information.

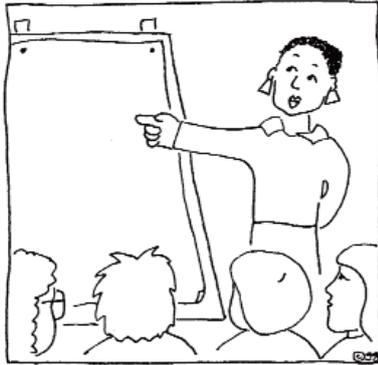


No parents had been given information about sex and relationships without asking for it. They “had to fight for it”.



Parents and teachers said young people really need information that they can take away.

4. Support



Young people said they didn't always get help from teachers if they asked questions about sex and relationships.



Sometimes parents and teachers found it hard to work together on things to do with sex and relationships.



Parents and teachers both said training would be helpful.



Some parents and teachers worried about how young people behave in public.

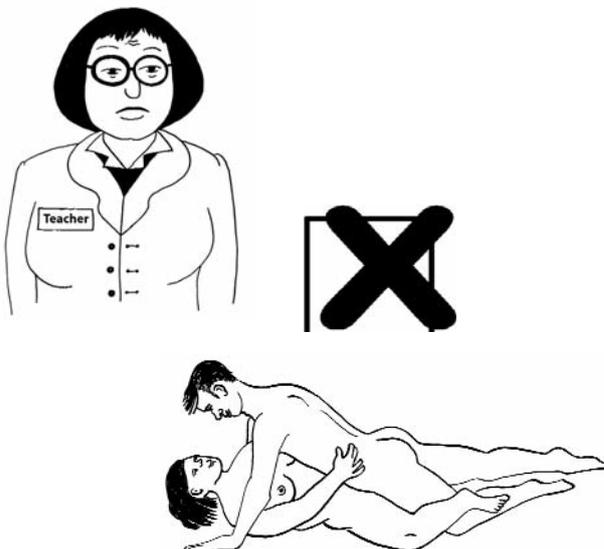


Parents didn't always feel ready for their child becoming a teenager. Teachers said that many parents didn't want to talk about this.

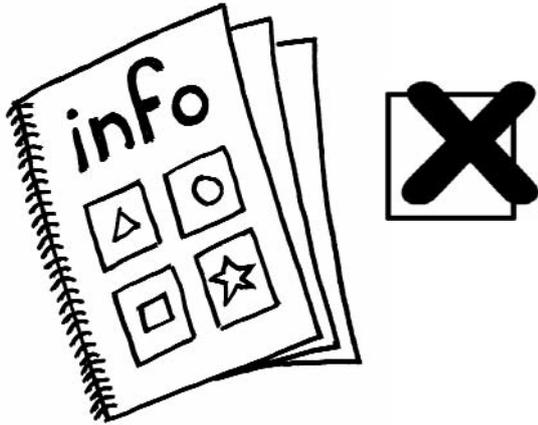


5. Wider issues

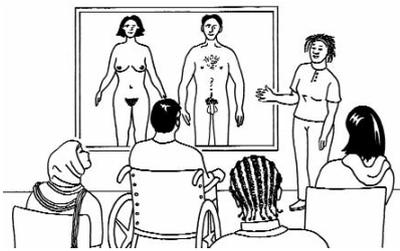
Some young people with learning disabilities we talked to thought that talking about relationships and sex could get them into trouble.



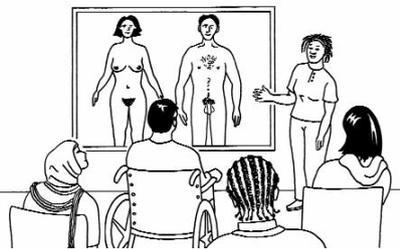
Teachers told us some parents and professionals think young people with learning disabilities should not have relationships or sex.



Parents said some people think young people with learning disabilities don't need information.



Many teachers said that sex education doesn't always get taught in special schools.

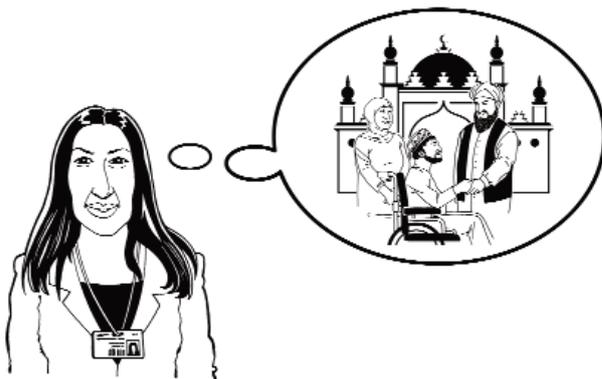


They said that sex education needs to be treated as more important by schools and by the government.





Parents from Black and Minority Ethnic (BME) communities also talked about religious beliefs to do with talking about sex in mixed groups, marriage, and gay and lesbian relationships.



Professionals need to be more aware of these beliefs.



Teachers said it is important to respect different views but also that all young people have a right to information.



Recommendations

This is what we think needs to change (based on what the project has found):



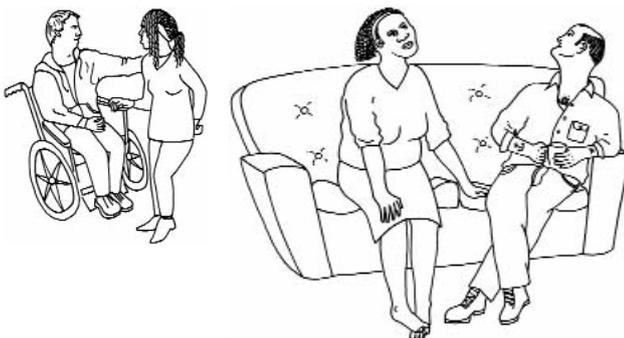
There needs to be more accessible information about sexual health.



There should be more support for young people with learning disabilities about sex and relationships.

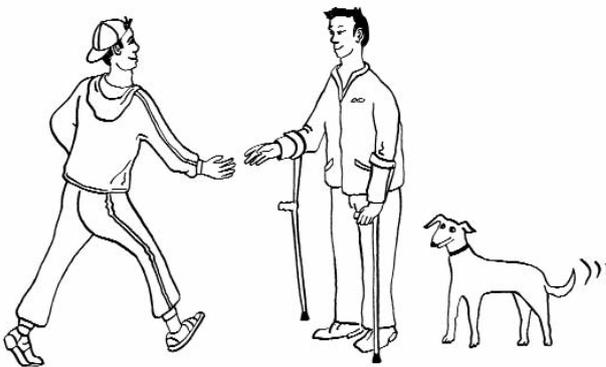


Parents of young people with learning disabilities should get more support around sex and relationships.

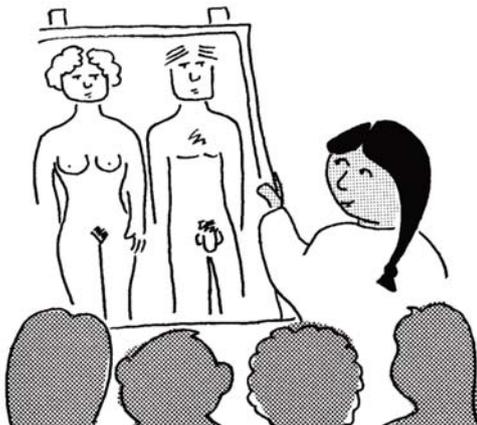




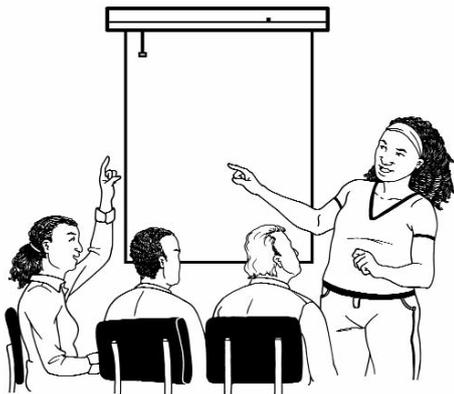
Families from BME communities should get the right support.



Young people with learning disabilities need more chances to meet with friends and be independent.



People should see sex education for people with learning disabilities as important.



There needs to be better training for professionals about sex education.



Young people with learning disabilities have a right to sex education.

Introduction

This report talks about the Sex and Relationships project. This was a 3-year project that took place at CHANGE, a leading national organisation led by disabled people that is based in Leeds, in England, that fights for the rights of people with learning disabilities. The project was funded by the Big Lottery Fund: Health and Social Research Grants Programme. We worked in partnership with the Centre for Disability Studies at the University of Leeds.

Format of the report

We looked at reports that had been written by other researchers. We found that most of the things that had been written used complicated language and jargon. We wanted to write in plain English so that everyone could understand it. We wanted people with learning disabilities to hear what we found out in our project because it affects them. Different people in the research team wrote bits of the report. This is really important because it makes the report more interesting, it gives us all a voice, and it means that everyone was equal in writing about the parts that were important to them. It is a project that has been important to us, it has affected our lives and hopefully it will also affect the lives of other people with learning disabilities.

Throughout this report we have used the term 'learning disability'. This means people who have been given a label of 'learning disability'. Some people prefer the term 'learning difficulty'. The people with learning disabilities at CHANGE prefer the term 'learning disability'. When CHANGE was first set up (in 1994), people with learning disabilities at CHANGE wanted to campaign for changes for all disabled people, including people with learning disabilities. They wanted to be seen as part of the 'disability' movement. This is why CHANGE prefers the term 'disability'.

We have used false names when we have quoted people who participated in the project. We did not want anyone to be identified in the report. We have used male names to indicate the person was male and female names to indicate the person was female.

Brief outline of the project

There were 5 workers on the Sex and Relationships project:

- John Tattersall (Project Coordinator with a learning disability)
- Rachel Boycott-Garnett (Project Coordinator without a learning disability)

- Ruth Garbutt (Researcher without a learning disability)
- Jo Dunn (Illustrator without a learning disability)
- Durbali Roy (Volunteer with a learning disability).

There were two Research Consultants from the Centre for Disability Studies at Leeds University who gave us advice:

- Professor Colin Barnes
- Dr. Geoff Mercer.

There was a Project Advisory Group (PAG) that provided specialist advice and helped us to make sure we met our targets. They met twice a year, each year.

In our project we wanted to find out about the views and experiences of young people with learning disabilities in the area of sex and relationships. This was done by:

- Drama work with young people with learning disabilities
- Interviews with parents of young people with learning disabilities
- Focus groups with teachers from special schools
- A national survey of special schools
- A review of sex and relationships education resources.

We will tell you more about all these things later in the report.

For this report we will talk in detail about the drama work with the young people with learning disabilities. This is an unusual method of doing research and we want to tell you about the different techniques we used and how it worked. We will talk about the findings of the research and the way that the drama helped us find out information from the young people. We will also talk about the findings of the interviews, focus groups and survey and how they fitted with what came out of the drama work.

Background to the project

Here are the reasons why we thought sex and relationships for people with learning disabilities was an important subject:

- Adults with learning disabilities at CHANGE said that they hadn't had much sex education when they were younger. They told us that if they had learned more about sex and relationships they might have made different choices as adults
- Professionals who worked with CHANGE said that sexuality and relationships were a priority area to be developed now that people with learning disabilities were living, working and spending time with everyone else in the community
- There has not been much previous research done on the topic. There have been only small amounts of research about sex and relationships and people with learning disabilities, which has looked at:
 - Sexual behaviour (Lesselliers, 1999)
 - Staff attitudes (Murray et al, 1999; Grieve et al, 2009)
 - Parent attitudes (Johnson et al, 2002)
 - Effectiveness of information (Cambridge, 1999; McCarthy and Thompson, 1995; Barber and Redfern, 1997)
 - Sexual knowledge (McCabe, 1999; Simpson et al, 2006))
 - Women with learning disabilities (Gillespie-Sells et al, 1998; McCarthy, 1999)
 - Men with learning disabilities (Yacoub and Hall, 2009)
 - Gay, lesbian and bisexual relationships (Abbott and Howarth, 2005).

Our research has looked at things that haven't been looked at before. It is important in the following ways:

- People with learning disabilities themselves have led the research as equal partners (on equal salaries)
- We have used drama as a research tool
- We have focused specifically on the experience and views of young people with a learning disability
- Our project has taken place in a rights-based organisation.

There are also now lots of laws and policies that are relevant to people with learning disabilities around sex and relationships. These include:

- UN Convention of the Rights of the Child (1989)
- UN Convention on the Rights of Persons with Disabilities (2006)
- Human Rights Act (1998)
- Disability Discrimination Act (1995)
- Mental Capacity Act (2005)
- The Education Act (1996)
- The Learning and Skills Act (2000)
- The Dept for Education and Skills (DfES) SRE guidance (DfEE 2000)
- The Valuing People White Paper (2001)
- Valuing People Now (2009).

Appendix 2 gives more details about these laws and policies. The important things that the laws and policies say are that people with learning disabilities have a right to:

- Sex, relationships and a family life
- Access to information so that they can make decisions about their own health
- Equal treatment in relation to using services and organisations
- Make their own choices
- Sex education.

In this way, it is important to make sure that people with learning disabilities are aware of their rights and are able to make their own choices in this area. The aim of our project was to find out about the views and experiences of young people with learning disabilities in the area of sex and relationships. We wanted to find out what young people with learning disabilities knew about sex and relationships, what they wanted to know and how they wanted to know it. We wanted to make some recommendations as a result of our project so that we could make things change for people with learning disabilities.

Summary of each section

Here is a run down of what is in this report:

Section 1 tells you about how we did the research. In this section, we talk in detail about how we did the drama work with the young people. We also talk about how we did the interviews, the survey, and the focus groups. We will also tell you about how we told others about the research.

Section 2 tells you about what we found out from all our research. This is split up into the following areas: young people with learning disabilities and their knowledge about sex and relationships; sex education; information; support; and wider issues.

Section 3 summarises what was important about the research and says what we think should happen now as a result of the research. It also tells you the recommendations that have come out of the research. This means the things we found out from our project that need to be changed about sex and relationships for young people with learning disabilities.

The last section is the **Appendices**. This is a section where we have put in lots of extra information that were too big to go into the report. There is a list on page 102 of all the things that are in the Appendices.

We have also produced an Accessible Report of our research which is at the beginning of this report. You can get a separate copy of the Accessible Report from us if you contact us at CHANGE (contact details below). If you have any comments about either report, or you would like to talk to us further, please get in touch with us at:

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web: www.changepeople.co.uk

Section 1: How we did the research

1.1 People with learning disabilities leading the research

In our project people with learning disabilities led the research and were fully involved right from the start. This is very important. There is a lot of research that has been done about people with learning disabilities by people without learning disabilities. We think that people with learning disabilities should play a big part in doing their own research. Here are the ways in which people with learning disabilities were fully involved in our research:

- People with learning disabilities have led the planning of the project
- People with learning disabilities have been on the board of trustees at CHANGE
- People with learning disabilities at CHANGE are employed on equal salaries to people without learning disabilities. In the Sex and Relationships project team one worker had a learning disability. We had a volunteer with a learning disability who was also fully involved in the project
- Young people with learning disabilities gave their views and ideas about sexuality and relationships using drama. Some of the young people also looked at existing training packs and leaflets about sex and relationships to tell the team what they thought of them. They also helped us design some new booklets about sex and relationships for people with learning disabilities
- A group of adults with learning disabilities based at CHANGE, called the Rainbow group (now Trainers for CHANGE), who deliver training, helped young people with learning disabilities create a play about their experiences and views on sex and relationships
- The project involved interviewing parents of young people with learning disabilities. When we talked to parents, we made sure that this included parents with a learning disability
- A group of volunteers with learning disabilities helped the illustrator, who drew pictures for all public documents that were produced to make sure that everything was accessible for people with learning disabilities. The volunteers suggested pictures and gave the illustrator advice
- When we told people about our research at conferences and workshops, people with learning disabilities made up a large part of the audience because the research was about them and affected them

- People with learning disabilities have been involved in writing up this report and they have given presentations about the research. We have also produced an accessible summary report that uses easy words and pictures.

When you do research it is really important to do things in the right way and to get permission to do things. This is called ethics. At all stages of the research we made sure that we did things in the right way and got permission to do things. We have written more detail about this in Appendix 1.

1.2 Running the drama group

People with learning disabilities have become more involved in research in the last 20 years (see Booth and Booth, 1994; Ramcharan and Grant, 2001; Whittaker et al, 1990; Deacon, 1982, to name but a few). But sometimes people with learning disabilities can find answering lots of general questions difficult. In our research project, we worked with young people, aged 16-25, with learning disabilities. For most of the time we had about 20 young people on our weekly register. However, we had 2 young people who came to the first few taster sessions and then decided not to continue. We also had a few young people who left at different stages to go to college courses/ jobs and we recruited more young people in the first year because of this. In total, we had 29 young people who attended the group at some point.

Out of this 29, 18 were male and 11 were female. This reflects the higher number of young men who have learning disabilities, and the higher number of young men with learning disabilities attending special schools and colleges. We recruited 7 young people from Black and Ethnic Minority (BME) communities in total, although 2 of them attended for only a couple of weeks. Out of the 29 young people, 7 had communication difficulties and 8 had physical impairments as well as a learning disability. We felt that we had a good range of young people who were representative of the wider population of young people with learning disabilities.

People with learning disabilities working at CHANGE have used drama in other projects before so there were volunteers with learning disabilities that had a lot of experience and helped with planning and running the drama group. It was helpful to use drama in our research, particularly with the topic of sex and relationships because it was less embarrassing for a young person with learning disabilities to play a character instead of themselves. They could separate their lives and express themselves in a safe way.

The young people met with us once a week for about 2 years. We had a theme each week on a different sexual topic such as friendships, public/ private space, masturbation, gay relationships etc. We also talked about using a condom and the pill. We wanted to find out what the young people knew. We did warm up activities and fun games to make sure people felt relaxed, and got used to working together. We supported the young people to use props as different characters for a play and this helped them to express themselves as individuals. We used familiar ideas, like being interviewed on television shows, so young people could give opinions. We asked young people to say what worries people might have, and think about what advice they would give to other young people in different situations.

