

Sexual Health Needs Assessment

Children, young people & adults with learning difficulties

for

NHS Bristol

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Noshin Emamiannaeini & Joanne Ferry

***If we get sexual health services right for
people with learning difficulties, they
would be good services all round for all.***

Sexual Health Promotion Specialist, NHS Bristol

Acknowledgement

We would like to express our gratitude to all the people who gave their time to take part in this review through interviews, focus group discussions, completion of questionnaires and informal discussion.

Language use

People with learning difficulties are often referred to in government documents and by many large organisations as 'people with learning disabilities'. Many journals use the term 'intellectual disabilities'. These terms are rejected by some self-advocacy organisations, because they are considered to be discriminatory. Among these are People First, a large national organisation, which works in partnership with NHS Bristol. In order to respect their preferred term this report uses the term learning difficulties throughout. However, where people or journals are quoted, their words are not altered.

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1. Executive Summary

A Bristol wide Sexual Health Needs Assessment was undertaken to investigate increasing local evidence that Sex and Relationships Education (SRE) and access to sexual health services may not be meeting the needs of children, young people and adults with learning difficulties.

Through engaging with local people with learning difficulties, the people that support them, sexual health services and learning difficulty organisations, it was identified that there are multiple gaps in current services and the provision of SRE needs improving.

The process identified local examples of good practice, as well as professionals dedicated to improving the provision of SRE and access to sexual health services for people with learning difficulties. The clear lack of coordinated strategy in this area however highlighted the need for multi-agency leadership for this agenda, in which local professionals and organisations need to reach a consensus about where the responsibility lies for delivery of specialist Sex and Relationships Education for children, young people and adults with learning difficulties.

Key findings of the assessment include a lack of sustained Sex and Relationships Education post adolescence for people with learning difficulties, a lack of confidence in supporting people in their right to sex and relationships, and a reliance on community learning difficulty nurses to 'deal with' sexuality issues at crisis points. The need for specialist training was also identified and coordination of the wealth of resources that can be used for delivering Sex and Relationships advice for this population.

Extensive evidence was gathered highlighting the range of attitudes of those who support people with learning difficulties within family and service settings and the impact this has on people accessing sexual health services.

Summary of key recommendations:

- ✦ Establish a multi-agency steering group, inclusive of people with learning difficulties, to drive forward the agenda for positive sexual health for people with learning difficulties.
- ✦ Progress local data collection about learning difficulties to inform service improvement.
- ✦ Develop a multi-agency approach to support the delivery of high quality SRE for all people with learning difficulties which should be jointly developed.
- ✦ Improve opportunities for specialist training to support the delivery of the SRE agenda.

2. Background

National evidence suggests that people with learning difficulties can experience a number of barriers in relation to achieving good sexual health. Increasing local evidence suggests that Sex and Relationships Education (SRE) and access to sexual health support services may not be meeting the needs of this population, across both child and adult services in Bristol.

This review was commissioned by NHS Bristol to improve the understanding of the sexual health needs of children, young people and adults with learning difficulties residing or accessing services in Bristol. The findings of the review will contribute to the planning and development of local sexual health services and the delivery of Sex and Relationships Education.

3. Objectives

- ✦ To identify the needs of people with learning disabilities in relation to positive sexual health and highlight gaps in current service provision.
- ✦ To identify the provision, including gaps, and where possible quality and consistency of Sex and Relationships Education for people with learning disabilities, to highlight the sources of this education, and to find out what improvements they would like to see.
- ✦ To provide information about the attitudes of staff, teachers, family carers and health professionals toward the relationship and sexual health needs of people with learning disabilities in their care.
- ✦ To inform the further development of policy and guidelines relating to the relationship and sexual health needs of people with learning disabilities.

4. Overview

National context

'People with learning difficulties face some of the biggest restrictions in terms of availability of sex education. Whereas in other areas of life the trend is towards 'normalization', in other words, fitting people with learning difficulties into the roles and values of the rest of society, this does not seem to prevail in the area of sexuality'(Garbutt, 2008).

The Office for Disability Issues estimates that there are over 10 million disabled people in Britain, of whom 5 million are over State Pension age and 800,000 are children. This estimate includes those people with a longstanding illness, disability or infirmity, and those who have significant difficulty with day-to-day activities (Department of Health, January 2010). The sexual health of people with learning disabilities raises important management and practice issues for health services, and should be examined in the context of the current policy emphasis on advocacy, person-centred services and social inclusion (Department of Health, 2001).

Garbutt (2008) explains the historical context prior to the introduction of Community Care policies in the UK in the 1990s:

A large number of people with learning disabilities lived in institutions, and were often segregated. In such institutions, people with learning disabilities were not usually encouraged to have relationships, and the opportunities for any kind of sexual experiences were very limited, since there were very few areas where people could have their own privacy. During the Eugenics movement, particularly in the late nineteenth and early twentieth century, it was argued that the procreation of people with learning disabilities should be discouraged to prevent what was seen as their 'defective' genetic material being passed on and endangering the human race and, as a consequence, many women with learning disabilities were sterilised. Quite often, people with learning disabilities were seen as 'eternal children' because they were considered innocent and asexual and, consequently, '...adults often assumed that sexuality was irrelevant to young people with learning disabilities.

People with learning disabilities may have limited access to mainstream health services, and sexual health and genitourinary medicine (GUM) services are no exception (DoH, 2001; 1998). They are often excluded from society, either because they are 'segregated' within specialist support services in the community or because they live in isolation with carers, and health and social care models do not always join up locally to meet their needs (Cambridge, 2003). People with learning disabilities have also been labelled as 'vulnerable', and at risk of being abused, all of which, historically, has

given professionals and parents reason to be cautious in terms of encouraging them to have any form of intimacy (Garbutt, 2008).

UK Legislation

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. Although the rights of people with learning disabilities have improved with legislation, sometimes they are still on the receiving end of negative attitudes and lack of information (Garbutt, 2008).

After extensive consultation, the UK Government planned to introduce compulsory Personal Social Health and Economic (PSHE) education, ensuring that all children would receive at least one year of compulsory sex and relationship education (SRE) by making PSHE compulsory, and lowering the age at which parents can withdraw their children from sex education from 19 to 15 years old. Legal advice to the Secretary of State was that increasing the age of the sex education opt-out within PSHE to 16 would have made the bill non-compliant with the European Court of Human Rights. In April 2010, following cross party discussions, the Government tabled amendments to the Children, Schools and Families Bill to enable some parts of the Bill to be passed into law before Parliament was dissolved. Due to a lack of agreement, compulsory SRE was removed from the Bill.

Department of Health approach

The Department of Health recognises that the Office for Disability Issues recommends the use of the definition of disability under the Disability Discrimination Act (DDA) 1995. It defines a disabled person as someone who '*has a physical or mental impairment which has a substantial and long-term adverse effect on his ability to carry out normal day-to-day activities*'. It is important to emphasise that the needs of people with disabilities will vary greatly, and policies should be considered for their impact on people with different types of disability (such as physical, sensory, mental and learning disabilities, as well as mental incapacity) and combinations of disabilities. Disabled people, like the rest of the population, can choose to have sexual relationships and can have a lesbian, bisexual, gay or heterosexual identity (Department of Health, January 2010).

Social skills/behaviours & Self esteem/body image

Social skills have been shown to be crucial in helping teenagers to build their self esteem, make healthy decisions and become independent. Over-protective parents, social isolation, a lack of

positive role models and negative stereotypes can lead to low self esteem and body image amongst teenagers with learning disabilities (Heer, June 2008). Social isolation means that teenagers have few people to talk to about issues such as drugs, alcohol, sexuality and anger. This can lead to feelings of loneliness and asexuality. According to the National Children's Bureau (Blake, 2004) young people with a learning disability need information about values, friendship, dating, love and intimacy and how to protect themselves from unwanted pregnancies and sexual exploitation. Research indicates that youth with disabilities are four times more likely to be abused than their peers (Heer, June 2008). Inadequate teaching and knowledge surrounding appropriate sexual behaviour and boundaries can leave such youngsters susceptible to becoming victims of sexual abuse.

Parents & carers

It has been found that parental attitudes can influence the experiences and rights, of people with learning disabilities around sex and relationship. Research suggests that some family carers want their children to have the same rights as everyone else but that they are concerned for their safety. In terms of professional practice, therefore, there is a need to work in a supportive way with parents, and to be sensitive to their experiences and concerns about their sons' and daughters' level of vulnerability. The main message coming from parents is that there is a need for clear, concise information about sex and relationships for young people with learning disabilities and there is also a need for professionals to give parents more support (Garbutt, 2008).

Professionals

Tackling sex and relationships for people with learning disabilities can be difficult for professionals and staff attitudes can greatly influence the experiences and rights, of people with learning disabilities in this area. Teachers of individuals with learning disabilities have been reluctant to become involved in sex education due to moral beliefs, attitudes, lack of confidence in their abilities to provide adequate sex education and the lack of availability of sex education materials (Garbutt, 2008). Whilst professionals may find it a difficult area to address, there is UK legislation that supports the rights of people with learning disabilities to have fulfilling relationships and sex lives if that is their choice.

Acknowledging diversity

Evidence suggests that sex between men with learning disabilities and other men is a relatively common behaviour and the risks of HIV are exacerbated by the fact that many men with learning disabilities who have sex with other men do not identify themselves as being gay. Of even greater concern is evidence that many men with learning disabilities who have sex with men are also likely to be having sex with women and other men with learning disabilities (Cambridge, 2003). Factors contributing to HIV risk include limited access to sexual health information and resources, and a reduced capacity to translate knowledge into safer sex practice. Collectively, these factors mean that both women and men with learning disabilities are at greater risk of HIV infection than other groups.

Research suggests there is a knowledge-practice gap which consequently puts people with learning disabilities at increased risk. Contributory factors include low self-esteem, poor negotiating skills, language and communication difficulties, and acquiescence. The sexual experiences of people with learning disabilities should inform the baseline to safer sex education work and support aimed at

empowering this group to develop positive sexual identities and safer sexual behaviours (Johnson, 2002).

Links to teenage pregnancy

Teenage pregnancy research by the University of York Social Research Policy Unit found that in a cohort of 169 teenage mothers known to the Connexions service in York (at October 2007) a total of 27 of the teenage mothers had an identified special educational need, including 5 relating to behaviour, emotional and social difficulties, 6 to attendance, and 11 to learning difficulties (Cusworth, 2007). There are certain limitations to this data: it is not known when each individual became a parent, how old they were when they gave birth, how many children they have, or when they became known to Connexions. However, whilst this information provides a general overview of teenage mothers in York and should not be used to draw general conclusions across other populations, it does highlight a link between young women with learning difficulties and teenage pregnancy. According to the National Longitudinal study a third of students with learning disabilities became mothers within three to five years of leaving school (Heer, June 2008).

Perhaps one of the greatest challenges is to bridge the sexual health gap between mainstream health promotion activities and GUM services, on the one hand, and specialist sex education and sexual health work in learning disabilities, on the other.

National policy framework

Equality impact assessment for National Sexual Health Policy. (Department of Health, January 2010)

The evidence outlined in the Equality impact assessment highlights the significant inequalities that exist within sexual health in England. However, many of those inequalities have already been addressed during implementation of the sexual health and HIV strategy. Policy initiatives have aimed to address the inequalities through targeted programmes, such as chlamydia screening for young people, or HIV prevention work targeted at men who have sex with men, as well as at people from African communities. The report states that there is limited data and research available on the needs of people with learning disabilities or physical disabilities. Consequently, people with disabilities have not to date been a focus for sexual health policy, and their needs should be considered in any future sexual health strategy development.

Valuing People Now: A New Three-Year Strategy for people with learning disabilities 'Making it happen for everyone' (Department of Health, January, 2009)

Valuing People Now outlines how better health for people with learning disabilities is a key priority. There is clear evidence that most people with learning disabilities have poorer health than the rest of the population and are more likely to die at a younger age. Their access to the NHS is often poor and characterised by problems that undermine personalisation, dignity and safety. The final report of the NHS next Stage Review sets out the vision for the NHS that it will 'deliver high quality care for all users of services in all aspects'. Key issues for the NHS are to achieve full inclusion of people with learning disabilities in mainstream work to reduce health inequalities and to ensure high-quality specialist health services where these are needed. The report has a section on relationships and having a family, which states the overall policy objective as, 'people with learning disabilities have the choice to have relationships, become parents and continue to be parents, and are supported to do so'. It goes on to state that:

The evidence is that people with learning disabilities have very few relationships and limited opportunities to form or sustain them, people are often lonely. One of the reasons for this is their exclusion from the kinds of places where other people form and maintain relationships, such as work, college, clubs, places of worship, leisure centres, etc, but there are other reasons for this, mostly based on assumptions about people with learning disabilities.

