

Audit of Sex and Relationships Education and sexual health provision for disabled children and young people

**Commissioned by Bradford Safeguarding Children Board,
2009-10**

**Carried out by Yolande Armstrong, ReFocus Training and
Consultancy**



'Disabled children are 3.4 times more likely to be abused than their peers'

<i>'They are:</i>	<i>3.8 times more likely to be experience neglect</i>
	<i>3.8 times more likely to experience physical abuse</i>
	<i>3.1 times more likely to experience sexual abuse</i>
	<i>3.9 times more likely to experience emotional abuse'</i>

(Sullivan PM, Knutson JF, 2000)

'It is estimated that 33%-50% of all young people who display sexually harmful behaviour have a learning disability or experience significant learning difficulties.'

'Learning disabled young people who demonstrate sexually harmful behaviour are 4 times more likely than their non learning disabled peers to have been sexually abused.'

(Data from NSPCC Disability Scoping Project 2009)

Limiting judgments for Ofsted inspection criteria for schools include the following:

'The effectiveness with which the school promotes equal opportunity and tackles discrimination'

'The effectiveness of safeguarding procedures'

A school is likely to be deemed inadequate if these are inadequate.

(Ofsted – The evaluation schedule for schools - from September 2009)

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I. Executive summary

Audit of Sex and Relationships Education (SRE) and Sexual Health Provision for Disabled Children and Young People, Bradford 2009-10

Summary of main findings:

Previous research shows that disabled children and young people¹ are more likely to experience abuse in various forms, as well as to suffer from bullying, and to lack the knowledge, understanding, skills and confidence which might protect them. Interviews and focus groups were carried out to collect information and opinions from young people, parents and carers and key professionals across the Bradford district. The aim was to find out what young disabled people and their parents and carers want from schools' Sex and Relationships Education and from sexual health services, to see what good practice might look like, and what is actually being delivered. The findings in Bradford show that in spite of some good practice, young people are at risk.²

Bradford young people who took part demonstrated at times a good factual knowledge, but frequently lacked the skills or understanding to protect themselves. On the whole, they wanted the same rights to good information and services as other young people, but clearly faced barriers to accessing these, including negative attitudes by parents/carers and staff about sexual health for disabled people, inaccessibility or inappropriateness of services or information (eg word-heavy leaflets and posters, etc). A few spoke of serious abuse, human rights violations or risky behaviour eg one young woman had been raped, one had been locked in by family. Many professionals gave examples of risky behaviour by young people they had come into contact with.

Findings show that much provision is failing to address the needs of disabled children and young people and that there is a clear need for awareness-raising of the safeguarding issues around sexual health for disabled children and young people. Staff from GPs through to youth workers and teachers have had little or no training in promoting good sexual health for disabled young people, and so are often either reluctant to engage with the subject or are unclear how to do so, or what resources might be available. There is a need for workforce development at all levels and for new and more flexible methods of delivery of sexual health provision.

There is good practice in some areas of SRE in some schools and good support for disabled children in other areas of school life. But overall there is a need for greater understanding, in mainstream schools in particular, of what disabled young people might need in order to be able to access the information on sexual health which is their right and to be able to build skills, positive values and attitudes and understanding. Teaching of certain important topics is either omitted, or does not begin early enough; teaching often does not include opportunity for reinforcement, and is not tailored to the specific needs of some children. Teachers and support

¹ For the purposes of this document the term 'young people' is to be understood to include 'children' except where this is stated.

² Where there is a reference in this report to children being at risk of serious harm, all cases have been dealt with following Bradford Safeguarding Children procedures.

staff have been given little or no training to enable them to develop good practice in SRE with disabled children, and schools are failing to monitor and evaluate teaching and assess learning effectively in this area.

There is evidence that in some schools, and in some faith schools in particular, governing bodies are reluctant to allow even the minimum SRE to be delivered. Many schools are still delivering in ways which were criticised by the Ofsted report on SRE in 2002.

Most parents who took part in the audit positively welcomed support in this area and the opportunity to work more closely with schools in designing an appropriate SRE curriculum for their children. Evidence shows that work should be culturally appropriate and should be designed to meet the needs of certain specific groups such as Deaf young people.

Main recommendations:

A commitment was made in the Bradford JAR report in 2008 to ensure that 'all partners understand and carry out their responsibilities for improving sexual health'. Within the Bradford Children and Young People's Plan one of the priorities is promoting 'healthy life-style choices', which includes sexual health. The Children's Trust partnership has the statutory duty to promote equality and well-being.