We filmed the weekly drama sessions. A research assistant from the University of Leeds listened to the videos and wrote down everything that was said in the session. This is called a transcription. As a team, we watched the videos of the drama sessions and read through the transcriptions. We compared early sessions to later ones. We wrote down the most important things that were said and done in the sessions.

It could be difficult for the young people at times because some people found it hard to separate characters from real life. This was one reason for using props, and a clear start and end to the sessions. We had Ground Rules and we had to remind the group of them when necessary.

Some of the young people found reading and writing difficult and there was a young woman, Rashida, who was deaf, so we used pictures a lot when we were explaining things. For most of the drama sessions we were able to have a signer for Rashida. However, Rashida was a Muslim from Somalia and had no verbal language or sign language before she came to Britain. She was therefore learning sign language and relied a lot on mime. Rashida's interpreter for the drama sessions was a white British male who was deaf himself but could lip-read well. He went through the drama sessions with Rachel and John (the project coordinators) each week before the session started so that he had a good handle on what was going to be covered. He knew Rashida well and had worked with her before so had built up a good relationship with her and knew the best ways of communicating with her. However, this situation threw up issues because Rashida did not know the signs for many of the topics e.g. condoms, vagina, contraception. She was also not able to understand finger-spelling in sign language because she had no comprehension of the English language. There were also cultural difficulties because a white British Male was signing information about sex and relationships to a Somalian Muslim young woman.

During one session, the young people visited a mainstream sexual health clinic. It was more difficult during this session for the signer to lip-read the sexual health worker, so the Director of CHANGE attended as well because she was fluent in sign-language. During this session, the Director of CHANGE was listening to the sexual health worker, signing the conversation to the signer, who then mimed the words to Rashida in a way that she could understand. One of the aims of the Sex and Relationships project was to be as inclusive as possible. However, these issues show some of the difficulties that had to be overcome.

After we had worked with the young people for nearly a year, we then worked with the Rainbow Group (now called Trainers for CHANGE). The Rainbow Group used the information from the young people to create a play based on what the young people said and thought. This play was called 'Hayley and Michael'. This was based on the characters of two young people with learning disabilities who were struggling with attitudes about them having a sexual relationship. Adults with learning disabilities in the Rainbow Group were good role models for the young people because they had lots of confidence and skills in acting. Here are some photos from the 'Hayley and Michael' play:



Figure 1. Scene from the 'Michael and Hayley' play: Michael goes to buy condoms at a chemist shop. He is embarrassed. There is a queue of people behind him.



Figure 2. Scene from the 'Michael and Hayley' play: Maria tells Hayley that she is getting bullied because she is a lesbian.

The Rainbow Group then performed the play to the young people. The young people thought about what could be done to improve the situation for the characters in the play, Hayley and Michael. The young people then made up their own play, called 'The Relationship Show'. The young people performed their play on the 3rd of December 2008 at Seven Arts Space in Leeds. It was important to perform the play at this venue because it was a real theatre space and not just a room made up to look like a theatre.

The three main points the young people's play, 'The Relationships Show', talked about were:

1. Professionals not listening to people with learning disabilities or not taking them seriously
2. Young people with learning disabilities having nowhere to go to meet their friends
3. Not enough accessible information about relationships and sex.

These points were important because they came directly from the research from the young people's drama sessions.

60 people came to see the play. There were people with learning disabilities, teachers and professionals. The audience enjoyed the play and one person in the audience said this was the best play he had ever attended. The play was a good way of telling people about the research because it got the point across about the issues being faced by young people with learning disabilities around sex and relationships. It was their way of expressing their views and demonstrating to professionals that they have a right to have a relationship.

Some of the best things about working with the young people have been seeing their confidence grow and building up their self esteem. As a group they have become friendlier and they have encouraged each other to join in. Over time, the group became more relaxed. They were able to talk about things that some of them were not able to talk about before and we felt that they could talk in confidence about sexual relationships.

One positive thing about the project was the high number of young people that stayed in the group for the whole of the project. This was partly due to the good relationships we built up with the schools and colleges that the young people came from and the commitment the teachers gave to the project. The young people also said that they 'had fun' in the group and 'had good friends' there. The group started with 20 young people (9 female and 11 male), and ended with 16 young people (5 female and 11 male). There were some changes during the course of the project and we had to recruit some more young people. We found that, often, young people aged 16-25, move on to college courses and jobs.

We asked staff from the schools and colleges that worked with us to find out from the young people in the drama group what they thought about coming to CHANGE. Most of the feedback was good. The young people said that they liked meeting new people and they enjoyed the games. In the early part of the project, one person did say he hated drama, and got very tired. This meant it was encouraging when he gave us positive feedback later on.

Some members of the young people's group attended for the last time in July 2008. The final session was an awards ceremony, with John playing the ceremony host. During this 'ceremony' many of the young people said they liked 'doing the drama' and 'acting'. Some people mentioned certain characters or scenes they had enjoyed (being a rock star, two people acting a couple). A lot of the group felt they had made friends, and liked seeing each other every week. Some people said they had found the group embarrassing. When the young people performed the play, one person told the audience that coming to the group had helped him when he had lots of stressful things happening in his life.

If someone else was doing this project the advice we would give is to be patient and understanding and listen to what the young people say. We think you should, at all times, be encouraging even if they only take part in a small way because it is very important to keep the confidence up of young people. It is important to plan sessions very carefully so everyone can take part.

The drama work with the young people was the most important part of the project. However, we did other things in our research as well. We did interviews with parents of young people with learning disabilities, focus groups with teachers and governors, and a national survey of special schools. We will now tell you a bit more about these things.

1.3 Doing the interviews

It was important to interview parents to get their views and opinions. We interviewed 20 parents (15 mothers, 4 fathers and 1 couple) whose sons and daughters had learning disabilities. It is important to stress that these were NOT the parents of the young people in the drama group. The parents volunteered to be interviewed after seeing the publicity leaflets we sent out to recruit parents. In this way, the parents wanted to talk about sex and relationships. This means that there might have been other parents who were not comfortable to talk about sex and

relationships who we did not talk to. We asked the parents 20 questions about their opinions and experiences about young people with learning disabilities having relationships and sex. A lot of parents wanted to get their point across and were eager to give their opinions and it was quite emotional talking to them about sex, marriage and children. The interviews were mostly in Leeds but we did a few outside Leeds. There is a copy of the questions in Appendix 5 at the back of this report.

Each interview was typed up (transcribed). The typed up interviews were put into a computer package called NVIVO. This computer package helps to organise information, when there is a lot of it, so that it is easier to understand. We went through all the information from the interviews and made a list of the important points. We also looked at whether the information from the interviews was the same as the information from the young people.

1.4 Doing the national survey

We designed a survey to send to special schools and colleges across England. The reason for doing the survey was to get a full view of what was being taught about sex to young people with learning disabilities in England and what some of the difficulties were. There is a copy of the survey in Appendix 4. We sent the survey to 200 schools and colleges and we got 76 surveys back. We entered all the information from the surveys onto a computer package (called SPSS) and then we looked at all the information and worked out what the important points were. We could then work out what the schools and colleges were saying about teaching sex and relationships education.

1.5 Doing the focus groups

We ran 4 focus groups of teachers and governors with about 8 people in each group. Focus groups are discussion groups where a person comes with some questions on the subject and the people in the group give their views. We wanted to find out some of the issues that faced teachers and governors when looking at sex and relationships education for young people with learning disabilities. All the groups took place in special schools in the Leeds area. A lot of the teachers and governors said they enjoyed the focus group because it gave them a chance to talk about the subject, which they hadn't been able to before. The focus group questions we used are in Appendix 6. We looked at the information from the focus groups in the same

way as the interviews, writing down the main points. We also looked at how the information from the focus groups compared with the information from the young people in the drama group and the information from the interviews.

1.6 Collecting resources

We collected resources about sex and relationships for people with learning disabilities. We wanted to find out what kinds of teaching packs and leaflets there were for sex education. We looked at leaflets from various organisations, DVDs, books, and training packs. There is a list of resources we collected in Appendix 7. We wanted to know if people with learning disabilities found these resources helpful and easy to understand. Volunteers from CHANGE, and the young people in the drama group looked at some of these. They talked about what they thought would make a leaflet easy to understand. They said that information that used bigger writing, clear pictures, and no complicated words would be best. They made a chart to keep a record of whether the books and leaflets were made in that way, and to say what they thought of each book.

Analysing all the information took a long time. It was important to do it properly rather than guessing what people said or relying on what we could remember. What we have found out comes directly from the information we have collected from the young people, the parents, and the teachers. When we make recommendations, they are based on the things we have found out. They are not just our views.

1.7 Telling others about the research

We told other people about the research through the play the young people performed, through conferences, through workshops and through writing articles for magazines and journals.

1.7.1 Telling others about the research: conferences

It was important to tell people about our research because we needed to get the message across that people with learning disabilities have a right to have a relationship and a right to information. When we talked about our research at conferences and workshops, the professionals who attended were very encouraging. The kind of conferences we went to were on Health, Parenting, and Sex and

Relationships. John felt that the best bits about the conferences were meeting different professionals and telling them about CHANGE and the sexuality project. We also ran our own conference in October 2009 to tell people about the way we did the project and what came out of it. We had keynote speakers, ran workshops and presented some drama about the research. Here are some of the comments from the day:

Thoroughly enjoyed the day. Gained an overview of what needs to be done to promote equal rights and opportunities of people to have fulfilling relationships.

Made everybody think about changes that need to be made to make information accessible.

Really good to have so many people with learning disabilities involved in presentations/ workshops etc.

Great buzz of excitement about sharing good practice and moving things forward

Really enjoyed being here and meeting lots of people.

Thank you, a very interesting day... look forward to seeing the booklets CHANGE is producing.

1.7.2 Telling others about the research: articles

We wrote articles about how we did the research, why it was important and what came out of it. Some of the articles went into magazines and some of them went into academic journals. Some of the articles were written by individual members of the team and others were written jointly by a few of us. We have put a list of all the articles we wrote in Appendix 3 of this report.

1.7.3 Telling others about the research: booklets

We also produced 5 booklets about sex and relationships for people with learning disabilities as part our project. We spent a lot of time getting the wording right, for the booklets, with the help of other volunteers and staff at CHANGE. We also had feedback from other learning disability organisations and sexual health professionals. Jo (our illustrator) drew pictures that she showed to the young people for their

feedback.

The subjects of the booklets came out of the priorities of the young people in the drama group.

The 5 booklets are:

1. Friendships and Relationships
2. Sex and Masturbation
3. Safe Sex and Contraception
4. Lesbian, Gay, Bisexual, Trans
5. Sexual Abuse.

The booklets are important because they give clear information about sex and relationships in easy words and pictures. They are available from CHANGE (www.changepeople.co.uk). We hope that they will be of great help to people with learning disabilities who want to know more about sexual health.

Section 2: What we found out

Section 2: What we found out

We now would like to tell you about the things we found out from the project. For each section we will give examples of the things the young people have said in the drama sessions to show you how the drama helped us to find out information. We will also talk about what parents and teachers said.

It has been difficult to be precise about how many young people in the drama group responded to different issues. For example, in the drama sessions there might be two people who would say something and other people (who might have difficulty in speaking) would smile or nod, rather than speak. This will be the case in any discussion group and particularly with people with learning disabilities who find language difficult and who are participating in drama sessions, rather than discussions sessions. This means that, quite often, there was no accurate measure of how many of the young people spoke.

Within the group there was also one young man who liked to say opposite things to other young people just to be different, so some of the things he said might not be the things he really meant. There was another young woman in the group who quite often repeated what other people said so, again, the things she said might not have been her views. We have therefore had to interpret some of the things coming out of the drama sessions. We have been able to build up good relationships with the young people over two years and we have looked back at the videoed sessions as a team.

Sometimes the same topic would be discussed over several weeks and maybe revisited at a later date. This has meant that, as a team, we have been able to come to some agreed general conclusions about what the young people were trying to tell us over the two years and these are the things we have written about in the report. For some of the issues we have been able to include numbers to show how many young people said what, but in other situations this has not been possible.

The importance of using drama has been in getting an impression, of what was said in general. The advantage of using drama in the research project was that people with learning disabilities were able to give some response, where they might not have been able to give any response using other research methods. The response they gave was from themselves as individuals. If we had used more traditional methods of research, some of the young people might have needed support workers

to understand written or verbal communication (e.g. surveys/ interviews etc). If people with learning disabilities answered questions with a support worker present, their answers might not always have been what they wanted to say, or they might have said what they thought the support worker would want them to say. For such a sensitive subject as sex and relationships, a respondent might not want a support worker around.

The interesting thing has been in the way in which the findings of the drama work were backed up by what the parents and teachers said and what came out of the survey results. It has been important to have all four parts of the research so that we can give an accurate, overall picture of what we found out.

This section is divided into the following smaller sections:

- Section 2.1: Young people and their knowledge about sex and relationships
- Section 2.2: Sex education
- Section 2.3: Information
- Section 2.4: Support
- Section 2.5: Wider issues.

Section 2.1 Young people with learning disabilities and their knowledge about sex and relationships

First of all we will talk about young people and their knowledge about sex and relationships. This section will be split up into the following smaller sections:

- Friendships and relationships
- Public/ private
- Sex and masturbation
- Puberty and pregnancy.

2.1.1. Friendships and relationships

Over a number of different sessions, we found that most of the young people understood about friendships and were happy to talk about friendships. They were also good at saying what they liked about their friends as the following example from a drama session shows:

RACHEL: Ok, what's one thing you like about one of your friends? Don't say their name just say what you like about them. ...

GEORGIA: He's funny.

RACHEL: He's funny that's a good one. Ok, thank you for that one...

MARK: ...Err, she talks, she never shuts up.

RACHEL: Is that what you like about them?

MARK: She laughs.

Rachel: Laughs a lot, thank you....Ok, one thing you like about one of your friends?

TIM: Erm, good-looking, he's got a handsome devil face.

RACHEL: You think he's handsome?

TIM: Yes.

...

RACHEL: Ok something you like about one of your friends?

ABDUL: Erm, she's cheeky, she's a good laugh and she talks a lot...

RACHEL: ...What do you like about him?

TIM: Mark.

RACHEL: But what do you like about him? One thing you like?

TIM: He just squeezed my hands.

RACHEL: Is that something you like?

TIM: Yes, he very spaced, he's very strong.

In general most of the young people were good at talking about feelings and about guessing the feelings and thoughts of other characters. They were good at thinking about why someone might feel sad, happy, tired, upset etc. We used pictures to stimulate discussion about feelings, as the following shows:



Figure 3. Drama session: John pointing to pictures of different couples

JOHN: Look at this person [*holds picture up*] and think about how they are feeling.

MATT: She must be feeling alone.

KEVIN: I think she should be feeling happy.

MARK: I think she's feeling nervous.

In several sessions the young people talked about going out with someone. In one session they said that if you want to go out with someone you should get to know them first. They also said in another session that when a couple are kissing or hugging each other, then this could lead to sex. They said that a couple would have sex if they really loved each other. In another session, the young people were presented with some pictures and were asked to put the pictures into an order in terms of a couple in a relationship. In general, the young people could do this well. They demonstrated a good knowledge about going out with someone.

In another session we used a picture story and asked one of the young people to explain what they thought the pictures were about. This is what one young person said:

MATT: This story is about two friends, are texting a message to a friend, Joanne and she is having a drink at the café and Sasha's having a drink in the bar and now she's touching Joanne and they kiss each other and having sex in bed.

This suggests that this young person had some ideas about relationships and could interpret the story of a relationship from pictures. Throughout the sessions, we talked about gay relationships as well as straight relationships, as the above extract shows.

From the sessions we found that most young people in the drama group knew that gay and lesbian meant people of the same sex in a relationship together. They knew some words that people used to describe gay people and knew that some of them were insulting. Some of the young people seemed uncomfortable with acting a gay character which could suggest that prejudice had been picked up already. Other young people were happy to act a gay character. Some of the young people were unsure about whether gay people could have sex. 3 people said it was against the law, as the following extract shows:

[John set up a chat show scenario with himself as the chat-show host].

JOHN (as Neil): Right, audience, are gay people allowed to have sex?

KEVIN: No...

- TOBY: ...No, gay people are not allowed to have sex cos that's against the law.
- JOHN (Neil): Against the law?
- RICHARD: Are you sure?
- TOBY : They are not allowed to have sex.
- RACHEL: How do you know?
- TOBY : How do I know? Cos I have seen gay people and gay men and I have seen them doing it, so there.
- Rachel: And how do you know they are not allowed to?
- TOBY : They, how do I know they aren't to have sex? Because I know a friend anyway and he works with them as well so that's how I know.
- JOHN (Neil): Does anybody agree with this?
- KEVIN : Yes...
- JAMES: ...I don't agree with what he says, gays are allowed to have sex.
- RACHEL : And how do you know that?
- JAMES: I know that cos it's nature and it's also life, like straight people are allowed to have sex, lesbians are allowed to have sex, everyone's allowed to have sex, when they are ready and they get older.

This extract indicates that, for some of the young people, they were very sure that it was against the law for gay people to have sex. However, there was one person in the group (at the end of the extract) who was quite clear that everyone can have sex. The 'chat show' was a useful, fun way of trying to get the young people's views on this. At the end of the session, we made it clear to them that it wasn't against the law for gay people to have sex. Since there was an uncertainty around this issue, we decided that it was important that one of the five booklets we produced should be about gay and lesbian relationships.