Supporting peoples' rights to have relationships is mostly about challenging stereotypes and changing attitudes. Some specific reasons for why people with learning disabilities have limited relationships are:

- ✦ *the way in which professionals take decisions about service delivery that ignore existing relationships and break up friendship patterns, eg when people are moved from one service to another;*
- ✦ *insufficient consideration being given to personal relationships in individual planning and care management processes;*
- ✦ *services getting the balance wrong between protecting vulnerable people and helping people have a life: positive risk taking should be a part of everyone's life, including those with more complex needs;*
- ✦ *people still not recognising and accepting that people with learning disabilities, like anyone else, want and need personal and sexual relationships.*

Dignity in health care for people with learning disabilities. (Royal College of Nursing, 2009)

This guidance, developed by the Royal College of Nursing Learning Disability Nursing Forum, aims to improve dignity in health care for people with learning disabilities. While designed primarily to support the nursing workforce working in all health care settings, other health care and social care staff may also find this publication a useful resource. The guidance concludes with information relating to the particular health needs that people with learning disabilities may have, and provides ideas on working in collaboration with other service providers.

Report of the Independent Inquiry into access to healthcare for people with learning disabilities. (Michael, July 2008)

The Inquiry has found convincing evidence that people with learning disabilities have higher levels of unmet need and receive less effective treatment, despite the fact that the Disability Discrimination Act and Mental Capacity Act set out a clear legal framework for the delivery of equal treatment. Health service staff, particularly those working in general healthcare, have very limited knowledge about learning disability. They are unfamiliar with the legislative framework, and commonly fail to understand that a right to equal treatment does not mean treatment should be the same. The health needs, communication problems, and cognitive impairment characteristic of learning disability in particular are poorly understood. Partnership working and communication (between different agencies providing care, between services for different age groups, and across NHS primary, secondary and tertiary boundaries) is poor in relation to services for adults with learning disabilities. Although the report highlights examples of good practice, it also documents how

witnesses describe some appalling examples of discrimination, abuse and neglect across the range of health services.

Clear sexual boundaries between healthcare professionals and patients: responsibilities of healthcare professionals. (Council for Healthcare Regulatory Excellence, January 2008)

This guidance is for regulators of healthcare professionals in the United Kingdom, to provide a basis for guidance for their registrants. It is also recommended that the principles set out in this document are followed by others working in the delivery of healthcare services. It aims to set out the responsibilities of healthcare professionals in relation to the maintenance of clear sexual boundaries with patients and their carers.

The Sexual Health Needs of Young People with Learning Disabilities. (NHS Health Scotland, December 2007)

This briefing paper brings together evidence on effective and promising practice and highlights the views of young people with learning disabilities. As well as drawing on commissioned research and inputs from practice, this work has been enhanced through the ongoing inputs from an advisory group of key stakeholders. The final section of this briefing paper identifies a number of potential future actions that, if pursued, will help ensure that sexual health services and sex and relationships education are better able to meet the needs of young people with learning disabilities, as well as those of their parents and the professionals that support them.

Good practice guidance on working with parents with a learning disability. (Department of Health and Department for Education Skills, June 2007)

The purpose of this practice guidance is to, help services to improve their support for parents with a learning disability and their children; and to increase the chances of the children of parents with a learning disability continuing to live with them in a positive and supportive environment that meets the children's needs. The guidance is for both adult and children's services. In particular, it is for commissioners of education and social care services, for all service providers and is for the information of Primary Care Trusts. A key aspect of good practice is multi-agency working and thus this guidance is concerned with social care, health and education services and with the role of both statutory and independent sector services.

You're Welcome quality criteria: Making health services young people friendly. (Department of Health, April 2007)

You're Welcome quality criteria sets out principles that will help health services (including non-NHS provision) become young people friendly. It covers areas to be considered by commissioners and providers of health services. Content is based on examples of effective local practice. This second edition includes a new section covering Child and Adolescent Mental Health Services. You're Welcome has been included in the NHS Operating Framework for 2009/10 and highlighted in DH/DCSF Healthy lives, brighter futures - the government strategy for children and young people's health. A companion toolkit (You're Welcome quality criteria self-assessment toolkit) is also available.

The needs and effective treatment of young people who sexually abuse: current evidence. (Home Office / Department of Health, October 2006)

This document draws upon various sources in order to provide a base line of evidence on the needs and effective treatment of young people who display sexually abusive behaviour. It provides an overview of the current literature and thinking around these behaviours and treatments for them. The research in this area is still very much in its early stages and therefore should be viewed as pointing the way for the future development of this work.

Sexual Health and Relationships A Review of Resources for people with learning disabilities. (NHS Scotland, 2005)

This review of sexual health and relationships resources for people with learning disabilities is intended to support professionals in their work. It collates reviews of resources, assessed by professionals from across the health, education, social work and voluntary sectors working in Scotland. This network of peer-reviewers included teachers, community learning disability nurses, clinical psychologists, health promotion specialists, other health professionals, and members of various voluntary organisations.

Better prevention, better services, better sexual health - The National Sexual Health and HIV Strategy.(Department of Health, July 2001)

The National Strategy for Sexual Health and HIV sets out the government priorities and targets for achieving a 25% reduction in HIV and sexually transmitted infections by 2007. The government is committed to reducing the prevalence of undiagnosed HIV and sexually transmitted infections; reducing unintended teenage pregnancy rates; improving health and social care for people living with HIV and reducing the stigma associated with HIV and sexually transmitted infections.

Planning, teaching and assessing the curriculum for pupils with learning difficulties - Personal, social and health education and citizenship. (Qualifications and Curriculum Authority, 2001)

These guidelines support the planning, development and implementation of the curriculum for pupils with learning difficulties. They draw on effective practice across a range of schools and can be used in mainstream and special primary and secondary schools, specialised units and independent schools. They also provide support to the range of services that work with these schools.

Local context

Demographics

Bristol has a population of 416,400 people, it is the largest city in the South West and one of the eight 'core' cities in England (excluding London). A 26.6% population rise is predicated by the year 2026. Of the 416,400 people residing in Bristol, there are 91,500 children and young people aged 0-19 years, making up 22% of the total population. This is lower than the England average of 24%. However, Bristol does have a relatively young overall population profile, with 91,200 young adults aged 20-29 years, which is 22% of the total population. There are more people under the age of 16 than over the age of 65 in Bristol which is in line with national trends.

Numbers of people with LDs in Bristol

The actual number of people with learning difficulties is unknown but using estimates suggested in Valuing People (DoH 2001) it is estimated that people with learning difficulties make up approximately two percent of the population.

Using this estimate, approximately 8,000 people living in Bristol may be thought to have learning difficulties, although only approximately 1,800 adults are currently registered as having a learning difficulty on Bristol GP registers. A further 400 children with learning difficulties are thought to be in the education system.

These figures suggest that a significant number of people with learning difficulties are not accessing the necessary health and support services to meet their needs.

The number of people with learning difficulties is estimated to increase in line with population growth. The table below shows both the current and projected population of people with learning difficulties in Bristol.

	2008	2011	2018	2028
Population projection	422 000	440 700	480 300	529 200
All LD – all ages (2%)	8 440	8 814	9 606	10 584
Moderate to severe LD	2 110	2 204	2 402	2 646

(Office for National Statistics, 2006)

Teenage Conception and Termination of Pregnancy Data

Teenage conceptions rate in Bristol for 2008* (48.7) is considerably higher than the England rate of 40.4 per thousand of the under 18 population and is 2% behind the national percentage for abortion of 50%.

Bristol conception rate for the under 18 population is higher than the South West rate of 34.7 per thousand of the population of under 18s and is 3% lower than the regional percentage of abortion amongst this population (51%).

2008			1998-2008
Number	Rate	% leading to abortion	% change in rate
309	48.7	48	-4.5%

*Teenage conception and abortion data is reported subject to a 14 month time delay as birth registration can be undertaken up to six weeks after birth (causing an eleven month delay) and three months is required by ONS to compile statistics.

Provision of Sexual Health Services in Bristol

Bristol Sexual Health Service

The recent integration and modernisation of Genito Urinary Medicine (GUM) and Contraceptive and Sexual Health Services (CASH) has led to the delivery of a new, integrated service model for contraception and sexual health that co-locates Sexual Health/GU, Contraception and Pregnancy Advisory (abortion care) services in this one location, providing a central hub co-ordinating services, clinical governance and training & education.

The service interfaces with The Bridge, a Sexual Assault Referral Centre (SARC) which occupies the second floor of Central Health Clinic.

Specialist clinics are run for:

- complex contraception
- male & female psychosexual care
- herpes counselling
- male chronic urethritis & pelvic pain
- female pelvic pain
- Fast-track access is provided for adolescents and commercial sex workers
- An outreach clinic operates for street commercial sex workers
- HIV services in Bristol are based within Southmead Hospital, in North Bristol Trust.

A further 16 sites provide specialist Sexual Health Clinics in community settings (for a full list of sites see Appendix 3). The majority of these sites are C-Card Outlets, a free scheme that enables registered young people to collect condoms and discuss sexual health. In addition to the 16 sexual health sites, there are 60 C-Card outlets at numerous pharmacies, GP surgeries and Youth Centres across the City. 90% of Bristol pharmacies offer access to emergency contraception.

NHS Bristol employs a sexual health promotion specialists and teenage pregnancy strategy coordinator. Within this team is also a training coordinator for 4YP.

4YP Bristol

4YP was launched in 2007 as part of the Teenage Pregnancy Partnership in Bristol. 4YP is a badging system for services offering sexual health or access to contraception, signifying that services are confidential, young people friendly and free. 4YP has significant involvement from young people including the development of the 4YP website but to date there has been no involvement from young people with learning difficulties. 4YP engages young people and their parents and carers through outreach work at local events. Currently 4YP is campaigning to support parents and carers to feel confident in talking to young people about sex and relationships.

The 4YP team also provides a range of training courses for parents and professionals in sexual health including:

Level 1 Sex and Relationships

This is a fundamental level of training for anyone wishing to train in any of the other 4YP training sessions. It is generic sexual health training in that it applies to all young people and does not have any targeted aspect for vulnerable groups. Once people have completed this course they can attend the Working with YP with LD and SH course. This course is designed for people working with young people aged 13 and above to enable basic awareness of sex and relationships work and the law and to refer YP to sources of further advice and services as appropriate.

Working with Young People with Learning Difficulties and Sexual Health course

This one day session focuses on developing a practical approach to working with young people with learning disabilities in the area of sexual health. The course is designed for professionals who want to develop sex and relationships work with young people with learning difficulties and it aims to develop awareness and confidence on working and supporting young people with LDs around their sex and relationship needs.

Schools and Educational Facilities in Bristol

Bristol has twenty secondary and 106 infant, primary or junior schools some of which are faith schools. A number of schools have nursery provision and there are additional stand alone nursery services across the city. There are nine special schools in Bristol, ranging from preschool to secondary school provision and four pupil referral units in Bristol, including a specialist centre for teenage mothers and a hospital based education service. Children with learning difficulties are educated within the general education system and special schools across Bristol.

Learning Difficulties Specific Services

NHS and Social Services

Specialist Community Learning Difficulty Services are commissioned through Bristol Community Health. Three integrated health and social care community learning difficulty teams are situated across the city. Bristol Intensive Response Team (BIRT) offer an additional service. This team works to improve the quality of support to children and adults with learning difficulties and their carers by supplementing existing services in planning for preventing crisis including health and social breakdown, interventions for crisis response, supporting the management of challenging behaviour and mental health needs.

Specialist Learning Difficulty Hospital Liaison Nurses are employed by UHBristol & and South Gloucestershire Learning Difficulty Service, working in NBT. NHS Bristol employs a Public Health Specialist for People with Learning Difficulties with a wide remit including the collection of evidence and improving health and social care for this population.

The Bristol Learning Difficulties Partnership has representation from people with learning difficulties, health, social care and other statutory and voluntary learning difficulties organisations. It is tasked with addressing the needs of people with learning difficulties and aims to make sure 'Valuing People' (Department of Health, January, 2009) and 'Valuing People Now' is implemented in Bristol.

River Street Peer Support Service, commissioned by Bristol City Council, is committed to enabling and empowering people with learning difficulties, in recognition of their individual needs for self-fulfilment, friendship and community access. The service works with local agencies to respond to the needs of people with learning difficulties, in areas such as education and health.

There are a range of residential services for people with learning difficulties in Bristol run by a range of private and voluntary providers. Accommodation includes residential homes, smaller group homes and supported housing. There are a range of day services including drop in centres for people with learning difficulties across Bristol.