This report recommends that the Bradford Safeguarding Children Board take action to influence the Children's Trust Partnership to ensure that they implement the following:³

1. Strategies for promoting good sexual health for disabled children and young people should be established within the Children and Young People's Plan across the authority at the highest level and implementation of those strategies should be prioritised.
2. In order to ensure this, an existing member of each of the ECM Outcomes groups be appointed to adopt the role of Champion to promote and take forward good practice in delivering sexual health services to disabled children and young people.
3. A request be made to the Young People's Sexual Health and Teenage Pregnancy Board to develop a policy for promoting good sexual health for disabled children and young people which will sit alongside the Sexual Health Strategy, and which is owned and acted on by all across the Trust. They should also be asked to support and performance manage policy delivery.
4. A review of systems for gathering and analysing data on sexual health and disabled children be undertaken and a framework should be established for doing this with reference to the Teenage Pregnancy Unit and Public Health Observatory.
5. All organisations who work with children should undertake an annual audit of how their current services promote sexual health for disabled young people, with reference to the policy above.

³ See the full list of fifty one recommendations on p52

6. Core training for all staff who work with children, including awareness of the issues around SRE and sexual health for disabled children and young people and practical and positive forms of support, should be included in the Workforce Development Strategy.
7. A short-term multi-agency task-force should be established to design and deliver such training for work-force development initially, which will then become mainstream.
8. The Safeguarding Disabled Children multi-agency training should include an element on promoting positive sexual health for disabled children and young people.
9. Every agency should evidence how they have involved young people and parents/carers in planning at all levels, using the successful Aiming High model of involving key stakeholders in the design of accessible services.
10. The Strategic SRE Group should be asked, as part of their current remit, to lead on the design and delivery of training for schools, to enable them to design and deliver good quality SRE for disabled children and young people, including training for head teachers and governors and for staff in schools on SRE and their duty within the ECM framework.
11. Bradford Parenting Board should be asked to consider the development of training for parents and carers to enable them to support their children in having good sexual health. This training should be promoted through targeted interventions in localities and schools. [This should apply equally to parents and carers of disabled and non-disabled children]
12. Bradford Safeguarding Children Board should re-launch an up-dated version of the Safe Parenting Handbook, with a section on sexual health and SRE for disabled children. This handbook should be promoted through the Children's Information Link.
13. A central contact and information service should be established with expertise in providing accessible support for staff, for disabled young people and for parents/carers (including accessible leaflets and other resources) and which would be able to provide information and to sign-post them to other appropriate organisations.

For the PCT

14. Flexible and accessible delivery methods of sexual health services should be developed to promote good sexual health for disabled children and young people and to respond to the needs of specific groups or individuals; a forum should be established to share good practice.
15. The Strategic SRE Group should look at provision of SRE for disabled children and young people within the PCT with a view to addressing any gaps.

For Education Bradford, Children's Services and Learning Services

16. Nurseries, children's centres, schools and colleges should be required to include reference to their provision for SRE for disabled children within their statutory Disability Equality Scheme as well as within their SRE policy, including reference to the following: systems for consulting and planning with parents and pupils (secondary) and staff development and monitoring to ensure that good teaching and learning is taking place.

Further work

17. A further piece of work should be undertaken to look at the issues to do with disabled children and young people who present or likely to present sexually harmful behaviours.
18. Further work should be undertaken to look at safeguarding issues for Lesbian, Gay, Bisexual, Transsexual and Questioning (LGBTQ) disabled children and young people.
19. A further piece of work should be undertaken to look at issues for Deaf children and young people in view of the high risk factors which have been identified in relation to this group and the specific communication and learning needs which they have.

The process of the audit

The Bradford Local Authority JAR report (2008) and Bradford Safeguarding Children Board Safeguarding Audit (2008) both recommended identifying and addressing the specific needs of disabled young people in terms of their access to SRE and sexual health services. A multi-agency steering group was established in 2009, an independent consultant was appointed in June 2009 and a three-phase plan was agreed.

Phase 1 Summer 2009 included mapping and gathering information from young people and parents/carers. Focus groups and interviews were held to allow the views of young people themselves and of parents and carers to lead the work. Education fieldwork was conducted across a variety of sites including mainstream and special schools, youth service provision, third sector education provision and health. Interviews with professionals involved in delivering sexual health provision at various levels across the district were carried out.

Phase 2 Autumn 2009 included gathering further information from professionals and agencies. Questionnaires were sent to schools across the district and to relevant other SRE and sexual health service providers and a small research project was undertaken by young people themselves to explore issues of access to sexual health services.

Phase 3 Spring 2010 comprised final information-gathering, a desk study of policy, previous research and good practice in this area, and giving feedback to contributors.

SRE and sexual health sit centrally within the current government priority of promoting the emotional, physical and social well-being of all children and young people, described as a 'cornerstone' of Every Child Matters Outcomes, and which is a statutory duty for Children's Trust partners. Ofsted has made safeguarding a 'limiting judgement' in its inspection and schools must develop an SRE policy in consultation with parents and with pupils at secondary level⁴. Equalities legislation is bringing about a wide range of changes to provide accessible services, and Bradford itself has recently agreed to adopt the Five Principles for creating accessible information across all services (Office for Disability Issues, 2008).