In another session two young people acted out a doctor and a person going to the doctor. They were talking about masturbation, since that was what the session had

focused on. The two young people, however, started to take the conversation in a different direction, as the following extract shows:

- PETE: Yes, actually doctor, I just realised something and I am thinking.... as well I am thinking about boys.
- TOBY: Why are you thinking about boys and not girls?
- PETE : Because I like girls better but I love men because I am gay, so my point is I am with him all week and we went for a meal in like a club and he wanted to have sex but I like kissing and sex as well so what his point is...in my arse, that is the problem.
- TOBY : Ok, have you talked to him? Have you ever talked to him about it? Why he wanted your...in his arsehole?
- PETE : Yes, course, yes.
- TOBY : And what has he said?
- PETE : Well, he said he feels; well what I feel is I feel good, do you know what I mean?
- TOBY : Yes, yes.
- PETE : And he feels.... Well we are both the same really.

This extract shows the level of understanding and detail that Pete and Toby had about being gay. This explicit expression may not have been uncovered in other forms of research where direct questioning might have been too personal. In another session, Pete did in fact tell the group that he was gay. Scenarios like the above might bring out some of his experience and thoughts that wouldn't have been brought out otherwise. The fact that the young people had brought this scenario up (rather than the coordinators setting the scene for them) could indicate that it was an issue that they wanted to say something about.

Marriage was not a subject that was looked at in detail in the drama sessions and it was not brought up by the young people themselves. However, marriage was discussed in the parent interviews. One of the questions in the parent interviews was: 'Do you think young people with learning disabilities should get married?' A few parents became emotional and tearful when we asked them this question. The following extract from a parent interview shows this:

- RUTH: Do you think that young people with learning

disabilities should get married?

PARENT (Mother): Absolutely that for me has never been... I think R and any other young person like her... I have got upset now... should have the same opportunities at everything.

Having children was not brought up by the young people either. This could be because they were all under 25 and might not have considered the issue of children yet. During discussion about contraception however, quite a few were aware that condoms prevented pregnancy and it was important to use them.

We found that when the young people acted out fancying people in a scene, they usually placed the scene in a school or college, implying that they were the places that young people met. They did not really talk about other places where they could meet. The following is an example of the young people making up a character for a scene, indicating that a young woman would meet her boyfriend at school:

RACHEL: ...So she's called Jessica, she's 15, do we know anything else about her? We know she's a McFly [UK pop group] fan, anything else that we know or we can guess from the picture?

MARK: ...She still might be at school.

RACHEL : At school, yes and what did you say Kate?

KATE: School.

RACHEL : School, ok, she's going to school. So the boy that she likes, do you think he goes to her school?

MARK : Yes, like them at Comp, they're all wearing black.

Lack of places to meet came up in other sessions and was also one of the main points that the young people highlighted in the play that they performed during the project.

This issue also came up during the parent interviews. 9 out of 20 of the parents we talked to said that often young people with learning disabilities don't have many opportunities to meet other young people and there were not many places where they could meet. They said that young people with learning disabilities often don't get the opportunities to build relationships and sometimes this means that they do not have many friends. Parents said that young people with learning disabilities can

be quite isolated. Many of the teachers said this too.

The young people talked about the practical difficulties of getting condoms e.g. catching a bus, counting the money, it being hard to tell your mum, not being allowed to go out on their own because they might get lost, difficult to ask people where the condoms are etc. In a later session, they talked about difficulties in using transport and one young woman said 'I can't go to the shop to buy tampons because it is too far away'. This suggests that there are some practical difficulties that young people with learning disabilities have that can stop them from getting the things they need, as the following suggests:

[Talking about going to buy condoms]

RACHEL: So he might not be allowed to go out on his own?

KATE: No.

....

JULIA: The reason why he can't go on his own is in case he gets lost. That's why he can't go on his own; if he gets lost then he can ring someone.

The parents told us that many young people with learning disabilities didn't use public transport on their own. This meant that parents had to give them lifts to places. This meant that young people did not get much chance to do things on their own away from their parents.

2.1.2. Public/ private

One of the drama sessions looked at the topic of public and private space. In this session, most of the young people were clear about the difference between public and private. Most of the young people said that a bedroom and a bathroom were private, but they said that if you had a carer they would be allowed to come in. Most of the young people were clear about who they could let into their rooms and the reasons why they would or wouldn't let them in. After talking in general about public and private spaces, we went on to talk about where you should have sex. The following extract shows the understanding of the young people around making sure that sex takes place in a private place:

RACHEL: So, he did have sex with his girlfriend, so what should have they been thinking about?

MATT: Should be thinking about...close the door and have sex in bed.

RACHEL : So you're saying they should have it in the right place?

MATT : Yeah.

When we started working on creating the five booklets we made sure that the booklets stated that sex should be in a private place. Even though most young people seemed to know this, we still felt that we should make it an important point, so that everyone looking at the booklets would be clear about this.

All the young people seemed to be clear about what a 'private part' of their body was. Some talked about private parts but found it embarrassing to name them. When one female member of the group, Niamh, said the name of a private part of the body ('boobs') another member, Matt said 'I can't believe you just said that'. We used a game to help the young people to think about what were the 'private parts' of their body. In this game, the coordinator called out a part of the body (e.g. leg, arm, bum, head etc) and the young people had to touch their own part of the body that corresponded to what had been called out. If the coordinator called out a part of the body that the young people thought was private (e.g. breasts, vagina, penis), then the young people had to shout out 'No, that's private'. This was a fun exercise in which the coordinators were able to get the young people to talk about private parts of the body without causing too much embarrassment.

Most of the young people recognised that being touched when you didn't want to could make you feel angry and scared. Some of the young people said that if you were being touched when you didn't want to then the head teacher at your school needed to know. Some young people suggested that you could talk to your dad if you were not happy. Some of the young people knew the words 'rape' and 'sexual assault'. The following example illustrates this. The young people were shown a picture and asked about it:

RACHEL : I've got one more picture....

KEVIN: Someone bumming someone.

RACHEL : So what's happening there?

RICHARD: Someone's murdering someone.

KEVIN : No.

RICHARD : It looks like it.

RACHEL : One of us has said murdering, what if it's not murdering, what else could it be?

KEVIN : Shagging.

RICHARD : Getting laid.

.....

MARK: I think that he's trying to rape her.

RACHEL : I think you could easily be right.

JAMES: He's sexually assaulting her.

RACHEL : Okay, what does sexually assaulting mean?

JAMES: It means touching people where they don't want to be touched.

The following shows another example illustrating that the young people had ideas of what they should do if someone abused them. Durbali (the volunteer on the sexuality team) played the part of Hayley and a young person played the teacher.

[NB: We did not ask any of the young people to play a character that had been abused, unless they suggested it themselves.]

DURBALI [as Hayley]: Hello teacher. I want to tell you something.

LOUISE [as the teacher]: What do you want to tell me?

DURBALI [as Hayley]: I don't know if I should say. My support worker touches me a lot and I don't like it. I don't want him to touch me. I told him not to touch me, I don't like it, but he touches me a lot. I don't want him to touch me there, I'll say no, but he doesn't listen to me.

LOUISE [as the teacher]: How many times do you see your support worker?

DURBALI [as Hayley]: Five times.

LOUISE [as the teacher]: What's his name?

DURBALI [as Hayley]: I don't know his name.

LOUISE [as the teacher]: You don't know his name?

- DURBALI [as Hayley]: No, I don't know his name at all.
- RACHEL: ...So Hayley told her teacher, what do you think the teacher should do next?
- BEN: Report it to the headmaster.
- RACHEL : Okay, so what do you think the teacher should say to Hayley?
- BEN : Office,... social worker don't touch that person again.
- RACHEL : So you think Hayley or the teacher would go to the headmaster and then the headmaster would talk to the support worker?
- BEN : Yes.

This example indicates that the young people were not aware that the police could be called if someone was being sexually abused. If young people were unsure about who to talk to if they were being abused, then this could make them more vulnerable. This is a topic that could be emphasised more in schools and colleges.

Although our role in the project was to find out information from the young people about sex and relationships, after the drama session about abuse, we spent some time explaining to the young people that abuse and rape was wrong. We wanted to make sure that the young people were clear on this issue. We told them that if they have been abused it was not their fault and that they should try to talk to someone they trusted about it. We also decided to have one of our five leaflets about abuse so that people with learning disabilities have clear information on how to recognise abuse and what to do if someone abuses you.

In one session we talked to the young people about different ways of saying 'no'. After the young people gave their suggestions, we looked at pictures of how people could say 'no', such as the following:



Figure 4. Illustration drawn for the project showing saying "No" without using your voice

The young people also talked about saying 'no' in a serious and non-serious way, thinking about how to put it across when they wanted people to take them seriously. This was followed by a game where the coordinators had a ball that they called a 'slimey' ball. They told the young people the slimey ball had been in the gutter and dragged through the bins. One member of the group volunteered the suggestion that the ball was covered with fly monsters as well. The coordinators asked different members of the group if they would like the slimey ball. They had to say 'no' in a convincing way. This game brought laughter and fun to the group. It also brought home the importance of saying 'no' as if you really mean it.

2.1.3. Sex and masturbation

We found that there were big differences in knowledge about sex and masturbation among the young people. Over the course of a number of sessions we found that some knew a lot and some knew very little. We found that some of the young people with the most knowledge seemed to be those that had been given one-to-one input

from school nurses or specialist sexual health workers.

In session 11 (after several group discussions about sex and relationships), the young people were asked the following questions:

- a) Where would you go to find out about sex? (with pictures of a park, a supermarket, and a teacher as answers)
- b) Which picture is sex? (with pictures of talking, hugging and sex)
- c) If you have sex what do you get? (with pictures of a baby, a medal and a puppy)

The young people were asked to point to the picture that they thought was the right answer. The purpose of asking these questions was to find out early on in the drama sessions whether the young people understood some basic concepts around sex and relationships. As this was an early session, we chose some pictures that were unusual answers because we wanted to find out whether some young people had very little knowledge.

For each of these questions, 3 young people out of 13 were not able to give the correct answers. This suggests that some young people with learning disabilities lack some very basic knowledge. Two of these young people had communication difficulties and the other came from a different country and did not speak English very well. This could mean that young people with learning disabilities who have additional needs might not be given information about sex and relationships. It could also mean that they had been given information but not understood it or that they could not express what they had learnt. The parents and teachers in our research also highlighted the fact that, in their experience, they felt that some young people with learning disabilities lacked some very basic knowledge about sex, so the lack of knowledge for the three people in the drama group may not be down to just communication difficulties or language differences.

In several sessions we talked about condoms, what they were for and where to get them. During one of the drama sessions, when the drama coordinators said that two characters in a play, Stephanie, and her boyfriend, didn't use a condom when having sex a lot of the young people said 'uh-oo' (i.e. They knew it was not good to not use a condom). One young person, when asked about what condoms were for, said that he didn't want to talk about it because he might get 'busted'. Over the weeks, we found that quite a few of the young people had a lot of knowledge about condoms,

such as what they were, and where you get them from, as the following shows [an extract from a chat show]:

RICHARD: Yeah, where do I get condoms from?

RACHEL: Does anyone know the answer to that? We've said that they're really important. Has anyone got any idea where Stephanie might find some? Anybody? Where do you think she could get them from?

KATE: I think you can get condoms from shops somewhere.

RACHEL: Say that again?

KATE: Condoms you can buy from the shops.

RACHEL: From the shops?

KATE: Special shops.

RACHEL: Special shops?

KATE: Yeah.

RACHEL: Ok, what kind of special shops sell them? Does anyone know?

TOBY: Oh god.

RACHEL: So there's some special shops where you can go and buy them from. Do you know where any of them are?

KATE: Yeah.

RACHEL: You do? Excellent. How did you find that out?

KATE: ...it near where that doctor is. The doctor blue packs.

RACHEL: Right you can get them in the doctors? Oh so where else. Some of this audience is very quiet. Does anyone else have any ideas? Where apart from the shops can you get them from?

TOBY: You could try to get the condoms from the shops, pharmacy or you could try and see the doctor....

NIAMH: You can try and get condoms from, if you go in any kind of toilet...like a machine with different things in and err you have to use a pound and if you want condoms you have to pull the things of condoms and when you pull it condoms come out. You

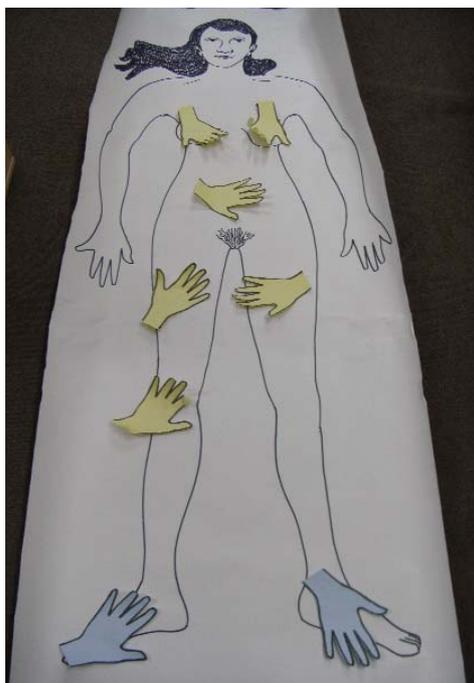
can actually have it from a condom machine which is rather based in any kind of toilet or any kinds of pubs in the toilets.

RACHEL : ...That's a good tip thank you very much.

In one session one young person, Kevin, brought up the topic of anal sex, calling it 'bum sex'. Others joined in the conversation. The coordinators hadn't brought the subject up. This, again, shows the detailed knowledge of a few young people with learning disabilities in the group.

We found that during many of the drama sessions the young people showed embarrassment about talking about sex. This was particularly so within the earlier sessions. In one session many of the young people giggled when they were shown a picture of a naked man/ woman. Often when sex was mentioned, they were quiet. When the sessions were not focused on sex then the young people seemed less embarrassed. In the later sessions they had got used to talking about sex more and were a bit less embarrassed.

One session was about masturbation. We found this session hard to plan, as the topic is not talked about very often. We asked the young people to put cut-out hands on parts of the body (drawn on flipchart) where they would like to be touched or where they would touch themselves as the following photograph shows:



Figures 5 & 6. Drama session: Cut-out hands are placed on the drawings of a man and a woman by the young people to show where they like to be touched or where they would touch themselves

The group was split into men and women for this session. The young women were not forthcoming about this, but the young men were more confident. The young men knew words for masturbation but didn't know the word 'ejaculation'. A lot of the young people said they found the session embarrassing.

When we talked to teachers in the focus groups, they pointed out that lack of knowledge and understanding about sex and masturbation can lead to inappropriate behaviour, such as masturbating in a public place. During the course of the focus groups with teachers, we found that masturbation in public could be a serious difficulty on some occasions. We found that they used some of the following methods to redirect inappropriate masturbation: 'wearing dungarees, a cold water spray, putting a tray on his wheelchair to restrict access, distraction, take him for a walk, cover him up, or move his hand away'.

We decided that one of our booklets should be about sex and masturbation. We felt that these were important subjects because young people, parents and teachers all highlighted the lack of knowledge about this.

2.1.4. Puberty and pregnancy

Other topics that we addressed in the drama sessions included puberty and pregnancy.

In one session we worked with the Josephine Project from Newcastle-upon-Tyne. The Josephine Project is an interactive project that has been set up to help young women with learning disabilities explore issues such as: puberty, sex, sexuality, pregnancy, periods, menopause, and cervical and breast cancer. Josephine was a life sized female model made of material that had detachable breasts that could be felt for lumps, a detachable 'feelings bag' for storing and exploring emotional issues, a clitoris that squeaked and a tummy that could be opened to show the female reproductive organs as the following shows:



Figure 7. Drama session: 'Josephine' during the workshop with the young people



Figure 8. Drama session: Close up of Josephine's face

The young people really enjoyed working with Josephine and one young man said he thought she was 'awesome'! The Josephine Project Coordinator talked to the young people about periods, fertilisation and about pregnancy, showing the young people the process in Josephine's body. At the end, when Josephine's tummy was

opened up further, it revealed a tiny baby:



Figure 9. Drama session: 'Josephine's' baby being born

Working with the Josephine Project helped us to explore what young people knew about these things. The Josephine Project Coordinator (JPC) continually asked the young people questions, to find out what they knew already. This was done in a fun, non-threatening way. When the young people were not sure of the answers, she was able to give them further information. For some of this session, the young men and young women were in different groups. We found that the young people opened up more in single-sex groups in this session, and the Josephine resources also helped the young women, in particular to talk more. We learnt a lot from the young people in this way.

We found that none of the young people could say how a period was connected to having a baby. Only one person (out of 17 who attended for the session) told us that a woman was pregnant for 9 months, as the following example shows:

- JPC: So how long do you think after meeting with the sperm it takes for this egg to grow into a baby?
- ? : Two to three weeks?
- JPC: It's not two to three weeks, how long do you think, N?
- ANGELA: Two weeks.

JPC: It's not 2 weeks.

RICHARD: Nine months.

ANGELA: Nine months.

JPC: Nine months, its nine months that it takes for this to grow eventually into a baby.

One person, Sarah, knew that if you have a period then you are not pregnant. Quite a few of the young women knew that a woman has a period every month, but none of the young men knew how often a woman has a period, even those who had lots of knowledge of other things. Most of the young men knew what an ultrasound scan was. Quite a few of the young men knew that babies come out of a vagina and that they can come out of the tummy. One person said that it hurts a lot to have a baby. Some young people thought babies came out feet first; some thought that babies came out head first.

Most of the young people knew that women don't have sperm. Most of the young people knew that men have lots of sperm, with one person offering that he thought a man had over 90,000 sperm. Quite a few young people knew that sperm came out of a penis, as the following shows:

JPC: ...Where might a sperm come from?

JAMES: It comes from us males.

JPC: It comes from men, that's right

ANGELA: Men?

JPC: Yes and whereabouts outside of a man's body would sperm come? You were mentioning it before...

KEVIN: The willy.

RICHARD: The testicles.

JPC: Out of the willy, yes out of the penis, the man's penis, ok, so...

RICHARD: Most guys store the sperm in the testicles, so yeah.

The young men in the group seemed to know more about sperm than the young women and all the young men (but none of the young women) laughed when the Josephine Project Coordinator talked about a man ejaculating/ having an orgasm.