Local Organisations

The Learning Difficulties Working Group is a sub group of Bristol LINKs which is a network of individuals and community groups who work together to improve local health and social care services. There is strong partnership working between this working group and NHS Bristol.

The Norah Fry Research Centre (based at the University of Bristol) is one of the leading centres in the UK for research into services for people with learning disabilities. Research studies at the Centre are based on a social model of disability, attempting to support disabled people and their families in identifying and tackling the barriers they face. Three core themes underpin the work of the centre;

people with learning disabilities have the same human value as anyone else, having choice and control over where people live and how they are supported is an important human right for all and there must be recognition of the individuality of people with learning disabilities.

In 2005 the centre, working in partnership with Terrence Higgins Trust and REGARD, found significant barriers were put in the way of people with learning difficulties exercising their human rights to consenting same sex relationships;

'Despite the very many messages telling men and women with learning difficulties that it is a problem for them to be sexual at all – never mind gay, lesbian, or bisexual – people were forging their lives and identities and striving to lead full sexual and emotional lives' David Abbot, Norah Fry

Outcomes of the research include a booklet about challenging homophobia and heterosexism for people with learning difficulties and the staff that support them and resources such as Phil's Story; A photo-story about a gay man with learning difficulties.

Bristol and South Gloucestershire People First is a user led organisation for people living with a learning difficulty in the local area. Services offered include advocacy and peer advocacy, training for people with learning difficulties and professionals. Support groups facilitated by BSGPF include a parent's support group who come together to discuss benefits, sexual health, health action plans, domestic violence, healthy eating and keeping safe. This group also work closely with NHS Bristol and other organisations to improve services for people with learning difficulties. Other groups include a black members group, Asian members group and a women's group.

BSGPF also run 'Stars in the Sky', a dating and friendship agency for people with learning difficulties. People are supported to attend dances and speed dating and go out for meals.

Local policy framework

Sexual Health in Bristol – High Risk Groups and Access to Services

In 2008 a Sexual Health Needs Assessment was undertaken in Bristol, led by NHS Bristol. In addition further work was undertaken with the aim of informing the NHS Bristol Sexual Health Strategy by identifying groups at increased risk of STIs, HIV abortion and teenage conception and to identify gaps in current service provision. The report recognised that there is a lack of knowledge on the levels of STIs in the local community and the actual level of unmet needs remained unknown at the time the report was written. With the knowledge that data is lacking on STIs, teenage conception and abortion it was predicated that young people, black ethnic groups, men who have sex with men, deprived populations and substance users are at increased risk. This report does not identify people with Learning Difficulties as a group at particular risk. Key recommendations include:

- ✦ An urgent need for more and better data if evidence based service planning is to be possible. Data sets should include demographic data and risk factor information, such as sexuality and ethnicity.
- ✦ An urgent need to engage with service users from high risk populations.

It is well documented that people with LDs fall into many of the groups identified as at risk by this needs assessment. The report highlights the need for at risk factors to be identified but fails to identify learning difficulties as a risk factor for poor sexual health or risk of teenage conception.

Sexual Health Research Project on Learning Difficulties – 1994, NHS Bristol

The project was established to enable the voice of people with LDs to be expressed in relation to their sexual health needs rather than through their carers. It identified a need for more investment in SRE, particularly for contraception and inclusion of homosexuality and training for staff and parents. Nearly two decades later, many of the key recommendations of this project are yet to be implemented in Bristol and the same issues are still present for people with learning difficulties

Health Needs Assessment for people with Learning Difficulties- 2008, NHS Bristol

A health needs assessment was undertaken to address the lack of evidence concerning the health status of adults with LD. The assessment aimed to assist the commissioning, planning and delivery of services to this population. A high level of serious health conditions within this population highlighted a very high level of health need, both in terms of prevention, assessment and management. However, the report did not include sexual health, teenage conception or abortion within its remit. The report highlighted barriers to accessing to health services within the LD population of Bristol; this is likely to be magnified when accessing sexual health services.

Barriers to Accessing Health Services - NHS Bristol Commissioning

Targeted work is currently being undertaken with the Bristol LINKs Learning Difficulties Working Group to identify barriers to accessing health services for people in Bristol and promote the need for reasonable adjustments in health provision of services. Findings include the need for extra time in appointments, use of accessible resources and plain English and the promotion of Health Action Plans.

Bristol Sexual Health Policy

This policy is NHS Bristol's response to the National Sexual Health and HIV Policy. The overarching aim of the Bristol policy is to ensure that people are enabled to exercise their right to refrain from or enjoy sexual activity of their choice without causing or suffering mental or physical harm.

The Bristol Sexual Health Policy was a key driver for the Sexual Health Service Development Group which was tasked with improving health outcomes and patient experience for people who access sexual health and HIV services, create a range of pathways for sexual health services which offer choice to patients in a variety of environments and continue to focus on prevention, screening, timely diagnosis, accessible and effective ongoing management. Achievements include the integration of GUM and CASH services in Bristol and the implementation of a termination of pregnancy pathway which includes a 24 hour a day, seven day a week central telephone booking service for Pregnancy Advisory Services and access to terminations.

Bristol Teenage Pregnancy Partnership Strategy

The teenage pregnancy partnership aims to reduce the number of under 18 conceptions in Bristol. The partnership is a multi agency group including NHS Bristol, Bristol City Council Connexions West of England and the voluntary sector. The partnership delivers a teenage pregnancy action plan which aims to:

- Increase awareness of teenage pregnancy amongst young people, parents and professionals.
- Ensure that professionals are supported to talk to young people about relationships and sexual health and signpost to appropriate services

- Increase access to sexual health advice and information services to ensure young people have someone to talk to and can easily access advice and contraception if they need it.
- Support the provision of sex and relationships education in schools
- Target young people most at risk of teenage conception and ensure that they are offered a package of support through the youth service and Connexions.

Equality Policy - NHS Bristol

The Equality Policy highlights NHS Bristol's commitment to eliminating discrimination on the basis of gender, marital status, age, disability, race, religion, nationality, ethnicity, sexuality or social class. NHS Bristol states that it will deliver accessible services in a way that respects the needs of each individual and does not exclude anyone. The policy outlines the commitment to promoting the social model of disability and addressing equalities in the NHS Bristol Local Delivery Plan. The Single Equality Scheme Action Plan details a number of actions relating to people with learning difficulties.

National Healthy Schools Programme

The Healthy Schools Programme (NHSP) is a joint initiative between DCSF and Department of Health (DH) - which promotes a whole school / whole child approach to health. The work of NHSP is aligned to four core themes relating to both the school curriculum and the emotional and physical learning environment in school. Sex and relationships education is included in the Personal, Social, Health and Economic (PSHE) education theme. In order to satisfy the criteria of the PSHE, schools must demonstrate that the PSHE framework is used to deliver a planned and progressive programme of PSHE and that there is protected time for delivery. In relation to the provision of SRE to children and young people or specifically those with learning difficulties, Healthy Schools does not set out guidelines.

Aiming High for Disabled Children

Aiming High for Disabled Children (AHDC) is the Government's transformation programme for disabled children's services in England. The vision behind Aiming High for Disabled Children is for all families with disabled children to have the support they need to live ordinary family lives, as a matter of course. To deliver this vision, Aiming High for Disabled Children has three priority areas; access and empowerment, responsive services and timely support and improving quality and capacity. Aiming High Bristol commissions workforce training including a course on sexual health support for disabled young people. This course is also available to parents and family carers as well as health and social care professionals and local voluntary sector organisations.

Bristol Relationships and Sexuality Policy

This policy has been developed by Freeways, Bristol PCT and Bristol City Council to support staff working with people with learning difficulties in Bristol around relationships and sexuality. It is also intended to support people with learning difficulties in accessing their rights to information on relationships and sexuality and their right to sexual and personal relationships.

Bristol Sexual Health Learning Difficulties Guidance

Bristol Sexual Health Service has produced brief guidance for staff providing care to people with learning difficulties. A full copy of this guidance can be found in Appendix 2. Aspects of guidance

include allowing extra time for patients with learning difficulties, ensuring appropriate communication methods and awareness of sexual health or relationship issues that are likely to be raised by people with learning difficulties.

5. Methodology

Process

- ✦ Desktop review of national policy and key documents
- ✦ Desktop review of all local evidence including service mapping
- ✦ Questionnaire for post holders and service providers
- ✦ Focus groups with people with learning difficulties and those who support them
- ✦ Interview with key stakeholders
- ✦ Recruitment
 - Identified and engaged key stakeholders
 - Offered opportunity to engage in review via adverts in local organisational newsletters

Contributors

- ✦ There was wide participation in the project in a variety of methods; completing questionnaires, taking part in one to one interviews and attending focus groups. They included people with learning disabilities, family carers, front-line staff and professionals.
- ✦ Attendance at the Learning Difficulties Health Group of the Local Involvement Network
NHS Bristol's commissioning department held a focus group meeting with Learning Difficulties Local Involvement Network Meeting with the aim of better understanding the barriers to accessing healthcare that people with learning difficulties may face in Bristol. 44 people with learning difficulties attended the meeting and 22 carers and support staff. The project team led a break out group with 14 attendees choosing to join the discussion around sexual health services. Included in the discussion group were people with learning difficulties, parents, family carers and support workers.
- ✦ Attendance at the Learning Difficulties Health Group of the Local Involvement Network
The project team was invited to attend a second meeting of the Learning Difficulties Health Group of the Local Involvement Network. A presentation was given on the sexual health needs assessment and attendees were invited to join a discussion group. 23 people chose to take part in the discussion group, the majority of who were people with learning difficulties, but also included a parent of a person with learning difficulties and professionals working in the field.
- ✦ Meeting with Health Trainers for people with Learning Difficulties
A focus group meeting was held with the four health trainers for people with LDs, all of whom have LDs themselves, and the health trainer coordinator. In addition the health trainers offered to assist in the writing of an accessible report produced to accompany this report.
- ✦ Key local stakeholders were identified and were contacted to contribute to the review (see appendix for List of contributors and respondents)

- ✦ Questionnaires were sent to all schools in Bristol, day services and drop in centres for people with learning difficulties, sexual health services, parents and carers organisations and support groups, social services, NHS Bristol, CLDT teams and other learning difficulty organisations.
- ✦ Adverts were placed in the 4YP bulletin, GP news bulletin, Bristol LINKs newsletter, and parents and family carer newsletters to ensure a wide range of people were able to contribute to the process.
- ✦ As well as focus groups with people with learning difficulties, support staff, parents and family carers, meetings were held with a range of professionals working with people with learning difficulties including public health, NHS Bristol commissioning, CLDT and health and social care professionals.

6. Findings

Strategic

Considerable weaknesses have been identified with regard to the strategic leadership of this agenda in Bristol. This is compounded by the lack of a local policy specific to the sexual health and wellbeing needs of people with learning difficulties, and a general sense that partnership working across this agenda is not strong as it needs. Linked to the lack of a long term strategy, is an inherent reactive rather than proactive approach to supporting sexuality and relationships for people with learning difficulties, often resulting in intervention at crisis point. This is highlighted by members of the Sexual Health Promotion Team who stated during interviews that they often *“respond to needs as they arise and requests for help by people working with people with learning difficulties, but this is difficult due to lack of capacity within the team”*. Lack of capacity was often cited as a challenge to this agenda.

Partnership working is a significant weakness, particularly between those who specialise in learning difficulties and those who provide sexual health services. It is also crucial that links are made to other agendas supporting this population, such as Aiming High, as there is potential for joint funding of initiatives. There is no consensus or shared understanding about who should lead on the provision of Sex and Relationships Education for all age groups of people with learning difficulties.

A lack of ownership of the provision of SRE to people with learning difficulties was identified by both LD and SRE professionals. Both staff groups recognise the importance of delivering SRE and are committed to the agenda. However there is an issue around which professional group needs to take the lead on this issue. Learning Difficulty professionals feel that the provision of SRE needs ownership from the sexual health service and conversely some SRE specialists feel that is the lead responsibility of learning difficulty workers to drive the agenda.

Despite this, there is evidence of good practice and examples of voluntary and statutory sector engagement especially around the provision of one to one and group support but this is often occurring in isolation and as needs arise. This reactive rather than proactive approach needs steering by a standardised Bristol wide approach to ensure that all organisations feel supported to deliver on this agenda and so all people with LDs have an opportunity to access the appropriate support at the time that they need it.

It was suggested that the lack of a sexual health policy and guidance at local authority and national level for people with learning difficulties means that progress is unlikely. This is supported by the fact that in 1994 Bristol undertook a needs assessment in this area, yet many of the issues identified in this report remain today. Particularly of note, there has been a lack of progress on targeted support for people with learning difficulties to access sexual health information and services.

The sexual health / sex and relationships agenda needs to develop an ‘everybody’s business approach, as highlight by the comments of one interviewee, *‘Sex and relationships advice needs to become a regular part of health in general with people with learning difficulties, this process would highlight the need to look at the training of parents, carers and professionals, it needs a system wide approach, so that delivery of SRE becomes a regular part for them to play’*.

Bristol should consider developing a comprehensive policy:

‘The aim of all sexuality policies and guidelines should always be to support with learning and disabilities in their sexual lives, not to dissuade them from having sex.... As well as the provision of support for all on an informal basis, all people with learning disabilities should have access to formal sex education as a matter of right’ (McCarthy, 1999).

Recommendations:

- ✦ Establish a multi-agency steering group, inclusive of people with learning difficulties, to drive forward the agenda for positive sexual health for people with learning difficulties. The multi-agency group should consider the following:
 - Building on the Bristol Sexual Health Services Guidelines for working with people with LD, develop a comprehensive Bristol wide SRE / SH policy and action plan
 - Undertake a review of local resources for LD SRE and develop and standardise a virtual library of resources
 - Identify and establish links to other agendas, such as teenage pregnancy, which have a higher local priority
 - Establish a forum for professionals to debate and agree a way forward of how SRE should be delivered to best meet the needs of all people with LD

Data

Learning difficulty status is not routinely recorded by sexual health services in Bristol and this limits the intelligence surrounding the levels of Sexually Transmitted Infections (STIs), HIV, teenage conceptions and abortions within the local learning difficulty population. The paucity of data on the prevalence of LDs within the population is an issue recurrently highlighted, although this is beginning to be addressed. The identification of a ‘number of information gaps around carers and people with learning difficulties’ in the local Joint Strategic Needs Assessment (JSNA) *Top 12 key findings* represents an opportunity to drive forward the improvement of local LD data. Given that the JSNA informs short term planning, 3 – 5 years ahead, by identifying priority groups or communities who are experiencing poorer health and wellbeing outcomes, allowing design or re-design of services to reduce inequalities. In order to achieve the services that Bristol expects, a full understanding of local needs is crucial, including a comprehensive understanding of the needs of people with learning difficulties.

In many services there is no formal screening process to identify people with learning difficulties. The Bristol Sexual Health Services has stated that this is a limitation of the current clinical IT system. However the service will be updating the system in June 2010 and there may be potential to record learning difficulty information.

Recording and sharing of data within sexual health services for all patients is an issue that is recognised by public health data analysts and health professionals due to the confidential nature of the information recorded. However, if the sexual health needs of people with learning difficulties are to be made a priority for the NHS and the city council, there needs to be a robust evidence base to start from. Similarities can be drawn with teenage conception data; there is a considerable delay in receiving intelligence on conceptions and so proxy data and wider health determinants are pulled together to provide contextual data to inform commissioning and performance management.

Among some professionals, there is concern about collecting and sharing data about people with LD. *'There is a fine balance between identifying people for positive support and labelling. The term learning difficulties rings alarm bells, but there is a wide range of abilities within learning difficulties. It is fundamentally about educating people who work with people with learning difficulties'*, Hospital Liaison Nurse for people with learning difficulties. This is amplified by the fundamental problem that sexual health services are confidential and this often means that there is no join up with other specialist services such as learning difficulty teams.

Whilst it is apparent that data collection is essential for improving commissioning of new or existing services and performance management, the issue of defining the term 'learning difficulties or learning disabilities' is a barrier that must be addressed. A Bristol wide consensus must be reached on the definitions of learning difficulties if there is to be synergy amongst all services that support people with learning difficulties.

As an example of where improved data collection would be beneficial, it has been suggested that young women with learning difficulties may be over-represented within under 18 conceptions. However, current evidence does not exist to either support or dispute this. Further understanding of this population could support better targeted services to support delaying pregnancy, which is well documented as being associated with better outcomes for both mother and child.

In addition to enhancing local and national intelligence on learning difficulties, there is a need to monitor the needs of service users with disabilities in order to ensure equity of service delivery. The Disability Discrimination Act requires that health services records the needs of people with learning difficulties to ensure that all reasonable adjustments are made to meet any different needs of people with disabilities including Learning Disabilities.

Recommendations:

- ✚ Utilise the opportunity of LD data being identified as a priority in Bristol's JNSA to drive forward meaningful local data collection to inform joint commissioning and performance management
- ✚ Improve local data collection for the LD population to improve how services are commissioned and to ensure they meet the needs of this group by:
 - Identify the prevalence of people with learning difficulties within the under 18 conception cohort
 - Identifying other data sources that can provide a proxy data set in the absence of LD specific information to support the delivery of sexual health services and SRE for people with LD

Communications

'The word sexual health puts people off straight away', Health Trainer for PWLD.

There is a lack of organised communications about this agenda, which if implemented, could contribute to clear messages about shared expectations and better joined up working.

There are at least two websites (4YP and NHS SH Services) providing information about sexual health in Bristol, but neither provides comprehensive, accessible information for people with learning

difficulties or their carers. Bristol Sexual Health Services are developing their website, and it has been suggested that this website could include videos on what to expect when visiting the clinic. The Health Trainers for Learning Difficulties also identified the inclusion of videos on the Bristol Health Trainer website as a useful way of engaging people with learning difficulties and informing them of local sexual health services. A specific section for young people with learning disabilities on the 4yp website would be beneficial to professionals and parents as well as young people themselves.

It has been suggested that where possible the term 'sexual health' should be widened to include a relationships aspect. This term is considered inaccessible in that it may be preventing people from talking about sexual health, sex or relationships as it may not be clear that it includes other aspects such as contraception. This is especially important in cases where people may only occasionally access health or other services as it provides an opportunity to initiate a discussion regarding the relationship and emotional side of sex. People with learning difficulties may be unaware of the link between sex and relationships.

It is important that there are appropriate references and images for people with learning disabilities in local authority and NHS generic publicity and information materials on sexual health. This would support 'myth busting' in relation to sexuality and young people with learning disabilities.

Recommendations:

- ✦ It is recommended that Bristol develop a formal Communications plan for this area of work, to ensure that a broad range of professionals are informed about local policy, emerging practice and training opportunities
- ✦ Consideration should be given to hosting a Bristol-wide event to raise the profile of this agenda, engage disparate professionals, share good practice, and potentially launch a new multi-agency approach / policy for LD Sexual Health and Well-being

Sex and Relationships Education in schools and other setting

It has been suggested that whilst improvements are necessary for delivery of SRE to all young people across Bristol, this is particularly pertinent to young people and adults with learning difficulties, for whom SRE provision is often ad hoc or non-existent. There are a number of reasons for this, including a lack of guidance on the provision of SRE, misunderstanding and misgivings about the needs and rights of people with learning difficulties, and a lack of access to appropriate training and resources.

A recurrent story told by health care professionals, people with learning difficulties and the people who provide for support them, is the inclination towards giving a negative spin on sex and relationships. This was mentioned by numerous people who contributed to the review, and is highlighted below:

'Why is sex and sexual relationships always talked about in a negative way when talking to people with learning difficulties? We are quick to tell them about the dangers and the bad bits, but what about the nice bits of having a fulfilling sexual relationship?' LD advocacy worker.

'I reckon what we are taught about sex puts people off. All we hear is about

diseases and all the bad stuff that that can happen to you, nothing about the nice feelings and good things about sex and relationships.’ Adult with LDs.

Similarly, negative attitudes are often displayed when people with learning difficulties are planning a pregnancy or expressing a desire to have a child in the future. In a focus group meeting it was highlighted that people with LDs who have sought support for planning a pregnancy have found themselves subject to barriers put in place by carers and health care professionals, instead of being recognised for taking responsible action. Contributors to this review highlighted the negative approach of professionals to women and men who want to have a child and in some cases a systematic lack of support.

‘There is a culture of ‘putting people off’ pregnancy, but some people just want to learn more in order to make their own decisions and want family planning advice to do so. There are lots of successful stories about women with LDs who have had babies.’ Hospital Liaison Nurse for people with LDs.

‘I know two people who are married that have learning difficulties, who have decided to have a baby. They went to the GP for advice on getting the coil removed and to get family planning advice and the GP was horrified that they wanted to have a child. The GP referred the couple back to social services. The couple were willing to go on any courses, such as healthy living and to learn about being parents, but it has taken six months and they feel discouraged to continue their plans to have a baby.’ Support Worker for people with LDs.

Evidence suggests that between 30 - 90% of children born to women with learning difficulties are removed due to child protection concerns (Supported Parenting for mothers and fathers with learning difficulties). Work currently being undertaken by NHS Bristol in improving maternity services for people with learning difficulties. It has been highlighted that there is the potential for some of these cases of removal to be prevented if the right support is available to women with learning difficulties before or at an early stage of pregnancy. This highlights the need for targeted support to be driven through the SRE agenda for people with learning difficulties, specifically around planning for children and where to access the appropriate services that can support women with learning difficulties.

A recurrent theme was the need to think beyond the mainstream issues addressed as a matter of course in SRE to meet the needs of people with learning difficulties. There are specific issues that need targeted education and support such as:

- ✦ More information on positive relationships
- ✦ Understanding consent and sexual legalities
- ✦ Awareness of abuse and sexual exploitation
- ✦ Opportunities to meet partners and establish relationships
- ✦ Inappropriate sexual behaviour

In addition, areas already covered in mainstream SRE need further attention when working with people with learning difficulties, such as;

- ✦ Safer sexual practices
- ✦ Access to contraception
- ✦ Same sex relationships

As well as reviewing the curriculum, there is a need to examine the methods of teaching used to deliver SRE in mainstream settings as people with learning difficulties may not respond well to teaching approaches used with children and young people in mainstream education. It has been highlighted that ‘schools and parents or carers need to work together, with the right support, to see that good SRE will enable people with learning difficulties to access life’.

The Leeds case study provided below is an example of a comprehensive approach to SRE for children and young people with learning difficulties, which Bristol may want to investigate further.

CASE STUDY:

Puberty & Sexuality - for Children and Young People with a Learning Disability

(A supporting document for National Curriculum objectives)

This award winning teaching pack has been developed to be taught to learning disabled children and young people between the ages of 9-18 years old. It is acknowledged however that depending on the age and the cognitive ability this may vary. It has been designed to include the needs of children and young people with severe learning disability to deliver extensive knowledge appropriate to this group but equally comparable to their mainstream peers. The pack is based on information from a variety of sources and supporting evidence. It uses an array of visual and tactile resources to enable children to maximise their learning including dance and movement, anatomically correct dolls, role play and experiential learning. It can be used with both individuals and groups of children and is effective in school, residential and home environments.

The Children’s Learning Disability Nursing Team, Leeds (January 2009)

It was also highlighted that sex and relationships education needs to become a regular part of health education in general for people with learning difficulties. Supported visits to sexual health services could begin to facilitate the ‘ordinariness’ of accessing sexual health services. This practice is already happening in a special school in Bristol and helps to break down the barriers to accessing sexual health services by ‘normalising’ the visit. This practice could be replicated by schools, colleges and other services that people with learning difficulties access.

One element of SRE for people with learning difficulties which is often disregarded is the differing needs within the group, both related to ability and individual preference, as highlighted by a Bristol Health Trainer, ‘*I’ve come across clients who do want to talk about sex and those who don’t – it’s their choice*’. Also highlighted by this comment from a Parent with LD, ‘*all of the legislation that is*

around and none of it addresses those people without speech'. However it is important to remember that not everyone wants or needs information and it must remain a personal choice.

It is particularly important to consider the needs of those people who are not accessing health services, do not have a voice, or who seek this advice from a carer, parent or health care professional who may not feel confident in discussing issues of a sexual nature. A number of review contributors highlighted these issues:

'The issue is confidence. Parents, carers and people who work with people with learning difficulties often don't feel confident in talking about sex and relationships' LD worker.

'I am very concerned about the lack of work with people who do not have the ability to communicate and do not have a voice. How do we ensure that they are getting the support they need to enjoy the right to sex and sexual behaviours?' Parent with LD.

'Health professionals should visit day centres and residential homes to talk about sexual health and contraception, and not only provide support for people with learning difficulties, but their parents and carers as well' key worker.