During the session, we found that the young men seemed to know more than the young women in general about the process of sex and pregnancy (except for the topic of periods) and offered more of the answers. We found out from staff at the schools and colleges that the young men who were more knowledgeable had been given one-to-one teaching about sex and relationships. The young women in the session seemed to join in more, and were more interested, when talking about babies and when the group was split into two groups, male and female. The 3 young people (two young women and one young man) from BME communities in this session were quiet and did not join in much. However, this could be because the session was designed very much as a question and answer session, and 2 out of 3 of the young people from BME communities had difficulties with language and communication. Some of the responses could also be due to the different levels of learning disability rather than gender or BME differences. Although much of the session run by the Josephine Project was visual and interactive, the question and answer style of delivery was less inclusive for some of the young people in the group.

From the session with the Josephine Project, from the parent interviews and teacher focus groups, we have gained mixed feedback. This can suggest that some young people with learning disabilities have been given knowledge about puberty and pregnancy while, for others, this is a difficult subject.

Although most of the young women (and some of the young men) in the drama group knew what periods were, during the interviews with parents, we heard stories from 7 parents (out of 20) about their son or daughter finding puberty frightening. Parents said that this was because the young people did not know what was happening to their bodies because no-one had told them. The young people therefore had told us, and shown us through drama, what they knew and did not know. The parents were telling us about the effect of not knowing about puberty and sexuality.

We heard stories from the parent interviews about young people who had become ill or wanted to hurt themselves when they reached puberty because they were so frightened and stressed, as the following quote shows:

He really felt upset going through puberty, getting pubic hair, which he tried to pull out with tweezers, which I didn't realise, I just thought he had boils coming. He was actually removing it all cos he didn't understand what was happening. Because he didn't have sex education he didn't understand what was happening to his body. He didn't understand erections and he thought

that something terrible, that he was terribly ill, when he was having, started to have erections and wet dreams and was also very embarrassed about it because he thought that it was something very shameful... (Mother)

The teachers in the focus groups also told us of an example of a young woman with a learning disability who was very distressed when a nurse told her about puberty. The teacher said that the young person was devastated, and was physically shaking because she was so frightened and had had no warning about it.

The parents said that the difficult experiences their young people can have around puberty and sexuality were made worse by lack of information and preparation as the following suggests:

[My son] became very aggressive, I couldn't approach him in any way, he became difficult to talk to and things like this. It's as though he'd changed from being the calm young man to this person I didn't know. I found it very difficult to try and come to terms with that....That's to do with the learning difficulty...You can teach them, or try and teach them what you're talking about, but when it comes to the actual being there, and feeling the way they do, it's hard telling them they are going to feel this or they're going to do that...So this sort of way they are not really prepared for it in the end. (Father)

...when those things [onset of puberty] did happen they were a shock for her and for me. (Mother)

She doesn't understand her body or monthly periods and she doesn't know how to deal with it. Hygienically she cannot handle it either, so I have to help her...I think they might have prepared her in some way to do with that, but the reality is different. (Mother)

Other parents talked about other personal and relationships situations that had been traumatic for their young people as the following suggests:

...my daughter had her first boyfriend and it all went badly wrong, she couldn't accept it. She became obsessed by this boy and was stalking him, she was running away from home, police involvement and it was all because her hormones and her mind was all over the place, it ended in her having a breakdown...that was all to do with the awakening of her sexual awareness. (Mother)

A while ago my son, when he was about sixteen or seventeen was unsure

about whether he was gay or not...He went out one day and I think he was contemplating the possibility of exploring, and encountered a man, it went wrong for him, he got frightened of this man and he called the police because he thought they would protect him. He was arrested and held and cautioned and interviewed under caution. They were talking about putting him on the sex offenders register and charging him with an act under the indecency laws. He was hanging around and met somebody at a public convenience and instead of supporting my son and protecting him, they threatened labelling him with a sex offenders stigma...it's always a difficult time and even more difficult for my son. (Mother)

In this way, support and information about sexuality and puberty is very important for people with learning disabilities. This is a really key point. When we designed the five booklets we decided not to cover puberty and pregnancy because we found many other leaflets and resources on this subject. We felt that there was not a lack of information on this subject but maybe that young people with learning disabilities were not always given the information they needed. We did however decide to make sure one of the booklets covered gay, lesbian, bisexual and trans as this was an area that the young people were unsure about.

RECOMMENDATIONS:

As a result of what we have found out about young people and their knowledge about sex and relationships, we have made the following recommendations:

- There needs to be more information for young people with learning disabilities about gay/ lesbian relationships; public/ private space; abuse; sex/ masturbation; contraception
- There should be more places for young people with learning disabilities to meet. There could be youth clubs and night clubs set up, for example that cater for the needs of young people with learning disabilities
- Young people with learning disabilities should get support to use transport more independently
- Accessible information about sex and relationships should be made more available for young people with learning disabilities, especially information about puberty so that it is less frightening.

Section 2.2 Sex education

The next section is about sex education. This section will be split up into the following smaller sections:

- What is taught?
- Who should teach sex education?
- Mainstream/ special schools
- Sex education- a right?

2.2.1. What is taught?

In some of the sessions we found out about the kinds of sex education the young people had in schools/ colleges. When the young people in the drama group were asked what sex was, no-one talked about sex for pleasure. They mainly focused on meeting boyfriends/ girlfriends and on having babies. When the young people were asked if they had seen pictures of naked men and women and of sex, 9 young people (6 young men and 3 young women), out of 13 who were present for the session, said that they had. In one session, two of the young people (Matt and Niamh) recognised a picture that was shown to them out of a sex education resource book (published by British Institute of Learning Disabilities) and said that they had talked with someone at school about it. Most young men said that they had heard a lot of information before. Sometimes young people seemed to know snippets of information but were not always clear about things.

In general, the teachers in the focus groups felt that sex education for young people with learning disabilities needed developing more. A number of teachers said that there was not enough adequate sex education in special schools.

We also had some feedback about this in the survey. Of the 76 schools/ colleges who responded to the survey, most of them (90.3%) said that they provide some kind of sex education to their students. This could mean that a lot of young people with learning disabilities get some form of sex education. There were only a few schools/ colleges (9.7%) who said they didn't provide sex education. Their reasons are summarised below:

- The students are not at a level to understand or have profound disabilities
- Teachers haven't been told they need to do it

- Governors haven't approved it
- Religious ethos
- Not seen as important as other topics.

Although most schools/ colleges provided some form of sex education, it was not compulsory in all schools/ colleges. It was only compulsory in about two-thirds (69.2%) of the schools and colleges in the survey. If something is compulsory this means that you do not have a choice. This means that in a lot of the schools and colleges, who filled in our survey, students had to do sex education but also there were some schools and colleges where students (or the parents) could opt out of sex education lessons (30.8%) even when they were provided. This meant that there are some schools/ colleges where young people with learning disabilities could miss out on learning about sex and relationships.

Our overall impression from the focus groups with teachers was that quite often sex education was done on an as-and-when-needed basis with individuals. In this way the teachers were complying with their duty under the Dept for Education and Skills (DfES) SRE guidance (DfEE 2000) in which there is a recommendation that Social and Relationships Education is delivered as part of PSHE (Personal, Social and Health Education) and Citizenship programmes (See Appendix 2). The guidance states:

'Mainstream Schools and special schools have a duty to ensure that children with special educational needs and learning difficulties are properly included in sex and relationships education. Sex and relationships education should help all pupils understand their physical and emotional development and enable them to make positive decisions in their lives.'

However, we found that, for some schools, this education was not necessarily delivered in structured classes or programmes. The examples given by parents in the previous section indicates that, for some young people, a lack of understanding about puberty and sexuality can lead to trauma and distress. This indicates that schools and colleges need to improve their programmes in this area.

Teachers in the focus groups talked about the kinds of things that were taught in sex education at the moment. These included: relationships, interpersonal skills, inappropriate behaviour (e.g. touching, personal space, masturbation), self esteem, doing things for yourself, working with others, friendships/ relationships, public/ private, friendships/ trust, miscarriage, abortion, morning after pill, Sexually

Transmitted Infections, body parts, empowerment, assertiveness, legal issues, and intercourse. The survey showed that similar topics were taught in other special schools and colleges.

The reasons schools/ colleges in the survey gave for not teaching some of the topics were:

- Not appropriate for our students, e.g. age and understanding of students
- Programmes tailored to individual needs
- Time pressures
- The subject hasn't been raised in class discussions
- Staff uncomfortable/ not confident about some issues.

As a result of our project one of the 5 accessible booklets we produced was entitled 'Sex and Masturbation'. We wanted young people to have some clear information about what sex and masturbation was. The first line of this booklet states 'Having sex can be fun and exciting'. It then goes on to talk more about sex between two people and knowing when you are ready to have sex. Since none of the young people or teachers talked about sex for pleasure we felt that it was important to state at the beginning that sex could be fun and exciting.

2.2.2 Who should teach sex education?

In several of the drama sessions, most of the young people had good ideas of who they might talk to if they had questions about sex and relationships. They suggested people like teachers, doctors, nurses, parents, etc. The following example illustrates this:

RACHEL: ...The people that said she should tell somebody, who do you think she might tell?

KEVIN: Her Mum.

NIAMH: Her Teacher or her Headmaster.

RACHEL : Her Mum, her Teacher, her Headmaster.

MALIK: Her friend.

KATE: Her Granddad, her family.

KEVIN: Her Nana.

TOBY: The Police.

Even though the young people suggested parents as a source of information, we found that when they acted scenes about telling members of their family about problems, they were quite often embarrassed, and less embarrassed when acting scenes with a doctor/ other professionals. Some scenes the young men acted seemed to suggest they would find it very difficult to have a conversation with their family about sex and relationships. The scenes suggested that they felt that they might get negative or shocked responses. This could indicate that young people felt more comfortable talking to professionals.

15 parents (out of 20) in the interviews said that they would not usually go to their GP for information on the subject. However, the young people did see the doctor as a source of information, even though they said that there is a lack of accessible information they could understand. Parents suggested that maybe an outside person needed to teach sex education to young people with learning disabilities. The parents said that it would be a good idea for many professionals to be involved in giving young people with learning disabilities sex education, not just one person. However, they also said that they thought that there were not enough well-trained professionals to do this. The young people talked a great deal about who they would talk to. The teachers however talked about who should teach sex education, rather than who should be available to talk about it.

There were different views from the teachers about who should teach sex education. Some teachers felt that community nurses were good at teaching sex education because they could go between school and home. Some teachers said that sex education would be better with specialist staff from outside, who had been specially trained. Some teachers said that teachers themselves were the best people to teach sex education. This was because they would know the young person and have a good relationship with them. Many teachers said that it should be teachers and parents together.

There were also some teachers who said that two people at once should teach the young people, such as specialist staff, along with someone who knew the young person, like a teacher. This was actually happening in some schools we talked to. One school said that community learning disability nurses worked with the teachers to plan the delivery of sex education. One school said they had input from the police about legal issues and being pressurised by others. One school said that the school nurse was anxious about delivering sex education so worked with the teacher to plan

it. In these examples the teachers stated that they had more confidence when they worked with another professional who knew about sex education.

The teachers in the focus groups said that often they did not know where to start in teaching sex education to young people with learning disabilities. They said that there was a lack of training around sex education for people with higher support needs. Very few teachers in the focus groups said they felt confident about delivering sex and relationships education to pupils with learning disabilities. These tended to be those who had been given previous training and had been teaching sex education for several years.

Teachers said that sometimes they were also worried about the responses from parents. Sometimes they were worried about teaching sex education to young people who had been involved in child protection issues because they don't want to bring up memories of abuse for the young person. However, previous research with women with learning disabilities (McCarthy, 1999) has found that the vulnerability of women with learning disabilities to being abused was made worse by lack of understanding and knowledge about sex and relationships. One of the leaflets we designed as a result of the project has the title 'Sexual Abuse'. We felt that it was important for young people to be able to recognise abuse and to know what to do about it.

For most of the schools/ colleges in our survey, the main person who taught sex education was a teacher or lecturer at the school/ college (93.9%). A few schools/ colleges used a school nurse (27.3%), a specialist sexual health worker (19.7%) or someone else (30.3%) such as care staff, counsellors, or support staff.

This suggests that, on the whole, teachers take a large responsibility for teaching sex education but quite often they don't feel prepared or are not trained to do so.

2.2.3. Mainstream/ special schools

Most of the young people in the drama group came from special schools in the Leeds area (14 out of a total of 25 young people who attended the drama group over the course of the two years). Of the others, some of them (4 out of 25) attended an inclusive unit within a mainstream school, some of them (4 out of 25) attended a life skills course in a mainstream school and only a few of them (3 out of 25) did not attend school or college.

Many of the teachers in the focus groups told us that a lot of sex education in special schools was done on a one-to-one basis when a difficult situation or crisis arose around sexual behaviour, and not through structured courses. The teachers said that they thought it would be better to have structured sex education classes rather than just dealing with crises on an individual basis.

Some of the teachers did say that young people with learning disabilities could miss out on sex education if they went to a mainstream school because the sex education classes were not always at a level that they could understand. The teachers said that young people with learning disabilities in a mainstream school could be more aware of relationships and sexuality because they would hear things from other young people, but they might not get clear, accurate information that they understood. All the teachers in the focus groups were from special schools so they were unable to comment with detailed knowledge about the situation in mainstream schools, but they were able to give their opinions and overall impression of mainstream schools.

The UN convention on the Rights of the Child states that children and young people have the right to enjoy the highest attainable health, access to health facilities (Article 24) and access to information which will allow them to make decisions about their health (Article 17). It also states that children have a right to education (Article 29) and a right not to be discriminated against (Article 2). 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 (See Appendix 2 for further details). These laws are saying that schools and other sexual health services have a legal obligation to give young people with learning disabilities an equal service. In this way, if mainstream schools do not provide adequate sex and relationships education to young people with learning disabilities they are discriminating against them and denying them their rights.

Further systematic research needs to be done in the future around the provision and extent of adequate sex education for young people with learning disabilities in mainstream schools.

Some teachers said that sex education was not good in either mainstream schools or special schools. However, many teachers said that in a special school you can respond to the needs of the students more and it can be done in a more sensitive way. They also said that in special schools it is easier to have small groups, that information can be adapted more easily, that teachers knew the students better and

a child could do a sex education programme again if they missed out on it or didn't understand it.

Many of the teachers felt that school was the best place for young people with learning disabilities to learn about sex education. Several teachers said that school was the only place young people with learning disabilities would get sex education. Teachers felt that young people with learning disabilities needed sex education, they should be taught in small groups who would be at the same level, and the information should be repeated again and again. The parents we interviewed also said this.

2.2.4 Sex education - a human right?

In the drama sessions we asked the young people if they thought it was a right for young people with learning disabilities to have sex education, as the following shows [chat show extract]:

RACHEL: ...somebody who was on this news report earlier said young people should not have any sex education. What do you think about that? Do you think everybody should have sex education? Any comments on that?

NIAMH: I think they should have sex education to make them aware of what they are going to be doing. If you have sex with someone you've got to be aware that they might give you AIDS or crabs.

RACHEL: So they might have diseases?

NIAMH: Yes.

RACHEL: What do you think would happen if people didn't have any sex education?

RUPERT: They wouldn't know about it.

RACHEL: Do you think they should know?

RUPERT: Yes.

Later in the same session, the following was said:

NIAMH: If you want to know about sex I think it's really important that you learn about it and what you are going to get.

RACHEL : So you think everybody should learn about sex?

NIAMH : Yes.

17 (out of 20) parents we talked to said that they wanted their young people to have relationships because it was a right, as the following 3 quotes from the parent interviews show:

I don't think we can just leave them, I think we owe it to them really to help them. (Mother)

[It] comes down to equal rights really doesn't it, I don't see why just cos they've got learning difficulties why should they...be penalised..?(Mother)

I really hope that my son has the opportunity to have a full sexual relationship, get married and have children. (Mother, Muslim)

Parents did not want the young people to miss out. However, they indicated that they worried about them and they did not know the best way of approaching it. These examples show that young people with learning disabilities and parents in general thought that people with learning disabilities should have a right to sex, to relationships and to sex education. Valuing People Now, (Department of Health, 2009- see Appendix 2 for more details) which sets out the Government's strategy for people with learning disabilities for the next three years states that its vision is:

'...that all people with a learning disability are people first with the right to lead their lives like any others, with the same opportunities and responsibilities, and to be treated with the same dignity and respect.' (p.2)

It also goes on to talk about relationships, talking about:

'...the importance of enabling people with learning disabilities to meet new people, form all kinds of relationships, and to lead a fulfilling life with access to a diverse range of social and leisure activities.' (p. 8)

The Human Rights Act (1998, Article 8- see Appendix 2 for further details), also states that every human being has a right to respect for private and family life.

In this way, most of the parents in our study agreed with the policies and laws in that they wanted young people with learning disabilities to access their rights to lead a fulfilling life, including sex and relationships if they wished.

RECOMMENDATIONS:

As a result of what we have found out about sex education, we have made the following recommendations:

- Young people with learning disabilities should have a human right to sex education. This is also enshrined in policies and laws e.g. Valuing People Now, (Department of Health, 2009) and the Human Rights Act (1998)
- Sex education should be provided at a level that young people can understand
- There needs to be better training for professionals (e.g. teachers) about sex education for people with learning disabilities
- There needs to be better support for young people with learning disabilities in mainstream schools around sex education. The UN convention on the Rights of the Child and the Disability Discrimination Act (1995) state that if sex education isn't provided on an equal basis to people with disabilities then schools and other services are breaking the law
- It needs to be clearer who will teach sex education and teachers (and other professionals) need to work together more
- Sex education should include sex for pleasure and not just the biological aspects.

Section 2.3 Information

The next section is about Information. This section will be split up into the following smaller sections:

- TV/ internet
- Not enough information/ don't know where to get it
- Resources used.

2.3.1 TV/ internet

We found that the young people talked a great deal about television programmes and films they had seen, as the following shows:

JOHN: Can anyone of you suggest a girl's name Durbali is going to be on stage? Yes Matt?