Some people felt that because they had not proactively sought information about sex, this was being interpreted as a lack of interest. Furthermore, there is a fundamental difference in disregarding people's need and rights to information and in supporting people to make the choice as to whether they want sex and relationships advice or not. As the quotes below illustrate, people cannot ask questions about an area that they do not know exists, or that they do not have the vocabulary for:

'I like to be shown things but that's the problem, I don't know things about what STI names there are but no one has ever engaged me'

'People think that people with LDs don't want to know about sex, but if you don't know that something exists, you can't ask questions about it!'

'When I don't know things, I need to be shown how things work, then I will be interested in it. But if people don't talk about it with me, or hide it, how am I going to know what questions to ask?'

Recommendations:

- ✚ A multiagency approach to support the delivery of high quality SRE for all people with learning difficulties should be jointly developed. This might include the following:
 - Undertake an audit of SRE provision in all special schools in Bristol
 - All school should identify a 'champion' for SRE
 - Develop Bristol wide policy and curriculum for LD SRE in schools

- ✦ Undertake a gap analysis of SRE for adults with learning difficulties in Bristol

Changing needs

A powerful message that is often overlooked is the changing sexual health needs of people with LDs as they go through life. *'We need to remember that the issues of people will change as they get older, such as problems with sex drive and erectile dysfunction, we need to remember that it's not just about how to have sex or how to use a condom.'* People with learning difficulties will need targeted support that is sustained and tailored to suit the needs of the individual at that moment in time.

Lack of SRE after leaving school

Throughout this review, many people raised concerns about the lack of access to ongoing Sex and Relationships Education for people with learning difficulties once they leave school. *'We know that targeted sexual health support and initiatives do not often go beyond the teenage years or early adulthood, we need to look beyond these models for people with learning difficulties and not be bound by what we provide for other groups'*. There is some evidence that day services deliver gender specific group sessions, although it is unclear if the content spans the breadth of SRE and meets the SRE needs of people with learning difficulties. Others go on to make the point that, *'this needs to become a priority; it is a human right issue, we have to acknowledge people's rights'*.

There are a variety of settings that provide the opportunity for young people and adults to be engaged in SRE. It has been highlighted that youth workers are providing this within young people's disability groups that are held across the city. There are potential opportunities for the development of these roles but there is a feeling that youth workers are already at full capacity. It has been suggested that young people who have been accessing the youth services and are transitioning to adult services could be employed to deliver the SRE agenda as there is already recruitment as youth workers amongst this group. This would support a peer education approach and also facilitate involvement of people with learning difficulties to be at the centre of service planning.

Lack of support for 'coming out' or same sex relationships

It was identified during the review that there is a lack of support for same sex relationships amongst people with learning difficulties. This was raised by focus groups members on the three separate occasions, as well as by youth workers and other professionals, and is highlighted by their words below:

'If you have learning difficulties it is hard enough to have a friendship or a man woman relationship, let alone a same sex one.' Manager of Health Trainers for PWLDs.

'A massive issue is coming out as homosexual when you have learning difficulties.' LD advocacy worker.

These barriers can lead to concealment of sexuality and can result in risk taking behaviours such as having opportunistic sex. *'I have seen men and women who have not felt supported to come out as homosexual taking risks by having sex wherever they can such as in the toilets, because they feel that they have to hide their sexual orientation.'* Learning Difficulties advocacy worker.

Health Action Plans

Health Action Plans are recommended for all people with learning difficulties and provide an opportunity for identifying any support needs around sexual health and relationships. The Bristol Health Trainers highlighted the inclusion of a sexual health question within the health action plans but also identified a number of problems;

‘There is a question about sexual health in the health action plan and we always ask people if they want information on sexual health. The problem is that not everyone has a Health Action Plan, and we are shocked at the number of people who don’t even know what one is.’

Safe Spaces

People with learning difficulties often do not have the opportunity to have sex; the lack of opportunities for ‘safe spaces’ where people with learning difficulties can engage in consensual sexual activity was a recurrent theme through this review. The lack of ‘safe spaces’ can be attributed to the majority of people with learning difficulties living with parents or family carers, in residential homes for people with learning difficulties or in supported accommodation with other people with learning difficulties. This lack of a private space to use for sexual activity coupled with the barriers that people with learning difficulties face in establishing and maintaining sexual relationships has resulted in people taking risks and having opportunistic sex which may be unprotected.

Part of this issue may be overcome by improved communication between people with learning difficulties and their parents, family carers and support workers. Fostering an environment of openness will address the issue of ‘hidden’ sexual activity but will not entirely address the need for private safe spaces.

Recommendations:

- ⊕ Review the Health Action Plan questions to ensure Sex and Relationships questions are integral and appropriate so as to initiate a discussion about relationships
- ⊕ Further investigation is needed into alternative solutions to the need for ‘safe spaces’. A strong multi agency approach is necessary to ensure that the right expertise is available to tackle this complex issue
- ⊕ Review the provision of and access to ongoing sex and relationships education for adults with learning difficulties

Access to Sexual health Services

‘People are not supported to access sexual health services. Carers and support workers are often gatekeepers as they are the people who can enable people to attend clinics. The attitude is ‘why do you need a sexual health check, you are not having sex’. But this is wrong and risky.’

Access to sexual health services was highlighted in two ways; firstly, there is the lack of knowledge surrounding sexual health services in Bristol. Secondly, there is a sense that the way sexual health services are currently provided may not be the way that people with learning difficulties want them delivered;

‘We should have a sexual health service just for people with LDs in Bristol.’

There is one in London, but why should you just have it in one city where everyone else is excluded, it should be everywhere'

There was a consensus that sexual health services need to do more outreach to meet the needs of this group; it is felt that currently the responsibility lies with people with learning difficulties to find out where the sexual health services, and that this may be contributing to poor outcomes. Evidence suggests that people with learning difficulties face barriers to accessing many health services, such as GPs and as a result many do not receive the health care that they need. The same barriers (confounded by factors such as the negative view towards people with LDs having sexual relationships) may well be preventing people with LDs from accessing sexual health services.

'Health professionals should visit day centres and residential homes to talk about sexual health and contraception, and not only provide support for people with learning difficulties, but their parents and carers as well'. Key worker.

'We need a sexual health minibus to go to people and not expect people to come to the service'

'People in residential care are supported with housing but are not supported around sex and relationships. We need to ensure that we can reach everyone who wants support with this.' LD worker.

'There are too many steps and barriers to accessing sexual health services. We need one phone number or at least to know that if we need information on sex, we know who to go to. There are too many different routes.' LD worker.

Furthermore, it was generally felt that there is an opportunity for better joined up working; for example, hospital liaison nurses could get involved with termination of pregnancy services, as well as provide support with long acting reversible contraceptives for women who did not plan to get pregnant. Bristol Sexual Health Services are making steps to achieve partnership and outreach work. For example, they have already identified the need for outreach work by joining up with key local learning difficulty organisations; health advisors attended a sexual health promotion day organised by Bristol and South Gloucestershire People First. NHS Bristol were approached by nurses who work with people with learning difficulties to offer C-Card service and is currently being implemented.

CASE STUDY: SHIELD Service

SHIELD (*Sexual Health Innovation Education for Learning Disabilities*) is a programme developed on the Isle of Wight to give people with learning disabilities access to sexual health information and support. The sexual health service provides a high quality, accessible and equitable sexual health service to people with learning difficulties. The SHIELD Team worked with a large number of stakeholders to establish a wide-ranging service which offers people with learning disabilities the information they need to lead sexual lives, while respecting their dignity and human rights.

The SHIELD clinic, in partnership with the local sexual health service, gives people the

time to express their needs in a way which suits them and information is in a format they can understand. The clinic is supported by a network of more than 60 SHIELD 'links' -professionals working in organisations which work with people with learning disabilities, such as residential care homes, who have attended a specially created SHIELD training course that includes a section on sexually inappropriate behaviour.

SHIELD offers the screening, diagnosis, treatment and management of sexually transmitted infections, including HIV, and the promotion of sexual health and well-being. Appointments are longer than those in other sexual health services to ensure that clients are able to understand information given to them but also so that they can ask questions. In addition, pre- appointment resources and support is available via a SHIELD link in order to promote access and capacity to consent. Pre appointment visits are also offered when needed to promote understanding, access, and capacity to consent and facilitate a positive patient experience. SHIELD is provided in a safe and comfortable environment. All individuals receive expert and efficient sexual health care delivered by skilled and qualified professionals. Care is delivered to the same clinical standards as patients attending other Isle of Wight sexual health services.

Staff at first point of contact have a responsibility to promote inclusion and their aim is to ensure people with learning disability have equal access to sexual health services. Front desk staff and all other professionals that clients will have contact with have been trained to identify and provide the most appropriate method of communication for the person. A simple system is in place for staff who need third party support to meet the communication needs of individuals and appropriate additional support can be arranged for appointments if requested by the client, such as an advocate, carer, SHIELD Link or speech and language therapist.

CASE STUDY: The Pearl Service

This project is a dedicated and innovative easy access sexual health service for people with learning disabilities driven by a perceived need for a dedicated sexual health service. The service was developed by a sexual health and learning difficulties steering group.

The Pearl Service is part of the West London Centre for Sexual Health at Charing Cross Hospital, London. At the Pearl Service clients are met on arrival by a sexual health adviser. If a client brings someone to support during the appointment the client is asked if they are happy to have the accompanying person in the room with them when they are asked about their sexual history. Clients are supported throughout the entire sexual health process from registration and screening to obtaining results. All literature is specially designed and written and includes photos and pictures about the service to aid comprehension.

It is felt that this is an initiative that could be replicated in other sexual health or general health services in other areas.

Referrals can come from the individual themselves, carers, parents or family carers, GPs and other professionals. Service uptake is at times low; this has been attributed to the subject of sexual relationships still being very much taboo amongst people with learning difficulties and those who support them.

The service has recognised that there is paucity in evidence of STI prevalence in the LD population and plans to routinely record learning difficulty status. It is recognised that is often difficult to assess whether people have learning difficulties especially if people are reluctant to or do not want to self report their learning difficulty.

There are a range of barriers making access to services more difficult for people with learning disabilities. They include:

- ✦ Issues of consent
- ✦ Communication barriers
- ✦ Psychological difficulties of the patient, such as fear of being told off
- ✦ Managing emotions and feeling
- ✦ Anxiety due to perceived safeguarding issues
- ✦ Behaviour

It was also suggested by a health trainer with learning difficulties, that to help remove barriers to access, *'We need a specially trained sexual health liaison nurse for people with LDs, so that they don't feel rushed and the nurse understands their needs'*.

The need for sexual health professionals to come to the services where people with learning difficulties are was recommended by people with learning difficulties and those that support them on numerous occasions throughout this review. However, it must be recognised that sexual health services can deliver SRE on a number of topics outside of the clinics but work still needs to be targeted at bringing people into the clinic. It has been suggested that it would be beneficial for the clinic to outreach to local parents, carers and residential homes to encourage young people to use the service as well. The requirements of people accessing the service on a drop in basis are assessed on a need by need basis; when notice is given; extra time in appointments is allocated to people with learning difficulties. Health advisors are available to see partners on request and occasionally parents or carers; however resources for this can be limited due to demands on the service.

CASE STUDY:

In touch project – relationships, sex education and sexual health

Leonard Cheshire Disability is delivering an exciting 3 year project to give disabled people greater and easier access to services around sexual health. Working together with young disabled people, schools, colleges, sexual health services and other key partners this groundbreaking project aims to:

- ✦ Research into existing sexual health services and provision

- ✦ Research into the views and needs of young disabled people
- ✦ Influence local sexual health services using these viewpoints
- ✦ Develop materials and resources for use with young disabled people
- ✦ Help young disabled people make informed choices around sex, relationships and their own sexual well-being
- ✦ Help young disabled people to make and keep appointments with clinics
- ✦ Build a toolkit of best practice
- ✦ Share the findings with Primary Care Trusts and Strategic Health Authorities to achieve lasting change

Young disabled people will be closely involved in all aspects of the project, from sharing their views and experiences of sex, sex and relationship education, and sexual health services, through to taking part in workshops and helping to directly improve access to local sexual health services. The lasting legacy of this work will be in the long-term changes it brings about. By the end of the 3 years, young disabled people who have participated in the project will have found ways of protecting themselves and their sexual partners; will feel they are the sexual 'equal' of non-disabled young people; will be less likely to take part in risky sexual behaviour and will take greater responsibility for their own sexual health than they would have otherwise done.

www.lcdisability.org

As people with learning difficulties are less likely to access the full range of specialist health services available, attention should be given to identifying other opportunities with mainstream health services. A 4YP awarded GP practice highlighted that yearly health checks are carried out for people with learning difficulties, but sexual health is only included in discussions at the discretion of the GP and when it is assessed as 'appropriate'. However, it is unclear what is meant by 'appropriate'. Similarly, opportunities to provide sexual health support and SRE could be identified within existing learning difficulty services, such as the health trainers for people with learning difficulties, who were enthusiastic to develop their skill set to enhance the service they currently provide.