MATT: Halle Berry.

JOHN: What?

MATT: Halle Berry.

RACHEL: Halle Berry's a real person isn't she? Can you suggest just like a girl's name?

MATT: Julia Roberts.

RACHEL: How about just 'Julia' then?

.....

JOHN: Do you want to be an actor, T? Ok then. Right then, can anyone think of a name what T is going to be on stage?

MATT: John Travolta.

JOHN: Eh?

MATT: John Travolta.

JOHN: John Travolta?

MATT: Yeah.

RACHEL: Can we think of a name that's just a made up name?

MATT : Danny.

RACHEL : Danny?

MATT : Call him Danny Zuko.

The young people were able to give examples of things they had seen on TV, such as gay and lesbian relationships. In one session we talked about an Agony Aunt page in a magazine. None of the young people seemed to know what this was. This indicated that young people with learning disabilities, in general, probably did not get their information from magazines in the same way that other young people might do, but may get a lot of information from television programmes and films.

The parents and teachers we talked to also told us that young people with learning disabilities often got a lot of information from TV and the internet. The parents and the teachers were worried that sometimes young people may not be getting the right information.

2.3.2 Not enough information/ don't know where to get it

The young people acted out scenes about the difficulties in getting accessible information about sex and relationships. This was one of the main points highlighted in the young people's play, as the following extract from the accessible script shows:

[Scott visits the doctor to get some information about sex and relationships. The doctor is not very helpful and has not got any accessible information. Afterwards Scott is interviewed by 'reporters' who want to find out what could have made the situation better.]



RASHIDA (as Doctor)



ROSS (as Scott) (miming)/ TOBY (as Scott) (talking)

TOBY (as Scott) explains where he is going (Doctors), what he wants to know and how he is feeling. He says 'this is what happened'



ROSS (as Scott) goes to see the doctor because he wants information about sex.



The Doctor says things that aren't very helpful.

Scott doesn't understand.



The reporters (ABDUL and JAMES) interview Scott (TOBY):

Reporter (JAMES): How are you feeling?



Scott (TOBY): Made me feel stupid.



Reporter (ABDUL): What do you think would have made it better for you?



Scott (TOBY): If they had given me information to take away

13 out of 20 parents who were interviewed said that they often ended up giving their young person information about sex and relationships because no-one else had. This was in contrast to some of the teachers in the focus groups who said that school might be the only place young people with learning disabilities could get information. Parents and teachers both said that there is a need for better information.

None of the parents we spoke to had been given information from professionals automatically. They said that they had to fight for it. They said that information was often only offered when there was a problem with the young person (e.g.

inappropriate behaviour). There didn't seem to be one source of information.

Parents told us that they have got information from the following places: school nurse; the Downs Syndrome Association; a special needs youth club; the Learning Disabilities Team; community nurse; social workers; child development clinic; community paediatrician; internet; the Lesbian and Gay Foundation (Manchester); and the Terrence Higgins Trust.

Parents and teachers both said that there is a need for accessible information about all aspects of sex and relationships for young people with learning disabilities to take away. They also said that there is a need for accessible, visual information, such as anatomical models/ CD-ROMs/ TV programmes/ DVDs, role play and discussion.

The teachers in the focus groups also said that there is a lack of information for people who find communication difficult, those with autism and those with higher support needs/ complex needs. They said that resources were not always at a level that the young people can understand and often need adapting.

The 5 accessible booklets about sex and relationships that have been produced as a result of the project will address some of these issues.

2.3.3 Resources used

The young people and the project coordinators visited a sexual health clinic in Leeds. The outreach worker was very helpful but recognised that mainstream sexual health services were usually not equipped to support people with learning disabilities and sexual health resources are not always in an accessible format.

Some of the young people looked at some of the sex education resources we had collected. We found that there were a lot of resources about sex and relationships aimed at people who work with people with learning disabilities. There were books, leaflets, DVDs, Videos, and CD ROMs. The young people liked some of the resources. Some of them were not very accessible because the writing wasn't big enough and some pages had no pictures. Most of the resources were for teachers. There were not many accessible resources for young people with learning disabilities to take away.

From the survey we found that only half the schools/ colleges (50%) said that they used a training pack. See Appendix 7 at the back of this report for examples of the

kind of packs people use. From the survey results we found that the main ways of teaching sex education were by using videos (66.7%), booklets (51.5%), discussion topics (45.5%), a range of pictures (45.5%), a step by step pack (33.3%), DVDs (30.3%), and books (30.3%). The resources that were not used as much were leaflets (24.2%), anatomically correct models (21.2%), CD ROMs (21.1%) and models of genitals (15.2%). Most of the people (61.3%) said they used a pack that had been professionally produced for people with learning disabilities. Other schools and colleges (48.4%) said that they used a pack for young people in general, they made up their own pack (45.2%), or they adapted someone else's pack (25.8%).

Examples from the survey of where schools/ colleges got leaflets and booklets from include the following places: Family Planning Association (FPA), Brook, Government, Connexions, Health Education, Primary Care Trust (PCT) library, National Health Service (NHS), Youth Action Theatre (YAT), outside agencies, and internally produced leaflets. Most of the resources young people could take away were professionally produced and designed specifically for young people with learning disabilities (51.1%) or for young people in general (51.1%).

Of those colleges and schools that didn't use resource packs their reasons are summarised below:

- Resources not suitable for young people who are deaf, have visual impairments, have complex needs, have Autistic Spectrum Disorder (ASD)
- We use a variety of resources to meet individual needs
- Resources not appropriate/ suitable/ useful for the students
- We adapt resources or combine different resources.

Some schools/ colleges in the survey did not have resources for young people to take away (25.8%). The reasons given for this are summarised below:

- College is residential so students can look at college resources.
- Young people come from abusive backgrounds
- Nothing useful/ suitable for the client group
- No resources that include sign language
- Students don't need leaflets because they have good sex education in the school/ college

- Not needed/ not applicable.

This shows that there isn't one central source of information or advice for young people, teachers or parents, and some of the information isn't very accessible.

RECOMMENDATIONS:

As a result of what we have found out about information, we have made the following recommendations:

- There should be clear, accurate information for young people with learning disabilities around sex and relationships so that they are not only getting information from TV and internet
- It would be helpful to have one main source of information, such as a helpline number, one key professional or a central resource centre so that parents/ teachers/ young people need to know where to get information
- There needs to be accessible information about sex and relationships for young people with learning disabilities to take away and look at
- There needs to be better information for people with higher support needs/ complex needs/ autism
- When producing accessible information about sex and relationships, people with learning disabilities should be consulted to make sure that it is in a format that they can understand.

Section 2.4 Support

The next section is about support. This section will be split up into the following smaller sections:

- Closer working between parents and professionals
- Worries of parents
- Parents feeling unprepared.

2.4.1 Closer working between parents and professionals

Throughout the drama sessions the young people indicated that they did not always get a helpful response from teachers about sex and relationships. For example, they talked about teachers and other professionals dismissing their worries and not having time for them to talk. The play devised and performed by members of the Rainbow Group (called 'Hayley and Michael') had a scene in it about this, which is below:

TEACHER (Joan from the Rainbow group): Dismisses class, says see you tomorrow.

[Everyone talks like students leaving the class. Teacher sits down.]

[HAYLEY tells the teacher that she has a boyfriend and needs to know about sex.]

TEACHER (Joan from the Rainbow group): I haven't got much time.

HAYLEY (Ann from the Rainbow Group): I need advice.

TEACHER (Joan from the Rainbow group): I don't think you'll understand. I'll need to talk to your Mum and Dad.

HAYLEY (Ann from the Rainbow Group): Please don't.

TEACHER (Joan from the Rainbow group): I could get in trouble. I think you should stop seeing him.

[HAYLEY walks off. TEACHER stands up and folds the chairs.]

All the scenes in the 'Hayley and Michael' play had developed from the ideas of the young people. This scene also showed that teachers felt that they might get in trouble if they gave young people information or if they went against what the

parents wanted. However, as we have mentioned before it is important that schools recognise their duty to provide Sex and Relationships Education under the Dept for Education and Skills (DfES) SRE guidance (DfEE 2000) despite the anxieties of parents.

Many of the parents and teachers we spoke to said that parents and teachers didn't always work well together on the issue of sex education. They both said that parents needed more support from teachers and from other parents. Some teachers suggested that parents could have more training on the issue as well as teachers. The parents told us that they wanted more support and information from professionals.

2.4.2 Worries of parents

In one drama session two young people acted out a scene about a father talking to his daughter. After the scene Rachel 'interviewed' the father as the following shows:

RACHEL:	So you said when you were talking about Stephanie, you said something about rape?
PETE [as Stephanie's dad]:	Rape, it's like someone, a man on top in bed. [inaudible] hands and legs.
RACHEL :	Right, and you were worried about your daughter?
PETE [as Stephanie's dad]:	Yes, I do.

This is an example of the way in which the young people were aware of some of the worries of their parents. In the final play the young people acted out a scene where a young person asked her dad if she can go to the cinema. Her dad says 'No' because he felt she would not be safe.

From the parent interviews we found that sometimes parents did not want their young people to have relationships because they were worried that the young person was vulnerable. They worried that their son or daughter would not understand the difference between relationships and friendships and that they would not be able to make decisions for themselves. Both parents and teachers worried about young people behaving in an appropriate way. From the previous

sections we have seen how important it is for young people with learning disabilities to have information and training about sex and relationships. Lack of information could make young people with learning disabilities more vulnerable.

The teachers told us that many parents did not want to deal with the issue of sex and relationships and often wanted the teachers to take the lead. Many of the teachers felt that when sex education was taught in schools, it could break the ice for parents. Teachers said that they felt that parents had many worries and fears about their sons and daughters.

2.4.3 Parents feeling unprepared

Working with the young people we found that sometimes they were worried about being treated as a child by their parents. The Rainbow Group incorporated this into their play, as the following shows:

- | | |
|--------------------------------------|--|
| MUM (Jane from the Rainbow Group): | ...You think you love him. He's using you. Why didn't you tell us? |
| HAYLEY (Ann from the Rainbow Group): | I went to the doctor. |
| Mum (Jane from the Rainbow Group): | You shouldn't go on your own. You're our baby. |
| DAD (Harry from the Rainbow Group): | You don't understand so you can't see him anymore. |
| MUM (Jane from the Rainbow Group): | We're looking after you Hayley, that's all. We love you. |
| HAYLEY (Ann from the Rainbow Group): | Michael loves me. |

[Parents send Hayley to her room, upset.]

We found from the parent interviews that 6 parents (out of 20) were surprised when their son or daughter reached puberty. The teachers also told us about parents being surprised. They gave an example of where a doctor had told a parent that their sons/daughter's body wouldn't develop and told them that 'their mind is not ready so their body won't be'. We found from talking to parents and teachers that parents often struggled with the idea that the young people could be sexual and they expected their young person to stay child-like. The teachers said that, from their experience, many parents wanted to ignore or deny the issues, didn't want to think about it and it

could be a taboo. The teachers told us about parents who tried to ask their doctors for drugs to suppress their sons/ daughter's hormones because they didn't want their son/ daughter to go through puberty or become sexual as the following extract from a focus group shows:

TEACHER: A lot of them actually go to GPs and things, to try and get things to suppress them.

RUTH: To suppress their hormones?

TEACHER: Yes.

RUTH: The parents take them?

TEACHER: Yes, the parents do.

RUTH: So a lot of kids have that do they? They take things?

TEACHER: I don't know if they actually have it, but I know a lot of people enquire about it and ask us about it. If you think about it there is sort of, 'oh my God', when people see people with any sort of disability getting into a relationship. People have decided it's just not nice and they are not meant to have it.

The teachers were therefore suggesting that the fear, or taboo, of people with learning disabilities having relationships that parents (and others) might have, could lead to the desire to want to prevent the young person developing into a sexual being. The findings of our project suggests that if the parents, teachers and young people all had better information and more support around sex and relationships then there would be less need to be worried about controlling or preventing natural sexual developments.

RECOMMENDATIONS:

As a result of what we have found out about support, we have made the following recommendations:

- There should be closer working between parents and teachers (and other professionals)

- Parents' worries and fears need to be acknowledged by teachers and other professionals
- There should be more information available for parents so that they are prepared, particularly around puberty for their son/ daughter.

Section 2.5 Wider issues

The next section is about wider issues. This section will be split up into the following smaller sections:

- Attitudes
- Issues for people from Black and Ethnic Minority (BME) communities.

2.5.1 Attitudes

Some of the young people felt that some adults have negative attitudes towards them about sex and relationships. For example, one young person said that if they asked their parents for condoms they would think he was insane. Another young person said that if he asked his parents for condoms his dad would say 'keep it a secret'. In one session, only 4 out of 17 thought that two characters in the play should tell someone they wanted to have sex. One young person, Rupert, who was playing the character of a teacher, suggested that Hayley, a young woman in a play, should keep her relationship with Michael secret and should 'keep it in your heart'. Only one person out of 17 in this session said that they would tell their parents if they wanted a relationship. This suggests that young people with learning disabilities thought they should keep secrets about relationships and sex so that they didn't get into trouble.

We have already said that quite often parents think that talking about sex and relationships can be embarrassing. Some parents said that they knew of other parents and professionals who thought that young people with learning disabilities shouldn't have relationships or sex. They suggested that young people could be stopped from having relationships because of these attitudes. They suggested that some people might think that there would be no need to give young people with learning disabilities any information because they would not want to encourage them to have relationships.

Many of the teachers said that they have heard negative attitudes about people with learning disabilities and relationships and sexuality. Examples of these include: people with learning disabilities shouldn't have sex in the first place; sex education shouldn't be taught; if we teach masturbation people might think we are sex perverts; it is a dangerous subject; you might open a can of worms; it is a taboo. This suggests that there are sometimes negative attitudes towards people with learning disabilities who want to have sex and be in relationships.

Many of the teachers said that the National Curriculum was restrictive in special schools because it didn't take into account the needs of young people with learning disabilities. Many of the teachers said that the National Curriculum was not appropriate for young people with complex needs. A number of teachers said that life skills, sex education, survival and happiness were more important subjects than reading and writing for some students. They said that, because of the National Curriculum, teachers couldn't respond to the individual needs of the young people in relation to their own development and independence. They suggested that sex education needed to be higher on the agenda in schools. They said that there was a need for a national recognition by the Government of the particular issues around sex and education faced by teachers working in special schools.

2.5.2 Issues for people from Black and Minority Ethnic (BME) communities

We found that it was difficult to recruit young people from Black and Minority Ethnic (BME) communities to the young people's drama group. At first we met very few young people from BME communities when we visited schools and colleges. We worked hard to get more young people from these communities and at one point there were 5 young people, which was a quarter of the group. One Asian young man came to the earliest sessions, but eventually decided he would not continue because he had other commitments. Another Asian young man came to one session but then his mother decided she felt the group was unsuitable for him. She was not happy that sex would be discussed openly and she did not want her son to be talking in a mixed gender group. For most of the time there were 2 Asian young men, and a young woman from Somalia. A Sudanese young woman was also part of the group for about a year.

We made sure that our leaflets included young people from BME communities in the pictures. We also made sure that the pictures and photographs that we used in the sessions included people of different cultural backgrounds.

We found that there were specific issues for parents from BME communities. We interviewed a small number of parents who were Muslim. The following are some of the views that were expressed. These may not be the views of all Muslim families, but they are viewpoints to be aware of.

Firstly, the Muslim parents stated that young people in many Muslim families did not have boyfriends or girlfriends because they had arranged marriages. They also said

that in their view sex was seen as something that was natural and therefore did not need to be talked about. They said that many Muslims did not agree with sex before marriage and they wouldn't want their young people to be in a group where sex before marriage might be discussed. They said that many Muslim families would not accept gay and lesbian relationships. They suggested that teachers and other professionals needed to be aware of different beliefs and cultures about sex and relationships for people with learning disabilities.

Some of the teachers in the focus groups said that sex education needed to be sensitive to cultural differences. One teacher said that she had been on a training course which said that sex education was a human right and that they should teach it even if parents don't want it for religious reasons. The teachers were saying that it is important to respect different views and to keep these views in mind, but to recognise that young people have a right to information.

We recognise that our sample of parents and young people from BME communities was small. We have been able to draw out some general issues, but more research needs to be done in the future in the area of sex and relationships education for young people from BME communities.

RECOMMENDATIONS:

As a result of what we have found out about wider issues we have made the following recommendations:

- There needs to be rights training and awareness raising for professionals and parents about young people with learning disabilities having relationships so that young people don't feel they have to keep things a secret
- Wider attitudes and stereotypes in society need to be challenged so that people with learning disabilities can exercise their right to have relationships if that is their choice. This could involve training and awareness raising and also media campaigns

- Sex education should have a higher priority on the national curriculum for people with learning disabilities in special schools. In mainstream school people with learning disabilities should have more support to understand the issues
- Sex education for young people with learning disabilities from BME communities needs to be approached in a way that is sensitive to their families, their religion and their culture.

Section 3: Conclusions and recommendations

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Conclusions

The Sex and Relationships research project has been important because we have found things out from young people with learning disabilities that have not been researched before. The use of drama within this research project was a key feature and it meant that young people with learning disabilities were able to have a powerful voice. The research found things out that would have been difficult to find out using other research methods because all the young people in the drama group were able to be involved in the research, even those with communication problems, language difficulties and higher support needs. The play that they devised and performed made the issues that were important to them public. Many of the young people gained confidence throughout the process and went on to do other presentations and performances at conferences and workshops. Their commitment, enthusiasm and hard work have made the project inspiring and very worthwhile. One of the articles we wrote as a team talked about the way in which we did the research. At the end of the article we put:

*The way the research is done is as important as getting some good results.
(Garbutt et al, 2009)*

We feel that our research was important because the way we did the research meant that people with learning disabilities were the key people and took centre stage.

Our research is important because it has found out some of the ways in which people with learning disabilities are not getting their rights. We have described in this report the laws and policies (see Appendix 2) that state that people with learning disabilities have a right to relationships and sexuality and to access to adequate information and services so that they can make their own choices.