Recommendations:

- ✦ Signposting and advertisement of sexual health services should be accessible and targeted at people with learning difficulties. People with learning difficulties should be consulted and participate in the production of advertisement resources
- ✦ Ensure the implementation of *You're Welcome* is responsive to the needs of young people with learning difficulties. It may be appropriate to provide additional local guidance on providing user-friendly sexual health services for people with learning disabilities
- ✦ Identify opportunities to support people with learning difficulties by working in partnership with other NHS services such as learning difficulties liaison nurses, and parents and carers

Support for parents and carers

'There are people with learning difficulties who have to hide their sexual relationship from their parents, like they are sixteen or seventeen year olds, waiting for their parents to go out and then

inviting their boyfriend or girlfriends over. Why should people in their forties and fifties have to hide having a relationship from their parents?’ LD advocacy worker

It has been identified that support for parents and family carers is lacking. Often support is given on a reactionary basis, for example during a perceived crisis such as when a child is involved in inappropriate touching. There is a need for proactive, progressive support so that parents and carers feel confident in approaching subjects and can access further support when necessary. Some participants in the review suggested that parents and carers would benefit from access to an SRE trained professional who can provide support individually, in family groups, or in other ways as requested to address issues. Parents and carers are experts on their children and the people they support; to supplement this expertise with SRE training and advice will go some way in ensuring that people with learning difficulties are given the best chance to make their own informed decisions.

However, whilst some parents are unable to talk to their children, we cannot assume that all parents and family carers are reluctant to discuss or support sexual relationships, as shown by the range of quotes below.

‘The problem is that parents are sensitive and prudish about talking about sex with their children.’ Person with LDs.

‘People with learning difficulties are sexual beings the same as the rest of us.’ Parent of LD.

‘I have looked for support in various places over the years and have found nothing of great use. The lack of support used to be a nuisance now there is a complete absence’. Parent with LD.

‘Parents are still cautious about allowing their children to be exposed to anything they don’t feel comfortable with; if we hold a ‘sex and relationships’ day, parents will say no, if it’s a friendship and relationships group that it’s a yes’. Advocacy Worker with PWLD.

‘We are all aware of the need to work with families, carers and professionals.’

The underlying issue appears to be a lack of confidence and feeling unsupported in broaching the topic of sexuality; this apprehension can be barrier to supporting people with learning difficulties to access other sources of support. Parents and family carers need to feel empowered to provide the necessary support around sex and relationships.

Recommendation:

- ✦ Explore the development of a tailored package of support for parents/carers, such as specific training and parent/carer support groups

Training & workforce development

There is a diverse but disparate range of roles within both the learning difficulty workforce and the educational and health community who have the potential to contribute to the delivery of the sex and relationships agenda specifically for people with learning difficulties. However, it has been recurrently reported that their training needs are unmet. It is essential to identify this workforce and

undertake a training needs assessment to establish a training programme that facilitates a workforce that can meet the needs of people with learning difficulties.

There is some training for working with young people with learning difficulties delivered locally in Bristol under the auspices of the 4YP programme. Following completion of the 'Level 1 Sex and Relationships' course, staff are eligible to attend the 'Working with young people with learning difficulties and sexual health' course. This course is designed for professionals working with young people aged 13 and above to enable basic awareness of sex and relationships work and the law and to refer young people to sources of further advice and services as appropriate. However, it is recognised that there is not the internal expertise to meet all of the needs of people working with learning difficulties, and that this is something the training team would like to develop so that Bristol based training can be delivered. It is felt that, 'the majority of people on the learning difficulties course have their thinking turned around; some people come with lots of preconceptions around people with learning difficulties and their rights to a sexual relationship'.

The following comments were made throughout the review about training:

'Training needs to be practical and tailored to the needs and target specific concerns'.

'The 4YP LD training is not held very often, but we have passed the resources on and made recommendations to the Knowledge and Resource Service to buy certain resources'.

'The LD training is comprehensive enough in terms of enabling people to identify resources to give a good overview of the needs of people with LDs, but it would in no way prepare someone as a 'sexual health worker for learning difficulties', and youth workers working with young people with LDs might find that it's not enough'.

'Sexuality and relationships should feature in all training courses for professionals who are involved with people with learning disabilities'.

Attitudes towards people with learning difficulties having sexual relationships

Perhaps the most striking and powerful finding of this review has been the acknowledgment that parents, carers or family carers, support workers and health professionals may be indirectly discouraging people from exercising their right to a sexual relationship, as demonstrated by the quotes below:

'We had a young person with LDs approach our sexual health stand at an outreach event and he suggested that he felt alienated from accessing information and contraception but also talking about sex and relationships. The attitude seems to be that if you are disabled in any way you don't have sex, this is about challenging institutional attitudes'.

'I've noticed at my drop in centre that people say things like 'why don't you two

go to bed together, you are in a relationship, you love each other' and the boyfriend of the couple will say 'No I'm not allowed, my carer won't let me.'
Adult with LDs.

'I feel that many professionals still do not want to accept that people with learning difficulties are not all asexual or 'sex mad' and that they need relationships, which may or may not be sexual, in the same way that people without learning difficulties do'. Student Social Worker, CLDT.

It was suggested that this fear of being open about being sexually active puts people at risk from STI's but also other diseases such as cervical cancer. Some women will not share the fact that they are in a sexual relationship and as a result be left out from cervical screening.

Similarities have been drawn to the health promotion work that was targeted at enabling young people to access contraception by challenging barriers from parents or carers;

'The acceptance that under 16s have sex and need to access contraception was an issue that took a long time to become accepted; it was a real battle, this is a similar issue but people with learning difficulties will have ongoing needs that need sustained support' Sexual Health Promotion Specialist, NHS Bristol.

Whilst the process of this sexual health needs assessment has identified many barriers to people with learning difficulties accessing sexual health services and receiving appropriate sex and relationships advice, it has also identified methods to break down barriers, for example, training to address the apprehension felt towards people with learning difficulties enjoying sexual relationships. Consideration needs to be given to how training opportunities are promoted and to whom they are made available. People working at a community level are often unaware of what is available in the way of training. Training is needed for all staff who work with people with learning difficulties to build confidence and foster an environment where there is open communication about sex, relationships and sexual health when requested.

Recommendations:

- ✦ Undertake a workforce review to ensure that all appropriate staff are Level 1 trained i.e. at least able to signpost to services
- ✦ In partnership with the Parenting Strategy Lead in the City Council, ensure LD specific SRE issues are addressed for parents / carers in existing parenting provision, and further developed if necessary
- ✦ Build on the existing 'Working with Young People with Learning Difficulties and Sexual Health course' to develop a more comprehensive course, aimed at those whose role is substantially about working with people of all ages with learning difficulties
- ✦ Ensure that training opportunities are well advertised and accessible to the broader workforce, including providers of supported living, voluntary sector and hospital based staff

Resources

Resources to deliver SRE were a common theme highlighted during focus groups, interviews and completion of questionnaires. There are a wide range of resources from national leading learning difficulty organisations available for educating people with learning difficulties in SRE (a list of resources can be found in appendix 4). However use of these by local organisations is ad hoc and does not appear to be evidenced based.

The wealth of resources available was often mentioned positively but there is a lack of local coordination and guidance for using resources;

‘There are masses of resources for delivering sexual health and relationships support to people with learning difficulties but we need to develop a set of competencies for people delivering SRE and working in this field’.

For example a day service in Bristol cites a number of SRE resources in use for adults with LDs accessing this service. These include resources produced by BILD, Wilslow Press, Norah Fry and 3Rs. There is an acknowledgement by local professionals that there is a need to identify the most appropriate resources ; there is no Bristol wide consensus on which resources are the most effective for people with learning difficulties.

‘There are a wide range of resources available, we need to be able to identify which resources are the most appropriate and hold them centrally so that anyone working with people with learning difficulties can access them’. Sexual Health Promotion Specialist, NHS Bristol.

Also identified is the need for specific resources such as anatomically correct models for use in delivering SRE, but these have been identified as ‘prohibitively’ expensive. The development of a centrally held bank of resources, accessible by all local professionals and staff groups, was highlighted as a potential solution to the problem of standardising resources but also sharing costs.

From talking to people with learning difficulties it became clear that there work needs to be undertaken on improving the current literature used to promote local sexual health services. In addition the need for services to think beyond the usual method of advertising and promote services via a range of media was also discussed.

This does not necessarily mean that costly new approaches need to be taken; for example existing websites such as 4YP could be adapted to ensure that they are accessible for people with learning difficulties and the Bristol Heath Trainers for people with learning difficulties suggested the addition of audio and visual advertising via their website. The Connexions website is an excellent example of a simple mechanism for making existing resources accessible, there is an option on the website for people with learning difficulties to change the wording and layout.

There is a recognition by local organisations that development of accessible resources is needed, which is an indicative that there is an awareness of the need for tailored communication but lack of funding is highlighted as a barrier;

‘We are looking at adapting the website and resources with a Learning Difficulty focus; professionals have approached us asking for learning difficulty appropriate materials but we can’t reproduce what we already have due to budget constraints but we know that there are excellent resources available through organisations such the FPA and Brook’. Communications Officer, 4YP.

The use of other methods for delivering SRE such as drama sessions was also highlighted. There is evidence of work previously being undertaken, such as a play on the subject of inappropriate touch. There was enthusiasm to revive existing work.

Recommendations:

- ✦ Coordination is needed to identify the most effective and appropriate resources for use locally
- ✦ A central bank of resources is needed so that all local organisations and professionals can access a wider range of resources than currently available
- ✦ Sexual Health services need to review current promotional methods and resources to ensure that they are accessible and appropriate to the needs of people with learning difficulties

Risk implications for people with LD

Condition	High Risk Groups / Behaviours	Identified risk and protective factors for PWLD in Bristol
Unwanted pregnancy	Any female who has unprotected sex ¹	<ul style="list-style-type: none"> ✦ Men and women with learning difficulties in Bristol have not received or understood information about contraception ✦ Men and women with learning difficulties are having unplanned sex opportunistically which may be unprotected ✦ Research suggests that a third of women with LDs become pregnant within 3 to 5 years of leaving school
Teenage pregnancy	Any female under the age of 20 who has unprotected sex	<ul style="list-style-type: none"> ✦ Teenage conception rate for Bristol is 54.7 per 1000 of the population of under 18s, this is higher than the England average of 41.7 and the South West (36.0) ✦ Men and women LDs in Bristol have not received or understood information about contraception ✦ Men and women with LDs are having unplanned sex opportunistically which may be unprotected ✦ Research suggests that a third of women with LDs become pregnant within 3 to 5 years of leaving school
Sexually transmitted infections [STI's] (gonorrhoea, syphilis, warts etc.)	<ul style="list-style-type: none"> • males and females who have sex without the use of a condom • black men aged under 25 years who have sex with men are at highest risk 	<ul style="list-style-type: none"> ✦ Men and women with LDs in Bristol have not received or understood information about contraception ✦ Men and women with LDs are having unplanned sex opportunistically which may be unprotected ✦ Men with LDs who are homosexual do not feel supported to 'come out' ✦ Lack of data, LD prevalence cannot be identified with ethnicity or sexual orientation ✦ Men with LDs who have sex with men are having unplanned sex opportunistically which may be unprotected ✦ Information on same sex relationships and sex is not routinely covered in SRE for people with LDs
Chlamydia	<ul style="list-style-type: none"> • the number of heterosexual partners • higher in the under 25 age group (males and females) 	<ul style="list-style-type: none"> ✦ People with LDs face barriers in meeting potential sexual partners and engaging in sexual activity ✦ Exact numbers of people under 25 with LDs in Bristol are unknown

¹ Unprotected sex – sex without use of a condom and/or other form of contraception

7. Conclusion

This review has identified many local examples of good practice, as well as professionals dedicated to improving Sex and Relationships Education and Sexual Health Services for people with learning difficulties. However, it became clear throughout the review that it is critical that there is multi-agency leadership for this agenda. This would be well supported by the further development of Bristol-wide policy and guidelines relating to the relationship and sexual health needs of people with learning disabilities.

It is essential that there is a long term commitment to this agenda and to implementing the changes needed to provide equitable and appropriate sexual health services and education. In 1994 a similar review of sex and relationships education for people with learning difficulties was undertaken in Bristol which identified the same issues as this review. It is concerning that after such a long period of time that these issues have still not been addressed. With the recent launch of the Bristol Sex and Relationships Policy it is the right time to commit to this agenda.