The following summarises the main things that came out of the research and the key recommendations:

Knowledge about sex and relationships

Some young people knew a lot about sex and relationships and some knew very little. Most young people in the group understood about friendships and relationships and the difference between public and private places. Most people did not know much about puberty and pregnancy. The parents and teachers talked

about young people with learning disabilities finding it very frightening when their body changes. Most of the young people knew what condoms were for. They could list places to get condoms from.

Most of the young people knew what the words 'gay' and 'lesbian' meant. 3 young people thought it was illegal for gay people to have sex. The young people said there were not many places to meet. The teachers and parents agreed with this. Teachers and parents worried about young people being unsafe. Some young people told us that it was difficult to use transport on their own. This made it hard to be independent. Some young people left the drama group as they could not travel to the sessions alone.

Sex education

Everybody we talked to felt sex education should be better. Sex education often only talks about what sex is, rather than having sex in a relationship, or to feel good. Teachers and parents said sex education should happen in small groups, and young people should get sex education more than once. Parents said that they would not go to a doctor for information about sex education. The young people said they would go to a doctor for information about sex education. Some parents and teachers thought there could be one person whose job is to teach sex education. Teachers felt responsible for sex education but some teachers felt they needed more training. Parents often didn't know where to get information. Teachers said that in mainstream schools sex education wasn't always taught in a way that made sense to young people with learning disabilities. Teachers said sometimes if there was a problem with sexually inappropriate behaviour from a pupil, that person would be given sex education individually, instead of sex education happening in a lesson. Some young people thought they should have a right to good sex education. Most of the parents we interviewed said young people should have the right to have sex and relationships.

Information

Some young people got information from the TV and internet. Parents and teachers worried about young people getting the wrong information. The young people told us it was difficult to get accessible information. No parents had been given information without asking for it. They "had to fight for it". Parents and teachers said young people really need accessible information that they could take away.

Support

Young people said they didn't always get help from teachers if they asked questions about sex and relationships. Sometimes parents and teachers found it hard to work together. Parents and teachers both said training would be helpful. Some parents and teachers worried about how young people behaved in public. Parents didn't always feel prepared for their child becoming a teenager. Teachers said that many parents didn't want to talk about this.

Wider issues

Some young people with learning disabilities think talking about relationships and sex could get them into trouble. Some parents and professionals think young people with learning disabilities shouldn't have relationships or sex. Parents said some people think young people with learning disabilities don't need information. Many teachers said that sex education doesn't always get taught in special schools. They said that sex education needs to be treated more importantly by schools and by the Government. Parents from Black and Minority Ethnic (BME) communities also talked about religious beliefs about marriage, talking about sex in mixed sex groups, and gay and lesbian relationships. Professionals need to be more aware of these beliefs. Teachers said it is important to respect different views but also that all young people have a right to information.

We have some useful findings that have pinpointed areas of difficulty and things that should change. From our research we have also found that more research needs to be done in the following areas:

- Sex and Relationships Education for young people with learning disabilities in mainstream schools and
- Sex and Relationships Education for young people with learning disabilities from BME communities.

The research was based within a disability rights organisation, CHANGE, which meant that there was a focus on making sure the research process, and any information produced, was accessible. As a result of the research, CHANGE has produced 5 booklets on sex and relationships, with the following titles:

- Sexual Abuse
- Friendships and Relationships

- Safe Sex and Contraception
- Sex and Masturbation
- Lesbian, Gay, Bisexual, Trans.

The booklets are available from CHANGE (www.changepeople.co.uk). In this way, CHANGE is beginning to address some of the issues that have come out of the research, e.g. the need for accessible information about sex and relationships that young people with learning disabilities can take away.

We want people to hear about our research and to listen to the things that need changing. We will campaign about the things we have found out and we will try to work to improve sex and relationships education for all people with learning disabilities.

MAIN RECOMMENDATIONS

As a result of the research we have come up with the following main recommendations of how we think things should change:

- **Young people with learning disabilities have a right to sex education**
- **There needs to be more accessible information and support for young people with learning disabilities and for their parents. This needs to include information about sexuality, abuse, and practical information such as where to get contraception.**
- **There should be more places for young people with learning disabilities to meet other young people and spend time together**
- **Sex education should be improved through giving teachers access to more resources and more training, and building stronger links between schools and sexual health professionals. It should have a higher priority on the National Curriculum for people with learning disabilities**
- **There needs to be better training for teachers, sexual health professionals and learning disability nurses about delivering sex education or sexual health information for/ with people with learning disabilities**
- **Negative attitudes of professionals, parents and other people towards people with learning disabilities around the issue of sex and relationships need to be challenged by awareness raising and education.**

The recommendations that we make come directly from the research we have undertaken. We feel that they will also go some way to addressing the need to increase the choices and control for people with learning disabilities in all aspects of their lives. In this way, people with learning disabilities can become more empowered, more independent and live fulfilling lives.

As a result of the Sex and Relationships research, CHANGE will continue to campaign for the rights of people with learning disabilities to have relationships and to have

accessible information to help them to make choices about their lives.

If you would like any further information about the Sex and Relationships project or have any comments to make, please contact us at:

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Appendices

List of Appendices

- Appendix 1: Ethics
- Appendix 2: Laws and policies in relation to relationships and sexuality for people with learning disabilities
- Appendix 3: List of articles written
- Appendix 4: Copy of survey
- Appendix 5: Parent interview questions
- Appendix 6: Focus group questions
- Appendix 7: List of resources
- Appendix 8: Final thoughts by the Sexuality team

Appendix 1: Ethics

Ethics

These are the ways in which we made sure that we did the research in the right way.

Ethics: Getting permission to do the research

We talked to the Department of Education and Skills, which is part of the Government. We asked them if we had to get special permission to work with young people. They said that there are no set rules on this. They told us we should follow any rules that the University, the Big Lottery Fund: Health and Social Research Grants Programme, and the schools and colleges had about doing research. We went to the University and talked to them. They gave us permission to do the research. We went to the Big Lottery Fund, who gave us money for the project, and they gave us permission to do the research. We told the schools and colleges we worked with that we had permission from all the right people to do the project. We asked the schools and colleges if we needed to get permission from anyone else and they said that we didn't.

Ethics: Young people

All the workers who were on the Sexuality project had a CRB check. CRB stands for Criminal Records Bureau. If anyone works with young people under 18, or vulnerable adults, they have to have a CRB check. This means that workers are checked to make sure that they haven't been arrested for harming young people in the past. This is to make sure that the young people will be safe.

We talked to the teachers at the schools and colleges. We built up trust with them. We told them about how we were going to do the project and answered their questions if they were worried about anything to do with the project.

We made an information sheet in easy words and pictures for the young people, to tell them about the research. We also made a consent form in easy words and pictures. The young people and their parents had to sign the consent form to say that they understood what the project was about and they were happy to be working on the project.

We had a taster day for the young people to come to CHANGE to find out what the drama group would be like. If they did not like it they did not have to come again.

We told the young people that we would record the drama sessions on a video but we would not show them to anyone else outside the project. We told them that when we write our report we would not put their names on it. We told them that they did not have to say anything in the group if they did not want to. This was very important because we were talking about a very personal subject. We spent lots of weeks getting people to work together and trust each other. We wanted the young people to feel safe. This was very important. The topic of sex and relationships can be emotional. We found out about other organisations that we could talk to if the young people needed more help about emotional things that came up for them in the project.

Ethics: Interviews with Parents and Focus Groups with teachers

We interviewed 20 parents of young people with learning disabilities. We didn't want to talk to the parents of the young people in the drama group because it wouldn't be fair on the young people. They might have worried that we would tell the parents things they had said. So we interviewed parents of young people who were NOT in the drama group.

We also ran four focus groups with about 8 teachers and governors in each one.

We sent the parents and teachers/ governors an accessible leaflet to tell them about the project. We told them that if there were any questions they did not want to answer in the interviews then they did not have to answer them. We told them that we would record the interview/ focus group but that we would not let anyone outside the project listen to the recording. We told them that when we write the report we would not put their names in it.

Ethics: National survey

We told the people who filled in the survey that the survey was just for the research project and we would not tell any one else who had put what. The purpose of the survey was to get a general idea about sex education in schools and colleges. It wasn't there to pinpoint what individual people were saying. We told them we would not put their names on our final report.

Ethics: Working as a team

We had a team of five people working on the sexuality project. We made some

Ground Rules as a team to make sure that we all worked in a fair way and respected each other. We all had supervision with the Director of CHANGE and we had meetings as a team so that we could talk about how we were getting on and about anything in the project that we were finding difficult. We talked to the people at the university and also the people on our Project Advisory Group about any problems in the project. We also made links with other organisations that could give us advice.

Any information that we had for the project that was private or personal we made sure we kept safe and away from everybody else. The information was just used for the research project and we didn't show it to anyone else.

Ethics: Final Report

In this final report we have written about all the things that have come out of our research. We have not put anyone's name in the report without asking them. We did not want anyone who reads it to know who had said what.

Appendix 2: Laws and policies about relationships and sexuality for people with learning disabilities

There is now a growing body of laws and policies that are relevant to people with learning disabilities and sex and relationships.

Laws

UN convention on the Rights of the Child states that children and young people have the right to enjoy the highest attainable health, access to health facilities (Article 24) and access to information which will allow them to make decisions about their health (Article 17). It also states that children have a right to education (Article 29) and a right not to be discriminated against (Article 2).

Convention on the Rights of Persons with Disabilities (2006) states that people with disabilities have a right to participate in all aspects of life, and to have equal access to information and services (article 9); a right to not be discriminated against in all matters relating to marriage, family, parenthood and relationships (article 23); a right to access to education (article 24); and good healthcare, including the area of sexual and reproductive health (article 25).

The Human Rights Act (1998, Article 8), 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.

The 1996 Education Act and 2000 Learning and Skills Act, states that every LEA, head teacher and governing body have statutory responsibility to take account of the guidance that requires SRE to be taught. A written SRE policy must be available and open to Ofsted inspection.

Policies

The Dept for Education and Skills (DfES) SRE guidance (DfEE 2000) recommends SRE is delivered as part of PSHE (Personal, Social and Health Education) and Citizenship. The guidance states:

‘Mainstream schools and special schools have a duty to ensure that children with special educational needs and learning difficulties are properly included in sex and relationships education. Sex and relationships education should help all pupils understand their physical and emotional development and enable them to make positive decisions in their lives.’

(C) Further guidance is available from revised National Curriculum Handbooks for teachers (QCA 1999a and 1999b) and from PSHE and citizenship for children and young people with special needs: an agenda for action (Blake and Muttock, 2004).

The governors of each school are legally responsible for ensuring that an SRE policy is developed and made available to parents/ carers if needed.

The Valuing People White Paper (Department of Health, 2001) promoted rights, independence, choices and inclusion. Sexuality is hardly mentioned except once, to say that services will help people with learning disabilities to form relationships, including ones of a physical and sexual nature.

Valuing People proposed that:

‘Good services will help people with learning disabilities develop opportunities to form relationships, including ones of a physical and sexual nature. It is important that people can receive accessible sex education and information about relationships and contraception’ (para

7.39, p. 81)

Valuing People Now, (Department of Health, 2009) which improved and developed some of the plans of Valuing People (2001,) says more about relationships and sexuality and emphasises:

‘...the importance of enabling people with learning disabilities to meet new people, form all kinds of relationships, and to lead a fulfilling life with access to a diverse range of social and leisure activities. It also emphasises their right to become parents and the need for adequate support to sustain the family unit.’ (para 18, p.9)

Appendix 3: List of articles written

Tattersall, J. (2009) Let's talk about sex, *OurSay magazine*, May/ June, 2009.

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Tattersall, J., Roy, D. and Zulu, P. (2009) Letter, *Disability and Society*, Vol. 24, No. 6.

Affleck, F., Adderley, P., Harrison, T. and Garbutt, R. (2009) Book Review of: Enjoying sport and exercise by Sheila Hollins and Caroline Argent, illustrated by Catherine Brighton, London, RCPsych Publications/St George's University of London, (2007), *Disability and Society*, Vol. 24, No. 2, March 2009, 245–252.

Garbutt, R. (2009) Let's talk about sex: using drama as a research tool to find out the views and experiences of young people with learning disabilities. *Creative Approaches to Research*. (June 2009).

Garbutt, R., Boycott-Garnett, R., Tattersall, and Dunn, J. (2009) Accessible article: Involving people with learning disabilities in research. *British Journal of Learning Disabilities* (Article accepted, awaiting allocation).

Garbutt, R. (2009) Is there a place within academic journals for articles presented in an accessible format? *Disability & Society*, 24(3), pp.357 – 371.

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Garbutt, R. (2008) People with learning disabilities and sex education. *The Journal*, Issue No. 116. Downs Syndrome Association, Middlesex.

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Garbutt, R. (2008) The Forbidden Fruit: a Sexually Fulfilling Life. *Community Connecting Magazine, Jan/ Feb 2008 pp. 9-10.*

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Sexuality Team/ Garbutt, R. (2008) Sex and relationships for people with learning disabilities: young people, parents and professionals have their say, *Ann Craft Trust Bulletin, July.*

Sexuality Team (2008) CHANGE project to do new research on sex education *Shaping our Lives, Summer 2008, Issue 13.*

Tattersall, J. (2008) People with learning disabilities can be professionals too. *Interconnections online journal, Vol 1: Issue 3, July, p. 30-33*

Sexuality Team (2007) People with Learning Disabilities and sex education, *WISH online Bulletin, December.*

Sexuality Team (2008) Talking about sex and relationships: the views of young people with learning disabilities. <http://www.leeds.ac.uk/disability-studies/projects/change/index.htm>

Appendix 4: National survey

Sexuality & Young People with Learning Disabilities

Please Note!

This questionnaire can be completed on your computer and returned to us by email at: info@change-people.co.uk

Alternatively, you can print it out, fill it in by hand and post it back to us using the enclosed stamped addressed envelope.

Please click all boxes that are applicable.

Please be as honest as possible. Your answers are for research purposes only and the details you give will remain anonymous.

Thank you.

THE SURVEY

Name of School/ College:

Your Job Title:

What kind of school/ college is it?

- A school/ college just for people with disabilities
 A school/ college that is inclusive of people with disabilities

How many students attend your school/ college? (Please state)

How many students have a learning disability? (Please state)

How many students have other disabilities? (Please state)

What is the age range of your students? (Please state)

1. Do you provide training on sexual education to the young people in your school/ college? (This may be a specific course on sex education or you may cover aspects of sex and relationships within other programmes such as personal and social independence, citizenship programmes, rights and

responsibilities, interpersonal skills etc.)

Yes (Go to Question 3)

No (Go to Question 2)

2. If 'No' what are the reasons for this? (Please state)

(Go to question 33)

3. Is the sex education provided compulsory or optional for students?

Compulsory

Optional

4. How often do young people receive sex education?

(Please state, e.g. "2 hour session every x week(s) for xx weeks")

5. How many students do you teach in a group?

6. Do you teach sex education in single sex or mixed sex groups?

Single sex

Mixed Groups

Both

7. Do you teach sex education just in groups of people with learning disabilities or are the groups integrated (i.e. including non-disabled people)?

People with learning disabilities only

Integrated groups

Both

8. At what age do you starting teaching students sex education?

Under 10 years old

10-11 years old

11-12 years old

12-13 years old

13-14 years old

14-15 years old

15-16 years old

Over 16 years old

9. Do you use a training pack to help you teach young people with learning disabilities about sex?

Yes (Go to Question 10)

No (Go to Question 13)

10. If yes, what is the title of the pack used? (Please state)

11. What format is the pack in? (tick all the items that apply)

- Booklet
- Video
- DVD
- Book
- A range of pictures to look at
- A pack that takes you step by step and tells you what to teach
- CD-ROM
- One that uses anatomically correct dolls
- Leaflet
- One that uses 3D models of genitals
- Discussion topics
- Interactive media (using computers etc)
- Other - Please describe:
- Don't Know

12. What kind of pack is it?

- A pack that has been professionally produced for people with learning disabilities
- A pack that has been professionally produced for young people in general
- We have made up our own
- We have adapted someone else's pack
- Other – Please describe:

13. If you don't use a training pack, what are the reasons for this? (Please state)

14. Do you have other resources about sex education that the young people can take away?

- Yes (**Go to Question 15**)
- No (**Go to Question 19**)

15. If Yes, please state what other resources these are:

16. What format are these resources in?

- Booklet (easy to read and/ or with pictures)
- Video
- DVD
- Book (easy to read and/or with pictures)
- Book (for parents to go through with the young person)
- A range of pictures to look at

- An accessible pack that takes you step by step through the subject
- CD-ROM
- Anatomically correct dolls
- Leaflet
- Models of genitals
- Discussion topics
- Interactive media (using computers etc)
- Other - Please describe:

17. Who are these resources designed for?

- Young people in general
- People with learning disabilities specifically (e.g. an accessible format)
- Parents
- Other – Please say who for:
- Don't know

18. Have these resources been professionally produced, adapted from somewhere else or have you made up your own?

- Professionally produced resources for people with learning disabilities
- Professionally produced resources for young people in general
- We have adapted someone else's resources
- We have made up our own
- Other – Please state where:
- Don't know

19. If you don't have resources for the young people to take away, what are the reasons for this? Please state:

20. Who teaches the young people about sex education?

- A teacher or lecturer at your school or college
- A community nurse
- A school nurse
- A youth worker
- A parent comes in to do it
- A specialist sexual health worker
- Nobody
- We leave it to the parents to do at home
- Someone else – Please state who:
- Don't know

21. What kinds of things do you discuss in sex education? (Please tick all those

that apply in your school/ college and indicate which topics you discuss with the pre-16 age group and which topics you discuss with post-16 age group)