For progress to occur in this agenda, it is important that professionals reach a consensus about where the responsibility lies for delivery of specialist Sex and Relationships Education for children, young people and adults with learning difficulties. To achieve this, it is crucial that a multi-agency steering group is established and provides leadership on this agenda.

Key issues for adults with learning difficulties are the lack of access to SRE, a lack of acknowledgement of their right to healthy sexuality, and a reliance on community nursing teams to 'deal with' sexuality issues, which often arose due to a lack of good access to education and information for people with LDs.

This review has also identified the needs of people with learning disabilities in relation to positive sexual health and highlighted gaps in current service provision. It has also identified a number of challenges for the provision of Sex and Relationship Education to children, young people and adults with learning difficulties, and highlighted the importance of doing this better. Extensive evidence about the range of attitudes of staff, teachers, family carers and health professionals toward the relationship and sexual health needs of people with learning disabilities in their care, and the impact this has on people accessing services have been highlighted.

This report identifies several issues that require further attention, but are beyond the remit of this review, such as, the management of inappropriate sexual behaviour in the criminal justice system and the need for 'safe spaces' for people with learning difficulties to engage in consensual sexual activity.

Finally, by building on existing good practice and improving coordination for this agenda there is the potential to improve the provision of SRE and sexual health service for the entire population of Bristol and not just those with learning difficulties.

8. Recommendations

Strategic

- ✦ Establish a multi-agency steering group, inclusive of people with learning difficulties, to drive forward the agenda for positive sexual health for people with learning difficulties. The multi-agency group should consider the following:
 - Building on the Bristol Sexual Health Services Guidelines for working with people with LD, develop a comprehensive Bristol wide SRE / SH policy and action plan
 - Undertake a review of local resources for LD SRE and develop and standardise a virtual library of resources
 - Identify and establish links to other agendas, such as teenage pregnancy, which have a higher local priority
 - Establish a forum for professionals to debate and agree a way forward of how SRE should be delivered to best meet the needs of all people with LD

Data

- ✦ Utilise the opportunity of LD data being identified as a priority in Bristol's JNSA to drive forward meaningful local data collection to inform joint commissioning and performance management
- ✦ Improve local data collection for the LD population to improve how services are commissioned and to ensure they meet the needs of this group by:
 - Identify the prevalence of people with learning difficulties within the under 18 conception cohort
 - Identifying other data sources that can provide a proxy data set in the absence of LD specific information to support the delivery of sexual health services and SRE for people with LD

Communications

- ✦ It is recommended that Bristol develop a formal Communications plan for this area of work, to ensure that a broad range of professionals are informed about local policy, emerging practice and training opportunities
- ✦ Consideration should be given to hosting a Bristol-wide event to raise the profile of this agenda, engage disparate professionals, share good practice, and potentially launch a new multi-agency approach / policy for LD Sexual Health and Well-being

Sex and Relationships Education in schools and other setting

- ✦ A multiagency approach to support the delivery of high quality SRE for all people with learning difficulties should be jointly developed. This might include the following:
 - Undertake an audit of SRE provision in all special schools in Bristol
 - All school should identify a 'champion' for SRE
 - Develop Bristol wide policy and curriculum for LD SRE in schools
- ✦ Undertake a gap analysis of SRE for adults with learning difficulties in Bristol

Changing needs

- ✦ Review the Health Action Plan questions to ensure Sex and Relationships questions are integral and appropriate so as to initiate a discussion about relationships

- ✦ Further investigation is needed into alternative solutions to the need for 'safe spaces'. A strong multi agency approach is necessary to ensure that the right expertise is available to tackle this complex issue
- ✦ Review the provision of and access to ongoing sex and relationships education for adults with learning difficulties

Access to Sexual health Services

- ✦ Signposting and advertisement of sexual health services should be accessible and targeted at people with learning difficulties. People with learning difficulties should be consulted and participate in the production of advertisement resources
- ✦ Ensure the implementation of *You're Welcome* is responsive to the needs of young people with learning difficulties. It may be appropriate to provide additional local guidance on providing user-friendly sexual health services for people with learning disabilities
- ✦ Identify opportunities to support people with learning difficulties by working in partnership with other NHS services such as learning difficulties liaison nurses, and parents and carers

Support for parents and carers

- ✦ Explore the development of a tailored package of support for parents/carers, such as specific training and parent/carer support groups

Training & workforce development

- ✦ Undertake a workforce review to ensure that all appropriate staff are Level 1 trained i.e. at least able to signpost to services
- ✦ In partnership with the Parenting Strategy Lead in the City Council, ensure LD specific SRE issues are addressed for parents / carers in existing parenting provision, and further developed if necessary
- ✦ Build on the existing 'Working with Young People with Learning Difficulties and Sexual Health course' to develop a more comprehensive course, aimed at those whose role is substantially about working with people of all ages with learning difficulties
- ✦ Ensure that training opportunities are well advertised and accessible to the broader workforce, including providers of supported living, voluntary sector and hospital based staff

Resources

- ✦ Coordination is needed to identify the most effective and appropriate resources for use locally
- ✦ A central bank of resources is needed so that all local organisations and professionals can access a wider range of resources than currently available
- ✦ Sexual Health services need to review current promotional methods and resources to ensure that they are accessible and appropriate to the needs of people with learning difficulties

9. Abbreviations and acronyms

BSGPF	Bristol and South Gloucestershire People First
CASH	Contraception and Sexual Health
CLDT	Community Learning Difficulties Team
DCSF	Department for Children, Schools and Families
DfES	Department for Educations and Skills (now DCSF)
DH	Department of Health
EqIA	Equality impact assessment
GUM	Genito-urinary Medicine
HIV	Human Immuno-deficiency Virus
JSNA	Joint Strategic Needs Assessment
LD	Learning disability / difficulty
LGBT	Lesbian, Gay, Bisexual and Transgender
PWLD	People with learning difficulties
SRE	Sex and Relationships Education
STIs	Sexually Transmitted Infections

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11. Appendix 1 - Contributors to the review

Alistair Henderson, Valuing People
Anna Barwell, NHS Bristol
Anne Colquhoun, NHS Bristol
April Whincop, NSPCC
Babs Mcphial, Bristol City Council
Brook Bristol
Christine Cox, Youth Education Service
Dennis Stinchcombe MBE, Riverside Youth Project
Eithne Burt, NHS Bristol
Elaine Spencer, GP Practice
Emily Greentree, North Bristol NHS Trust
Gill Brookman, NHS Bristol
Hayley Pert, Bristol City Council
Health Trainers Learning Difficulties Team, NHS Bristol
Jackie Haskins, Lawrence Weston Young People's Clinic
Jessica Dicken, NHS Bristol
Judith Berry, Bristol Sexual Health Services
K Coelho, Bedminster Down School
Katie Hopgood, UH Bristol NHS Foundation Trust
Kirsten Forseth, NHS Bristol
Learning Difficulties Working Group, Bristol Links
Lesley Russ, NHS Bristol
Lin Edenbrow, Kingsweston School
Lisa Bailey, Better Together Project
Louise Jenner, Central Community Learning Difficulties Team
Mandy Parry, NHS Bristol
Michaela Pain, Brook
Neil Davidson, Bristol Council
Noelle Evans, Youth Education Service
Paula Peck, NHS
Penny Denyar, St George Day Service
Phil Cotgreave, Bristol City Council
Rose Martin, Bristol & South Gloucestershire People First
Sharon Schools, Youth Offending Team
Stephen Barry, North Bristol NHS Trust / NSPCC
Tina Knockeman, Bristol City Council
Victoria Ralfs, Down's Syndrome Association

12. Appendix 2 – Bristol SH services guidelines for working with people with LD

Things to think about when patients with Learning disabilities attend Bristol Sexual Health Service.

Hopefully the clinic should be informed on booking an appointment if a patient with learning disabilities is to attend. We can then book a longer appointment slot. Staff should be aware of any special needs or behaviours upon booking and if needed a carer to accompany patient to clinic.

It is important to remember that people with learning disabilities have the same needs as everybody else that we see, but they may express them in different ways, making the consultation longer and more complex.

- Consent and capacity. Some patients may not be able to give consent, if this is the case the clinic should have been made aware of this when appointments booked and a plan discussed with carer. Patients who have capacity may not have been given a choice about attending and may not know why they have come to see you.
- Anxieties about asking for help and attending clinic. Will they be told off for asking? Will they be understood? Will they understand? Can they make their own decisions or do they have an advocate to help them.
- Lack of knowledge, being unaware about sexual acts, sexual health, which facilities exist and how to ask for information.
- How is communication best? Verbal, pictures, communication boards, computer or sign language (Mackaton). Use appropriate words and simple sentences.
- Physical examinations. Informed consent must be obtained. Remind the patient who you are, what you are going to do and why. Have a chaperone present and inform them you can stop at any time. It may be the patient has to come back another time. If you are using a speculum/ instruments show them and maybe let them hold one. Encourage, reassure and praise. Document everything.

Clinical situations that may present.

Adolescence.

- May be the carer or parent who wants to be seen/ takes over consultation.
- May be highly anxious about physical or emotional aspects.
- Management of menstruation/ PMS
- Behavioural problems/ seizures may be cyclically exacerbated.

Unacceptable Behaviour.

- What are they doing? I.e. smearing menstrual blood, hypersexual.
- Who is it unacceptable to?
- Is it the behaviour or what is happening in that time or place?

- Do they realise it is unacceptable?
- Why are they doing it?
- The answers to the questions may help to address the problems.
- A consistent response and laying of boundaries will help avoid confusion.

Relationships.

- Patients may have a small understanding of the difference with friendship/ boyfriend/girlfriend or a sexual relationship.
- The patient may not understand personal space or use of force.
- They may not understand that any activity needs to be mutual.
- They may not know that they each have a choice.
- Health worker should be aware of any imbalance of skills or ability between a couple.

Contraception.

- Needs to be considered as with non disabled people.
- Individuals need to be able to make their own choices.
- All methods are an option within usual medical contraindications.
- There is a need to teach effectively and realistically. No demonstrating on bananas as patients may take it literally.
- May need extra teaching and support to manage a specific method.
- Can they manage the side effects?
- Information on emergency contraception to be given to patient and carers.

Tools to help.

Talking together workbooks. Kept in Health Advisors office.

Healthy sex series about how a trip to the clinic works.

Learning disability link nurses in the BRI extension 2113.

Website:

www.outsiders.org.uk

www.speakingup.org

www.fpa.org.uk

www.sreresources.com

13. Appendix 3 - Bristol GUM, CASH and Termination Services

Bristol Sexual Health Centre Central Health Clinic Tower Hill Bristol, BS2 0JD 0117 3426900	Marie Stopes International Bristol 3 Great George Street Bristol, BS1 5RR 0845 300 8090
Amelia Nutt Withywood Centre Queens Road, Bishopsworth, Bristol, BS13 8QA 0117 946 545	Charlotte Keel Seymour Road, Easton Bristol, BS5 0UA 0117 951 2244
Clevedon Hospital Outpatients Department Old Street, Clevedon, BS21 6BS 01275 872 212	Cossham Hospital Lodge Road, Kingswood, Bristol, BS15 1LF 0117 967 1661
Cotswold Clinic Southmead Hospital The Cotswold Centre, Monks Park Avenue, Southmead Bristol, BS10 5NB 0117 950 6383	Downend Downend Clinic, Buckingham Gardens, Bristol BS16 5TW
Kingswood Alma Road, Kingswood Bristol, BS15 4EJ 0117 967 7191	Knowle West Walk In Centre South Bristol Walk-in Centre, Downton Road BS4 1WH 0117 903 0000
Wellspring Healthy Living Centre Beam Street, Redfield, BS5 9QY	The Old School Surgery Manor Road, Fishpond Bristol, BS16 2JD 0117 958 9128
Thornbury Outpatients Department, Eastland Road, Thornbury Bristol, BS35 1DN	Yate 21 West Walk, Yate, Bristol. BS37 4AX
YPC Amelia Nutt Queen's Road, Withywood BS13 8QA	YPC Cadbury Heath Cadbury Heath Health Centre, Parkwall Road, Bristol, BS30 8HS
YPC Chipping Sodbury Chipping Sodbury Clinic, 250 Station Road, Yate, Bristol, BS37 4RF 01454 319176	YPC Clevedon HC Clevedon Health Centre, Old Street, BS21 6DG
YPC Lawrence Weston Lawrence Weston Clinic, Ridingleaze Bristol, BS11 0QE 0117 982 3205	YPC Patchway Patchway Clinic, Thirlmere Road Patchway, Bristol, BS34 5PD
YPC Southmead Southmead Health Centre, Ullswater Road, Bristol, BS10 6DF 0117 908 4654	Brook Young People's Clinic 1 Unity Street, BS1 5HH 0117 929 0090
Brook School Outreach Service	