<input type="checkbox"/> Parts of the body	<input type="checkbox"/> pre-16	<input type="checkbox"/> post-16
<input type="checkbox"/> Bodily changes	<input type="checkbox"/> pre-16	<input type="checkbox"/> post-16
<input type="checkbox"/> Menopause	<input type="checkbox"/> pre-16	<input type="checkbox"/> post-16
<input type="checkbox"/> Reproduction	<input type="checkbox"/> pre-16	<input type="checkbox"/> post-16
<input type="checkbox"/> Pregnancy	<input type="checkbox"/> pre-16	<input type="checkbox"/> post-16
<input type="checkbox"/> Becoming a parent	<input type="checkbox"/> pre-16	<input type="checkbox"/> post-16
<input type="checkbox"/> Dating	<input type="checkbox"/> pre-16	<input type="checkbox"/> post-16
<input type="checkbox"/> Abortion	<input type="checkbox"/> pre-16	<input type="checkbox"/> post-16
<input type="checkbox"/> Marriage and divorce	<input type="checkbox"/> pre-16	<input type="checkbox"/> post-16
<input type="checkbox"/> Cross dressing	<input type="checkbox"/> pre-16	<input type="checkbox"/> post-16
<input type="checkbox"/> Cultural differences	<input type="checkbox"/> pre-16	<input type="checkbox"/> post-16
<input type="checkbox"/> Masturbation	<input type="checkbox"/> pre-16	<input type="checkbox"/> post-16
<input type="checkbox"/> Public/ private boundaries	<input type="checkbox"/> pre-16	<input type="checkbox"/> post-16
<input type="checkbox"/> Contraception	<input type="checkbox"/> pre-16	<input type="checkbox"/> post-16
<input type="checkbox"/> Relationships	<input type="checkbox"/> pre-16	<input type="checkbox"/> post-16
<input type="checkbox"/> Abuse	<input type="checkbox"/> pre-16	<input type="checkbox"/> post-16
<input type="checkbox"/> HIV/AIDS	<input type="checkbox"/> pre-16	<input type="checkbox"/> post-16
<input type="checkbox"/> Other sexually transmitted diseases	<input type="checkbox"/> pre-16	<input type="checkbox"/> post-16
<input type="checkbox"/> Pornography	<input type="checkbox"/> pre-16	<input type="checkbox"/> post-16
<input type="checkbox"/> Intimate personal care	<input type="checkbox"/> pre-16	<input type="checkbox"/> post-16
<input type="checkbox"/> Personal development	<input type="checkbox"/> pre-16	<input type="checkbox"/> post-16
<input type="checkbox"/> Giving consent to sex	<input type="checkbox"/> pre-16	<input type="checkbox"/> post-16
<input type="checkbox"/> Legal issues e.g. under-age sex	<input type="checkbox"/> pre-16	<input type="checkbox"/> post-16
<input type="checkbox"/> Prostitution	<input type="checkbox"/> pre-16	<input type="checkbox"/> post-16
<input type="checkbox"/> Friendships/ relationships	<input type="checkbox"/> pre-16	<input type="checkbox"/> post-16
<input type="checkbox"/> Oral sex	<input type="checkbox"/> pre-16	<input type="checkbox"/> post-16
<input type="checkbox"/> Anal sex	<input type="checkbox"/> pre-16	<input type="checkbox"/> post-16
<input type="checkbox"/> Sexual attraction (fancying someone)	<input type="checkbox"/> pre-16	<input type="checkbox"/> post-16
<input type="checkbox"/> Services available to help, e.g. advice/ counselling)	<input type="checkbox"/> pre-16	<input type="checkbox"/> post-16
<input type="checkbox"/> Emotions/ feelings	<input type="checkbox"/> pre-16	<input type="checkbox"/> post-16
<input type="checkbox"/> Who it is appropriate to touch	<input type="checkbox"/> pre-16	<input type="checkbox"/> post-16
<input type="checkbox"/> Puberty	<input type="checkbox"/> pre-16	<input type="checkbox"/> post-16
<input type="checkbox"/> Periods	<input type="checkbox"/> pre-16	<input type="checkbox"/> post-16

- | | | |
|--|---------------------------------|----------------------------------|
| <input type="checkbox"/> Wet dreams | <input type="checkbox"/> pre-16 | <input type="checkbox"/> post-16 |
| <input type="checkbox"/> Smear tests | <input type="checkbox"/> pre-16 | <input type="checkbox"/> post-16 |
| <input type="checkbox"/> Checking genitals for lumps/
diseases | <input type="checkbox"/> pre-16 | <input type="checkbox"/> post-16 |
| <input type="checkbox"/> Sexual positions | <input type="checkbox"/> pre-16 | <input type="checkbox"/> post-16 |
| <input type="checkbox"/> Making choices about
relationships | <input type="checkbox"/> pre-16 | <input type="checkbox"/> post-16 |
| <input type="checkbox"/> Gay and lesbian relationships | <input type="checkbox"/> pre-16 | <input type="checkbox"/> post-16 |
| <input type="checkbox"/> Love | <input type="checkbox"/> pre-16 | <input type="checkbox"/> post-16 |
| <input type="checkbox"/> Intimacy | <input type="checkbox"/> pre-16 | <input type="checkbox"/> post-16 |
| <input type="checkbox"/> Cleanliness | <input type="checkbox"/> pre-16 | <input type="checkbox"/> post-16 |
| <input type="checkbox"/> Enjoying sex | <input type="checkbox"/> pre-16 | <input type="checkbox"/> post-16 |
| <input type="checkbox"/> Other things - Please state: <input type="text"/> | <input type="checkbox"/> pre-16 | <input type="checkbox"/> post-16 |
| <input type="checkbox"/> Don't know | | |

22. If there are some things you do not cover, in the above list, what are the reasons for this? Please state:

23. Do you involve parents in teaching young people with learning disabilities about sex?

- Yes (**Go to Question 24**)
 No (**Go to Question 25**)

24. If you answered 'Yes', in what way?

- We ask for their consent before we teach the young people
 Parents are involved in deciding what to put in the training sessions
 Parents are on the board of governors
 We have some structured sessions with the parents before we deliver the sessions to the young people
 We give them a letter about what will be included in the sex education sessions
 Parents are in the class when we teach it
 We talk to them informally when we see them
 Another way - Please describe:

25. If you do not involve parents in teaching young people with learning disabilities about sex, what are the reasons for this? (Please state)

26. Do you have any policies/ statements/ guidelines at your school/ college about the teaching of sex education? (These maybe within one policy or it may come under a number of different policies e.g. general policy documents,

child protection documents, curriculum development documents etc)

Yes (**Go to Question 27**)

No (**Go to Question 29**)

27. If 'Yes', what kinds of things do these policies include?

- Making sure parents give consent for sex education
- How to deal with disclosure of abuse
- The age at which young people will receive sex education
- How to be inclusive in sex education
- Supervision for staff in relation to dealing with sexual issues
- Training for staff around sex education
- Guidelines on what topics will be taught within sex education
- The amount of sex education a young person would be expected to receive
- Gender specific issues (e.g. the requirement that women staff only deal with periods, etc)
- Expectations/ boundaries for staff in their expected level of involvement in sex education issues for pupils
- Cultural inclusion/ awareness in sex education
- Confidentiality in sex education
- Staff values in sex education
- The rights of people with learning disabilities to express their sexuality
- Other things - Please describe:
- Don't know

28. If there are things in the above list that you do not include, what are the reasons for this? (Please state)

29. If you don't have any policies/ statements at your school/ college about the teaching of sex education what are the reasons for this? (Please state)

30. Do you evaluate the success of the training you deliver on sex education?

Yes (**Go to Question 31**)

No (**Go to Question 32**)

31. If 'Yes', how do you do this?

- We ask the parents informally
- We ask the young people informally
- We make a formal assessment of the young people's *learning* (e.g. assessing their knowledge and understanding before the course and then testing them again after the course)
- We assess how behaviour has changed

We get feedback from the teachers who have delivered it

Another way - Please describe:

32.If you don't evaluate the success of the training you deliver on sex education, what are the reasons for this? (Please state)

33.Do you have any other comments/ issues that you would like to add regarding teaching young people with learning disabilities about sex and relationships education?

Thank you for filling in this questionnaire.

We value your comments.

Would you be willing to talk to us further about sex and relationships education in your school?

Yes

No

Please e-mail this back to us at ruth@change-people.co.uk

Appendix 5: Parent interview questions

Introduction

Hello, I am John Tattersall and this is Ruth Garbutt. We work for an organisation called CHANGE, an organisation that fights for the rights of people with a learning disability/ difficulty. We are doing some research with Leeds University about relationships and sexuality for young people with learning disabilities/ difficulties. We are talking to young people themselves, teachers and parents. We want to find out some of the issues and difficulties about relationships and sexuality.

We have some questions we would like to ask you as a parent of a young person with a learning disability/ difficulty. There will be some questions about your opinions around sex and relationships for people with learning disabilities. There will also be some questions about your experiences as a parent. When we ask about relationships we are naturally including gay, lesbian and bisexual relationships as well as heterosexual relationships. If there are any questions you do not want to answer then you do not have to answer them.

The interview will probably take about 45 minutes. We will record the interview. Everything you tell us will be treated as confidential. We will collect together information from all the interviews we do and we will write a report. We will not put your name in the report.

Have you got any questions before we begin?

Opinions

The first few questions are about your opinions.

1. Do you think young people with learning disabilities/difficulties need to know about sex and relationships? YES/NO
 - 1a. If yes, at what age do you think young people with learning disabilities/difficulties should be given information about sex and relationships?
 - 1b. If no, what are the reasons for this?
2. Do you think that coming to terms with puberty and sexual awareness is different for young people with learning disabilities/ difficulties compared with young people without learning disabilities/ difficulties? YES/NO

- 2a. Please explain?
3. Do you think that parents of young people with learning disabilities/difficulties need additional support to help their son/daughter with puberty and sexual awareness? YES/NO
4. Do you think parents should be involved in helping their son/daughter come to terms with sexual awareness? YES/NO
 - 4a. If yes, how?
 - 4b. If no, what are the reasons for this?
5. Do you think schools should be involved in helping young people with learning disabilities/difficulties come to terms with sexual awareness? YES/NO
 - 5a. If yes, how?
 - 5b. If no, what are the reasons for this?
6. Do you think doctors/nurses should be involved in helping young people with learning disabilities/difficulties come to terms with sexual awareness? YES/NO
 - 6a. If yes, how?
 - 6b. If no, what are the reasons for this?
7. Do you think information on sexual awareness for young people with learning disabilities/difficulties should deal with lesbian, gay and bisexual issues? YES/NO
 - 7a. If no, what are the reasons for this?
8. Do you think young people with learning disabilities/difficulties should get married? YES/NO
 - 8a. If no, what are the reasons for this?
9. Do you think young people with learning disabilities/difficulties should have children? YES/NO
 - 9a. If no, what are the reasons for this?
10. Do you think that young people with learning disabilities/difficulties should have the same sexual freedoms as those without learning disabilities/difficulties? YES/NO

10a If no, what are the reasons for this?

11. Do you think parents of young people with learning disabilities/difficulties have a greater role in influencing their son/daughter's sexual relationships than parents of other young people? YES/NO

11a. If yes, what are the reasons for this? If no, what are the reasons for this?

Own experiences

We would now like to ask you some questions about your own experiences.

Remember, if there is anything you do not want to answer you do not have to.

12. How old is your son/ daughter?

13. Have you encountered any difficulties/problems with your son/daughter going through puberty? YES/NO

13a. If yes, please explain

14. Has your son/daughter had a boyfriend/girlfriend? YES/NO

14a. If no, what are the reasons for this?

15. Do you think your son/daughter has a right to a "sex life"? YES/NO

15a. If no, what are the reasons for this?

16. Do you think that your son/daughter should be given help and information on about contraception? YES/NO

16a. If no, what are the reasons for this?

17. Have you had any information about young people with learning disabilities/difficulties and puberty and sexual awareness? YES/NO

17a. If yes, was this information helpful? Please say how?

18. Would you like any (additional) information or support to help you understand the issues that might arise for young people with learning disabilities/difficulties coming to terms with puberty and sexual awareness? YES/NO

18a. If yes, what kind of support or information do you think would be helpful?

19. Who do you think should provide information to your son/daughter about

sex & relationships?

(Prompts: parents? teacher? doctor? nurse? friends? Other?)

20. Are there any other issues that we have not covered in relation to young people with learning disability/difficulty that you would like to add or any other comments you would like to make?

Thank you for your help.

Appendix 6: Focus group questions

1. Introduction

Thank you for agreeing to be part of this focus group. We work for an organisation called CHANGE, an organisation that fights for the rights of people with a learning disability. We are doing some research with Leeds University about relationships and sexuality for young people with learning disabilities. This focus group is to try and find out some of the issues for teachers and governors around sex education for young people with learning disabilities. We will ask you some general questions, but please feel free to tell us things that are not direct answers to the question. We want to generate a discussion on the subject. We will record the focus groups and we will write down some bullet-points.

Everything you tell us will be treated as confidential. We will collect together information from the focus groups we do and we will write a report. We will not put any names in the report.

Have you got any questions before we begin?

2. Activity and discussion (25 minutes)

Have 2 pieces of flipchart paper headed:

- 1) Good things about sex education for young people with learning disabilities
- 2) Bad things about sex education for young people with learning disabilities

Ask participants to write one post-it for each flip chart and put it on the flip chart.

Come back and have a discussion based on the following question:

- In your experience, what are some of the difficulties and issues in providing sex and relationships education to young people with learning disabilities?

3. Activity and discussion (20 minutes)

Have the following statements:

- a) Young people with learning disabilities in special schools get the same sex education as young people with learning disabilities in mainstream schools
- b) Teachers and parents of young people with learning disabilities work together

well in relation to sex education.

- c) There are lots of resources to teach sex education to young people with learning disabilities
- d) The best place for young people with learning disabilities to learn sex education is at school
- e) Teachers are confident about teaching sex education to young people with learning disabilities

For each statement, the participants hold up a card -
AGREE/ DISAGREE/ DON'T KNOW

Then have general discussion on the statements, based on the following questions:

- Are there any issues/ difficulties around the parents of young people with learning disabilities?
- Are there any issues/ difficulties around sex education resources for young people with learning disabilities?

4. Activity and discussion (10 minutes)

Have another piece of flipchart headed:

If I could change one thing to improve sex education for young people with learning disabilities it would be...

Ask participants to write one post-it and put on flip chart. Come back and have discussion based on the following question:

- What further recommendations can you suggest in terms of making sex education better for young people with learning disabilities?

Appendix 7: List of resources

Resources that parents used

Here are some of the resources that parents said they had used. The list is quite short because, in general, we found that parents found it difficult to get resources to help them to talk to their son or daughter who had a learning disability.

- The 'Body Book' by Claire Rayner
- 'How Sex Works' by Elizabeth Fenwick and Richard Walker
- 'Talking together about sex and relationships'
- 'Freaks, Geeks'- written by an Asperger's boy about what its like to be different
- 'All about me'
- Board game that came out 10-15 years ago about sex and relationships called
- 'Grapevine' (or something like that)
- 'Girly magazines'

Teaching packs that teachers use [information from the survey]

Here are some of the resources the teachers said that they used:

- AQA PSHE
- ASDAN relationships and others
- BBC sex education
- Chalkface
- Channel 4 videos
- FPA leaflets
- Schools TV
- Girls all change
- Ready steady change
- Living your life
- Jason and Kylie's private world

- Life Tracks
- Me and Us
- Sex and the 3Rs
- Sex in context
- Bodywise
- Living with a willy
- Virtual baby
- Brailled information
- Information from Connexions service
- Government booklets
- Information from Brooke agency
- Health education materials
- Demonstration models
- Leaflets from local PCT library of resources
- Leaflets from YAT
- Wired for Health
- TRAX books
- Combination of packs/ adapt other packs/ devise own pack

During the focus groups, there was much discussion about resources/ problems with lack of resources, but no specific resources were mentioned.

During the drama sessions with the young people no specific resources were mentioned.

Resources we have collected

During the research project we collected some of our own resources, as we have talked about in the report. Here are the resources we collected:

What is it?	Title	Who is it by?	Who is it aimed at?
Booklet	How to use a condom	Green Park Day Centre/ Health Promotion Service, Avon	People with learning disabilities
Book	It could never happen here! Prevention and treatment of sexual abuse.	Association for Residential Care	Trainers/ staff
Report	Annual Report with various leaflets	The Lawnmowers Independent Theatre Company	Trainers/ staff People with learning disabilities
Book	A visit to a Brook Centre (1999)	Brook (Illustrated by Paul Mudie)	People with learning disabilities
Book	Sexuality and learning disability: a resource for staff	Family Planning Association (FPA) (Claire Fanstone and Zarine Katrack)	Trainer
Book	Sexuality- information for young adults	Family Planning Association (FPA)	Staff and parents (Book 1) People with learning disabilities (Book 2)
Book	Talking together... about growing up	Family Planning Association (FPA) (Lesley Kerr-Edwards and Lorna Scott)	Parents
Book	Learning disabilities, sex and the law: a practical guide	Family Planning Association (FPA) (Claire Fanstone and Sarah Andrews)	Trainers/ staff

What is it?	Title	Who is it by?	Who is it aimed at?
Book	No more abuse	Voice UK, People First, CHANGE	People with learning disabilities
Book	Out and about- supporting people with learning disabilities around same-sex relationships	Partners in advocacy	Young people Trainers People with learning disabilities
Book	Out of the shadows	Audrey Simpson, Attracta Lafferty, Roy McConkey	Trainers/ other professionals
Book	Talk to me	Downs Syndrome Association of New South Wales	Families
Book	Your rights about sex - a booklet for people with learning disabilities	Michelle McCarthy and Paul Cambridge	People with learning disabilities
Book	Helping people with a learning disability explore relationships	Eve and Neil Jackson, Tim Baker Illustrator.	People with learning disabilities
Book	Sex	BILD publications, illustrations by Jennifer Laurod	People with learning disabilities
Book	Sex and Sexuality	Speaking Up- James Fletcher, Ames Forgacs, John Hutchinson, Darren Moore	People with learning disabilities and their supporters
Book	Falling in love	Books Beyond Words, Sheila Hollins, Wendy Perez, Adam Abdelnoor	Families Trainers People with learning disabilities

What is it?	Title	Who is it by?	Who is it aimed at?
Book	Everything you ever wanted to know about safer sex	People First London	People with learning disabilities
Book	Phil's Story	Norah Fry, University of Bristol, Terence Higgins Trust	People with learning disabilities
Book	Jan's Story	Norah Fry, University of Bristol, Terence Higgins Trust	People with learning disabilities
CD-ROM	Chance to choose	Hilary Dixon	Young People
CD-ROM	Picture Yourself 1	Hilary Dixon	People with learning disabilities
CD-ROM	Picture Yourself 2	Hilary Dixon	People with learning disabilities
Film	Walk the Walk	The Lawnmowers Theatre Company	Young People
Film	Young Love	Skills for People	Young People
Film	The Big Sex Show	The Lawnmowers Theatre Company	People with learning disabilities
Film/ Leaflet	Speakeasy	Family Planning Association (FPA)	Families
Film	You, Your Body and Sex	Family Planning Association (FPA)	People with learning disabilities
Film	Kylie's Private World	Family Planning Association (FPA)	People with learning disabilities
Film	Jason's Private World	Family Planning Association (FPA)	People with learning disabilities

What is it?	Title	Who is it by?	Who is it aimed at?
Booklet	Let's talk about... periods (2005)	Downs Syndrome Association Scotland (Lynda Russell, Paul Mudie (Illustrator))	People with learning disabilities
Booklet	Let's talk about... puberty	Downs Syndrome Association Scotland	People with learning disabilities
Booklet	Puberty- Information for parents and carers	Downs Syndrome Association Scotland	Families
Booklet	Sex and Sexual relationships	Avert- Aids Education and Research Trust	Young People
Booklet	Getting a breast of it	'Grapevine'	People with learning disabilities
Leaflets	The Big Sex Show Leaflets, set of 5	The Lawnmowers Theatre Company	People with learning disabilities
Leaflet	Secret Loves, Hidden Lives	David Abbott	Professionals
Leaflets	Your Private Parts	Women's Health	People with learning disabilities
Leaflet	Whatever Turns You On!	Brook	Young People
Leaflet	Protect Yourself/ Respect Yourself	Black Health Initiative	Young People
Booklet	Love S.T.I.N.G.S	Comic Company (for the Family Planning Association)	Young People
Leaflet	Sex in the North (2005)	Leeds Health Education Youth Service	Young People

What is it?	Title	Who is it by?	Who is it aimed at?
Booklet	Loveline- Sexual health for young people (1999)	Health Education Authority	Young People
Leaflet	Is everybody doing it? Your guide to contraception (1995)	Family Planning Association (FPA)	Young People
Leaflet	Condoms, Pills and Other Useful Things	Avert- Aids Education and Research Trust	Young People
Leaflet	Time to talk about sex	Parentline Plus	Parents
Training pack	Growing and learning	Jane Keeling	Young people Families Trainers People with learning disabilities
Training pack	Listen to Us	Shepherd School, Nottingham	Young people Families Trainers People with learning disabilities
Training pack	Sex and Relationships Education	Shepherd School, Nottingham	Young people Families Trainers People with learning disabilities

What is it?	Title	Who is it by?	Who is it aimed at?
Training pack	Bodyworks	Shepherd School, Nottingham	Young people Families Trainers People with learning disabilities
Training pack	A PHSE programme for learners with autistic spectrum disorders	Fiona Speirs	Young people Families Trainers People with learning disabilities
Training pack	Doing it Toolkit: Practical Strategies for Sexual Health Promotion	Jo Adams	Trainers
Training pack	Be healthy and safe: Your life, your body, your rights	Skills for people	People with disabilities
Book	Let's do it, Let's plan it	Image in Action	Trainers
Training pack	Living safer sexual lives	Patsie Frawley, Kelly Johnson, Lynne Hillier, Lyn Harrison	Trainers People with learning disabilities
Training pack	Sex and the 3 Rs (and Sex and Staff Training)	Michelle McCarthy and David Thompson	Trainers People with learning disabilities
Training pack	Sexual Health Education, Children and Young People with Learning Disabilities: A Practical Way of Working (1996)	Karen Adcock and Gill Stanley (Barnardos)	Trainers

What is it?	Title	Who is it by?	Who is it aimed at?
Training Pack	Chance to Choose	Hilary Dixon (Me and Us Resource)	Trainers
Training Pack/ CD-ROM	Picture Yourself	Hilary Dixon, Ann Craft, David Gifford (illustrator)	Young people
Training pack	Sexual Health Skills	Hilary Dixon (Me and Us Resources)	Young People Trainers
Training Pack	Right to know: about friendships, sexuality and personal safety	Down Syndrome Society of South Australia	Families Trainers People with learning disabilities
Training pack	Talking together about sex and relationships	Lelsey Kerr-Edwards and Lorna Scott, Family Planning Association (FPA)	Parents and staff
Training pack	Working with the 'unthinkable' (Sexual abuse of adults with learning disabilities)	Hilary Brown and Ann Craft	Trainers

Other sources of information

Here are some other useful sources of information:

1. Useful book:

- Kat Hasler, Rachael Yates and Jackie Anderson, (2005) Sexual Health and Relationships: A Review of Resources for people with learning disabilities. Health Scotland.

Found at:

<http://www.healthscotland.com/uploads/documents/7819-AReviewOfResourcesforPeopleWithLearningDisabilities.pdf>

2. Websites that have lists of resources about sex and relationships topics for people with learning disabilities:

- NHS Scotland: http://www.mcks.scot.nhs.uk/section5/5_4.html
- Me-and-Us: <http://www.sreresources.co.uk/>
- Family Planning Association (FPA):
<http://www.fpa.org.uk/Shop/Learningdisabilitiespublications>
- National Children's Bureau:
http://www.ncb.org.uk/dotpdf/open_access_2/sef_sre_disresource07.pdf
- Ann Craft Trust:
<http://www.anncrafttrust.org/publications.html>

Appendix 9: Final thoughts by the Sexuality team

Final thoughts from John (Project Coordinator)

Our jobs were very serious because they dealt with the sex issues of young people with learning disabilities. The subject can be quite stressful so it was better to work in a team because you share the load. I worked with Rachel in the planning of each drama session. I found that it was good working with a co-worker because we shared the responsibility of the job. We talked to each other, shared ideas and planned things together. We found it easier to work in a team as we all supported each other. We sometimes had differences of opinion when we planned things but usually we worked well together.

I did worry quite a lot about doing the research because I had not worked with young people before because I had a stereotypical view of young people! I thought they all went around wearing hoodies and causing trouble but after I met the young people I felt really good and made friends with one of them on Facebook. The research has been very interesting for me because it has helped me to learn about young people with learning disabilities and the issues they face around sex and relationships. The drama sessions were difficult at first as I had not had any drama experience but it got easier and better every week because I looked at a few books that had drama subjects set out in them which gave me a few ideas, and discussed them with my co-worker.

At the beginning of the project I felt quite embarrassed to be talking about sexual matters. It's not something you usually talk about at work. I did not know what would be expected of me because office work is not something I usually do. I'm used to factory work. So this was something quite new to me in fact I would rather work in an office now than a factory any day.

I feel the project has gone very well because the young people have grown in confidence, and had the chance to talk about sexual matters and express themselves in a way that they've been restricted from doing in the past. I feel really good to have been part of that confidence building.

I have seen the young people grow from shy reserved young people to confident people with a positive attitude. I have found out that the young people have had to cope with a lot of restrictions in their lives, but now the project will help them to have the right to a relationship that people without learning disabilities take for granted. The best bits have been meeting people and finding out information from them, and

going to conferences. I have found it quite interesting, because this has helped me to find out about the issues that young people with learning disabilities face. I feel good about working on this project because I'm helping young people to have a relationship and the security that a relationship brings. Plus on a personal level I have done something good and rewarding with my life by helping other people in this job. The job gives me satisfaction in the knowledge that I have done something good with my life which is better than factory work which can be boring and repetitive and self centred.

I found planning the drama sessions difficult at first but it got better with practice. Sometimes the young people were a little bit rude and cheeky to me at times so it was a learning experience. Sometimes me and Rachel had differences of opinion on different subjects which is a good thing because we learned from each other. I have really enjoyed doing the project and have helped make a difference to the quality of life young people with learning disabilities have. I have enjoyed working with such a great team of people who treat me equally.

My final comment about my thoughts on the research is a title from an old Beatles song called 'All you need is love'. I think that we should just make this happen because I personally believe that love is God's gift to humanity.

Final thoughts from Durbali (Volunteer)

At the beginning of the project I enjoyed being with the Sexuality team and helping Rachel and John. I was happy to help the project which ran from 2007. The best bits have been helping the young people doing conferences, and warm up games such as Mad Chicken. The young people joined in with that and there were a big group of young people. I helped to do the Michael and Hayley play with the Rainbow group. I liked helping with the drama group. We also had meetings about the Sex and Relationships leaflets and we talked about what pictures should go in them. Some of the young people came last year to do a play in December at Seven Arts Space in Leeds. There was an audience that came and watched the play. The play talked about information about sex and about condoms for young people with learning disabilities between 16 to 25 year old. I think the worst bits were when young people were not listening to me or if there was someone shouting at me.

It is a shame that it is near the end and I would like to thank the Sexuality and Relationships project for putting up with me, and for their hard work.

Final thoughts from Rachel (Project Coordinator)

The research happening within CHANGE, where people with learning disabilities are employed, meant we were able to see successful ways of working together that other co-workers had developed. We also had support from other people with learning disabilities who had a lot of knowledge and experience of the issues we were finding out about.

Working within a disability rights organisation meant the research stayed focused on rights. It increased our understanding of how important it is to be definite about what needs to change, and how this can be done. The project was interesting because of working in a team of people who have lots of different experience. It also meant most of the research was truly led by people with learning disabilities, as the plans about how we would do the research were made together. An example of this is the way the drama sessions were planned. Planning together meant people with learning disabilities could lead activities with a proper understanding of what we wanted to find out – it also helped us to avoid delivering activities that were too complicated or relied completely on verbal feedback.

Working in a truly inclusive way means we have generated lots and lots of qualitative material, and the task of 'reducing' this into a written report whilst still including important issues that came out of it was daunting, and at times difficult. There is also the problem that the inclusive research has become less inclusive at the last stage, which is difficult to avoid. Using other methods, such as the accessible report and also the play produced by the young people are ways we have tried to tackle this.

A great advantage of this project has been the length of time, as it meant that there was time to work in a truly inclusive way. One of the highlights of the work for me was working with the young people over a long period. We were able to get to know the group, and also to find out what sort of work they preferred or got the most responses. If we had only been able to work with young people for short amount of time they may have given different responses.

As we have found out so much about what people think would improve sex education for people with learning disabilities it is important that this knowledge is now used to produce better resources, and provide training for those who deliver sex education.

I also hope that what we have learnt about how to successfully carry out research in an inclusive way can be passed on to other people. It would be good if research around other issues could be carried out in a similar way.

The experience has been challenging, rewarding and enlightening.

Final thoughts from Jo (Illustrator)

We've spent 2½ years doing the research for the sexuality project. We've done it carefully and with people who have learning disabilities leading the process. Because of this, the results are genuine and reliable.

It's not been a straightforward drawing job. It's been about watching, absorbing, listening and learning. I can be impatient and sometimes it's been frustrating.

I was part of the drama sessions. My best memories from the project are of spending time with the young people every Wednesday. My work on the project has come from the experience of being there with the young people as they expressed themselves in the drama group over dozens of sessions.

As an illustrator I've learned about simplifying things whilst working on this project, about how to reduce things to their essence. That's the art of communication and it's beneficial to everybody, not just people with learning disabilities.

We've tried to do this with the 5 booklets we've produced. We've tried to write simple sentences and illustrate straightforward information about things the young people wanted to know more about, or didn't know very much about.

We've learned that you can't make assumptions about what people understand. So I had to do explicit drawings about sex. It was worrying at first - I thought we didn't need to show so much and that people might be offended.

But we spent a year showing people (with & without learning disabilities) draft versions of the booklets and no-one complained. Some didn't like what several of the images showed but this seemed personal, not political.

The Sexuality Team at CHANGE hopes the booklets we've produced will be useful for many people. They can be looked at by individuals who can or cannot read. Or they can help parents, carers and professionals to explain sex & relationships to other

people on a 1-to-1 basis.

Final thoughts from Ruth (Researcher)

At the beginning of the project I was quite nervous about moving to Leeds, starting a new job and meeting new people. It looked like a really big research project and a lot of hard work. But I was also quite excited because I had done research before about disability rights and I wanted to do more. I was really interested in finding out more about how the drama was going to work and I was looking forward to working with young people with learning disabilities. I felt that relationships and sex was a really important topic to look at.

I feel that the project has gone really well. The young people have been inspiring and have had a lot of courage to talk about personal issues. I have really enjoyed it. It has been great working for CHANGE, which works in such a unique way, employing people with learning disabilities on equal salaries and making their workplace as accessible as possible. It has also been good working in partnership with the Centre for Disability Studies at Leeds University, which is internationally renowned for its expertise in disability research.

I think the best bits have been doing research in a creative way and working in a team of people who all have expert skills. I have always felt that the research we have done will make a difference to people's lives in the long term. It's not just a research project that ends up with a long boring report sitting on a shelf that nobody reads! The difficult bits for me have been having so much work to do and keeping up with all the different parts of the project e.g. the drama, the interviews, the focus groups, the survey, the analysis, the writing of articles, the writing of the report, the conference planning.

I feel sad that the project is coming to an end. I have learnt a lot, I have made good relationships with the members of my team and I have had fun along the way. When I first started the job I thought that 3 years was a long time, but it has gone by very quickly. I hope that people take on board the findings of our research and that, as a result, all people with learning disabilities in the future will be given more support and more information about relationships and sexuality.

Final thoughts from Professor Colin Barnes (Academic Consultant, Centre for Disability Studies, University of Leeds)

This project is an excellent example of user-led disability research. The project was conceived, developed and conducted by CHANGE, an organisation controlled and run by disabled people with 'learning difficulties'.

The Research Team comprised both disabled and non disabled people and used a variety of research methods. These included drama with young people with learning difficulties, a national survey of schools and colleges, and semi structured interviews with parents and teachers. The use of drama with young people as a method of identifying sensitive and contentious issues around sexuality is particularly noteworthy for its novelty and effectiveness. The project's findings are especially important as they show clearly the need for more accessible and useful information and support for all aspects of sexual matters and relationships for young people with learning difficulties in schools, colleges and the community at large.

These are complex research tools and the fact that the project has proceeded without major problems and produced original meaningful data and policy insights for policy makers and practitioners within the agreed deadline, provides a clear illustration of how effective user led/ partnership projects can and should be exercised. Overall this research is a credit to everyone involved.

Final thoughts from Philipa Bragman (Director of CHANGE)

It's been the first time in CHANGE that we've worked in partnership with a university working on a research project. This has been new, exciting and challenging. We've built on our knowledge of using drama in research and learnt more about the issues and gaps for young people with learning disabilities about their sexual health rights. It's been inspiring to have so many young people coming into CHANGE. In the past we have worked mainly with adults. It's also been interesting undertaking a research project in such an innovative, accessible way where people with learning disabilities are equal partners in the process as this is not generally how research works. It's been a really successful partnership working with the Centre for Disability Studies at Leeds University who share the same aims and work within the Social Model of disability, as we do.

In all of the areas of work at CHANGE, people with learning disabilities work as equal project workers to their non-disabled partners. We call this the co-working CHANGE model. People with learning disabilities are equal employees and are paid equal

salaries. Having people with learning disabilities as equal partners in a research project was very natural and easy for us- it's the way we work! We already had accessible systems and structures in place so that the member of the research team who had a learning disability felt included from the start.

It was a challenge to bring together different aspects of the project, such as drama, research, the empowerment of people with learning disabilities and working locally and nationally. We had to think about so many different things. During the drama group sessions, for example, the team had to work out which staff would join in the group and what role they were playing. We thought about whether the researcher was a participant in the group or an observer, or both. The illustrator also attended a large number of the drama sessions and made good relationships with the young people.

At CHANGE we always work in an accessible way. Documents, team meeting minutes, filing systems, policies, all are produced in easy words and pictures. This is different to the way in which the university works. They tend to write things in a more complicated, academic language. Generally, the culture of academia is inaccessible to most people with learning disabilities. This made us consider access - how should things be done and how should things be written up? We worked closely with the university and negotiated these things carefully so that both parties felt happy with how we produced things. Even though both organisations work from the Social Model of disability we had different ways of working and sometimes different expectations that we had to think and talk about.

I think it has been important having such a diverse team working on the Sex and Relationships project with each person bringing their own skills and experiences. It has been so interesting and important having young people using drama and it has been good for the young people to see role models of people with learning disabilities working as equal employees at CHANGE. The young people have developed new skills and greater confidence. Although the actual project is coming to an end, some of the young people continue to come to CHANGE and are learning skills so they can deliver training in the future.

CHANGE is, as always, taking forward the lessons we have learned from the young people and from schools and colleges across the country. We will continue to campaign for changes that are needed in order that young people can have their full sexual health rights.

People with learning disabilities continue to deliver training on sexual health and relationships to other people with learning disabilities and professionals across the country. We will disseminate the accessible booklets and support sexual health organisations to work more accessibly with people with learning disabilities.



Talking about sex and relationships: the views of young people with learning disabilities

This report describes a 3-year piece of research that looked at the views and experiences of young people with learning disabilities around sex and relationships.

The research was done by innovative drama work with young people with learning disabilities, interviews with parents, focus groups with teachers and a national survey of special schools.

The project was undertaken by CHANGE, a national organisation led by Disabled People that works for the equal rights of people with learning disabilities, in collaboration with the Centre for Disability Studies at Leeds University. It was funded by the Big Lottery Fund: Health and Social Research Grants Programme.

There is an accessible version of the report at the beginning.

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