14. Appendix 4 - National and Local LD specific SRE Resources

‘Feeling grown up’	A series of booklets for young people on: menstruation – at home, menstruation – at the disco, masturbation - male, masturbation –female, wet dreams, use of public toilets). £2.00 each plus P&P Available from: Shepherd School, Harvey Road, Nottingham, NG8 3BB or Tel 0115 9153265 or e-mail shepherd_school@hotmail.com
A curriculum for personal and social education.	Written by teachers from a secondary school for pupils with severe learning difficulties, this book provides a progressive health education curriculum for pupils with moderate and severe learning difficulties. Emphasis is placed on a whole school approach to sex and health education which builds on existing skills. A suggested curriculum (including activities) is provided in the areas of substance misuse and abuse, sex education, family life education, personal safety, food and nutrition, personal hygiene, advocacy and independence and leisure. OTTEN, L. (1999) London: David Fulton. 136pp.
Assessment, evaluation and sex & relationships education: a practical toolkit for education, health and community settings.	This toolkit was developed in response to teachers' and community workers' requests for support and information, and Ofsted's recommendations that assessment is strengthened in SRE. It puts the spotlight on why assessment and evaluation are important, offers practitioners clear advice on how assessment and evaluation can be used in SRE, and provides practitioners with practical activities for assessing learning and evaluating teaching. It includes: an overview of best practice in sex and relationships education; a summary of the theory and practice of assessment and evaluation; forty activities that can be used with individuals or groups, and can be tailored for a wide range of abilities and ages. London: National Children's Bureau. (Spotlight series).
Effective learning methods: approaches to teaching about sex and relationships within PSHE and Citizenship.	There are three elements to sex and relationships education [SRE]: the acquisition of information, the development of essential life skills, and the opportunity to explore values and attitudes. The methods of delivering SRE are as important as the content. This factsheet highlights these methods to ensure effective learning). (Replaces Forum Factsheet 12, Effective Learning Approaches). Available to download from the Sex Education Forum website. MARTINEZ, A. (2005) London: National Children's Bureau. 8pp. (Forum Factsheet 34).
FACTSHEET: Sexual health and people with Learning disabilities	This factsheet summarises current research into the sexual health and wellbeing of people with learning disabilities (fpa).
Growing up, sex and relationships: a booklet for young disabled people.	This booklet is for physically disabled young people and aims to provide them with information about sex and relationships, and sexual health. It includes sections about self esteem and body image, bullying, puberty, making friends, developing sexual relationships, contraception and sexually transmitted infections. Includes a directory of useful organisations. The booklet is available in full text on the Contact a Family website.
Growing up, sex and relationships: a booklet to support parents of young disabled people.	This booklet has been written for parents and families whose children have physical disabilities, including those who may also have mild to moderate learning disabilities. It looks at how being disabled might impact on issues around sex and relationships and offers guidance on what parents can do to support their child as they grow into young adults and start to form intimate relationships. Includes a directory of further publications and useful organisations. The booklet is part of a series of publications

	that have been produced by a group of organisations with expertise and experience in the field of disability and SRE. The booklet is available in full text on the Contact a Family website.
Holding On, Letting Go: Sex, sexuality and people with learning disabilities.	Directed at parents and other direct carers, Holding On, Letting Go is a practical book, well illustrated with a wealth of case studies with which parents will easily identify. It addresses the many stereotypes about disability and sexuality. It will be equally relevant to service providers where teachers and care workers may struggle to balance the need to provide 'safe services' whilst encouraging the development of choice and empowerment for young people who may have significant communication needs and limited life experiences. London: Souvenir Press Ltd. 127pp. (Human Horizons).
How it is: an image vocabulary for children about feeling, rights and safety, personal care and sexuality.	Provides an image vocabulary that has been developed to help disabled children communicate about a range of important issues including: children's feelings; their rights; their bodies; personal care and sexuality. Contains a booklet and CD Rom. NSPCC (2002) London: NSPCC.
Let's talk.....about sex and relationships.	Sheffield: Centre for HIV/Sexual Health. 22pp. A booklet for parents about how to listen and talk to children and young people about sex and relationships. Includes a section for parents of children with learning difficulties or special needs, and a list of contacts for more information.
Let's do it: creative activities for sex education for young people with learning difficulties.	This revised edition offers more than 80 drama based activities for use with young people with learning difficulties. Eight sections provide a framework for covering a complete sex education programme. These include: group building; body parts; gender; public and private; feelings; relationships; life cycle; developing skills. Adaptions are offered to meet the different needs of students. The layout is clear with each activity on a new page described under the headings of aims; resources; description; how to do it; what if?; and adaptions. A companion resource to On the Agenda, also by Image In London: Image In Action. 168pp. Action. JOHNS, R., SCOTT, L., and BLISS, J. (2002) Contact: Image In Action, Chinner Road, Bledlow Ridge, High Wycombe HP14 4AJ. Tel: 01494 481 632.
Let's plan it: A guide to planning programmes of sex education for young people and adults with learning disabilities.	This is a companion book to Image in Action's last publication 'Let's do it'. Based on the work of Image in Action over nearly 20 years, it aims to help teachers and tutors plan sex and relationships education for young people and adults with learning disabilities. It contains units for a term's work for different age and ability groups, with detailed session plans, and provides examples of good practice. It also contains a useful section of supporting information including resources, organisations, websites and templates). ('Let's do it': LIS record no.7521. Available from Image in Action Ltd., Chinnor Road, Bledlow Ridge, Bucks HP14 4AJ, Tel. 01494 481 632 SCOTT, L., and DUGNAN, S. (2005) High Wycombe: Image in Action 178pp. (
Living your life: the sex education and development resource for special educational needs.	A sex and relationships education resource aimed at pupils with special educational needs and/or learning difficulties aged 13 and above. Contains specific advice for teachers of pupils with autistic spectrum disorders. Topics include: the physical self; emotions; relationships; sexual expressions; choices and consequences; personal health and safety. London: Brook Publications.
Living your life: the sex education and personal development resource for special educational needs.	Aimed at PSHE teachers and others working in both mainstream and special schools with young people who have learning difficulties, this is a revised and extended edition of 'Living your life', first published in 1991. It provides a programme for teaching sex and relationships education and personal and social education with young people with learning difficulties and takes into account the changes which have

	<p>taken place with moves toward more mainstream and inclusive provision. The resource takes a practical approach, with readymade lesson plans and photocopiable worksheets. Appendices include student record cards, evaluation sheets and sample letters to parents regarding the provision of sex and relationships education. Includes a ring bound collection of 68 photocopiable worksheets. Coventry: Brook Publications.</p>
Male and female cloth models. Bodysense.	<p>Updated male and female cloth models, half-size, with removable clothes. Suitable for use with all age ranges, for people with learning difficulties, sensory disabilities or poor verbal communication, in the setting of a very structured sex and relationships framework. Bodysense also produce an anatomically correct 3D model of the female reproductive organs. Available from: c/o The Revd. Jane Fraser, Sunnybank House, Holly Green, Upton on Severn, Worcester WR8 0PG, Tel: 01684 594 715; Email: clothmodels@revjane.demon.co.uk BODYSENSE (2004).</p>
Sex and relationship education for young people with physical disabilities: a book for teachers.	<p>Focuses on SRE for children and young people with physical disabilities, including those who may also have mild to moderate learning difficulties. It aims to provide teachers and all those who work in schools with information on how being disabled might impact on issues around sex and relationships. It provides guidance on developing and reviewing SRE policy and practice to ensure it meets the specific needs of young disabled people, and on working with young physically disabled people, carers and parents. Includes a directory of useful resources and agencies. The booklet is available in full text on the <i>Contact a Family</i> website.</p>
Sex and relationships education for children and young people with learning difficulties.	<p>A fact sheet to support staff in special schools, mainstream schools and other settings in developing and reviewing SRE policy and practice. Available to download from the Sex Education Forum website. MARTINEZ, A. (2004) London: National Children's Bureau. Forum Factsheet 32.</p>
Sex education for visually impaired children with additional disabilities.	<p>A guide to developing SRE school policies and programmes for blind and partially sighted children with a range of physical, communication and learning disabilities. Also available in Braille or on a cassette. RNIB (1996).</p>
Sexual orientation, sexual identities and homophobia in schools.	<p>All children and young people should feel safe and included within the school environment, and this should be highlighted by the school's express commitment to equal opportunities, anti-bullying and anti-discriminatory practice. Personal, social and health education [PSHE] and Citizenship, including sex and relationships education [SRE], should support and reflect this ethos and be sensitive to the diversity and development of sexual identities. This factsheet supports schools to challenge homophobia and develop PSHE and SRE policy and practice which addresses sexual identities and is relevant to all children and young people. It explains why schools should address homophobia, sexual orientation and sexual identity, how to promote a whole-school ethos, how they can challenge homophobia and bullying, and suggests ways to address diversity and difference through the curriculum. Includes a list of useful contacts. Available to download from the Sex Education Forum website. MARTINEZ, A. (2005). London: National Children's Bureau. 6pp. (Forum Factsheet 33).</p>
Sexuality and learning disability.	<p>Highlights a range of creative approaches to working with people with learning disabilities. FANSTONE, C and KATRAK, Z. (2003) fpa. 67pp.</p>
Sexuality and relationships - supporting young people with multi-sensory	<p>Available to download from the RNIB magazine <i>Eye Contact</i>, no.2 (Summer) which is available on the RNIB website. The article explores the process of supporting young people who are deafblind or with multi-sensory impairments, to learn about their bodies, emotions, sexuality and relationships with others. Looks at some of the</p>

impairment.	barriers to effective sex education, offers suggestions for practice and a list of useful resources. FOSTER, M. (2005)
Shepherd School	Sex and relationships booklets. The school has produced a series of booklets for children with learning difficulties. Details and order form on the Shepherd School website.
Talking together..... about contraception: a book about contraception for young people with learning disabilities.	Aimed at young people with a learning disability, to help them get advice from someone they trust if they want to: understand their body; make choices about sex and contraception; and make sure they have safe sex. Uses clear pictures and easy-to-read stories to provide information. (Book Two, sold as part of a pack with Book One, 'Talking together..... about contraception: a practical resource for staff and parents working with young people with learning disabilities). London: fpa. (2005)
Talking together... about contraception	This two book pack supports young people with learning disabilities who wish to access contraception. Book one contains a guide to the types of contraception available. Book two has been written for young people and has clear pictures, easy-to-read stories and picture posters.
Talking together... about growing up	This is a workbook for parents of children with learning disabilities. It offers support to parents/carers of children with learning disabilities who are approaching or who are around the age of puberty. The easy to follow style is suitable for young people who may not be able to read. It will also help schools working in partnership with parents.
Talking together... about sex and relationships	This is a practical resource for schools and parents who work with young people with learning disabilities. It uses illustrated stories and activities for use in the classroom to explore a range of situations that young people with learning disabilities face as they grow up. It also has pages for parents/carers so that home and school can work in partnership.
You, your body and sex: the DVD.	20pp. Animated sex education DVD for use by people with learning difficulties. Features content and highlights from all SRE Life Support Productions videos. Contains DVD and booklet. Schools can purchase using e-learning credits. LIFE SUPPORT PRODUCTIONS (2003)

WEBSITES:

Bodysense: www.bodysense.org.uk

Brook: www.brook.org.uk

Centre for HIV and Sexual Health: www.sexualhealthsheffield.co.uk

Contact a Family: www.cafamily.org.uk/packs.html

fpa: www.fpa.org.uk

Life Support Productions: www.lifesupportproductions.co.uk

Me and Us: www.me-and-us.co.uk/index.html

National Curriculum Online: www.nc.uk.net/ld.PSHE_content.html

This section of the website covers planning, teaching and assessing the PSHE and citizenship curriculum for pupils with learning difficulties. It includes advice about approaches to sex education.

NSPCC Publications: www.nspcc.org.uk/Inform/Publications

Pavilion Publishing: www.pavpub.com

Rapport Learning: www.rapportgroup.com

RNIB: www.rnib.org.uk

RNIB Online Shop: <http://onlineshop.rnib.org.uk>

Sex Education Forum: www.ncb.org.uk/sef

Shepherd School: www.shepherdschool.org.uk and www.shep-net.com/site/index.html

Noshin Emamiannaeini

Email: Noshinem@hotmail.com

Joanne Ferry

Email: joanne@aurora-coaching.co.uk

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