⁴ Plans to make PSHE education statutory in 2011 were part of the legislation recently cut from the Children and Families Bill.

'SRE makes an essential and significant contribution to safeguarding children and young people during their school-age years and into the future.'

(DCSF, Sex and relationships education guidance to schools, Consultation 2010)

The DCSF makes it very clear that, far from promoting promiscuity, good information for young people about how their bodies work and, most importantly, about building good friendships and relationships, is an essential safeguarding tool. Those young people who have developed good knowledge, skills and attitudes and values are less vulnerable to abuse or manipulation.

This is therefore a particularly positive time to review curriculum and delivery and make positive changes.

Thank you to all of the children and young people and parents and carers who have given such honest and open responses. Thank you to the huge number of professionals across a wide range of services who have given precious time to contribute because they believe that this is important. Thank you to the Steering Group who have supported this work. People have spoken out strongly and powerfully because they believe that this is extremely important work. I have attempted to represent this as honestly and clearly as possible. The challenge now is to listen to what has been said and to act on it.

For Bradford Safeguarding Children Board



Yolande Armstrong
ReFocus – Training and Consultancy
March 2010

Steering Group members: Dave Benn (Barnardo's), Claire Whiteley (Young People's Sexual Health and Teenage Pregnancy), Sharda Parthasarathi (NSPCC), Maggie Warwick (Education Bradford), Richard Sutton (Bradford and Airedale Community Health Services), Andrea Medley (Young People's Sexual Health and Teenage Pregnancy)

II. Background to the audit and outline of the process

The Bradford Local Authority JAR report (2008) and Bradford Safeguarding Children Board Safeguarding Audit (2008) both recommended identifying and addressing the specific needs of disabled young people in terms of their access to Sex and Relationship Education (SRE) services and keeping safe. A multi agency steering group was established in 2009 to oversee an audit of SRE and sexual health provision for disabled children and young people across the Bradford district, and an external consultant was appointed in June 2009 to carry out the work.

The following extracts from the DCSF consultation on new guidance for schools to support delivery of SRE explain the context within which the audit was commissioned:

'SRE within PSHE education is an important part of a whole-school approach to pupil well-being. Pupils who are happy in their relationships with peers and adults at school are likely to be better able to learn. By addressing a range of personal and social issues and providing information about where and how to get help, SRE supports pupils who face difficulties to get help and thus helps them to stay on track with learning.'

'SRE is learning about our bodies, our health and our relationships. It should be taught gradually based on factually accurate information (section 2.1).'

'SRE should be set in the context of clear values, including the value of family life, marriage and of loving and stable relationships in bringing up children. It should teach children and young people to develop values, attitudes, personal and social skills, and increase their knowledge and understanding to make informed decisions and life choices (section 2.2).'

'Evidence shows that comprehensive programmes of SRE can have a positive impact on young people's sexual behaviour, helping them to make sense of the sexual messages and imagery around them, to understand risks and consequences and to gain the knowledge and skills they need to stay safe and be healthy (see section 2.4).'

(DCSF, Sex and relationships education guidance to schools, Consultation 2010)

The aims of the audit were:

- To provide an overview of the current curriculum content of sex and relationships education (SRE) available to disabled children and young people across the Bradford district
- To review the quality and relevance of SRE currently offered to disabled children and young people
- To assess the appropriateness and accessibility of the provision of sexual health services for disabled young people in the Bradford district
- To identify and examine good SRE practice nationally/locally and identify gaps in both SRE and sexual health service provision
- To produce a comprehensive report including recommendations for future improved practice and service delivery.

The audit comprises two key areas: Sex and Relationships Education (SRE) and sexual health service provision. The education fieldwork was conducted across a variety of sites including mainstream and special schools, youth service provision, third sector education provision and health.⁵ The sexual health service provision included CASH services, Young People's Information Shop, GP surgeries and the context of the 'You're Welcome' developments and recommendations. It was anticipated that there would be a broad range of partners offering a combination of education and service provision and a key consideration of this audit would be underpinned by an understanding of Fraser competencies for those supporting disabled young people.⁶

The definition of disability was taken to include as wide a spectrum as possible, including children and young people up to the age of 25, and including mild to severe physical and learning disabilities, and Deafness and visual impairment. The focus was on how best to promote safety and well-being for those children who as a result of a long-term physical or mental condition face barriers or a lack of opportunity.

Although some Deaf young people choose not to identify as disabled, it was felt important to include them in this report because of the evidence which suggests that they face specific safeguarding issues as a group. The particular issues round providing accessible information and services for Deaf young people are given a separate section below.⁷

For the purposes of this study, the terms 'children' and 'young people' are used interchangeably to include 'children and young people' except where the context suggests a specific reference.

Stage 1 comprised: focus group discussions with children and young people in both mainstream and special schools, as well as in youth groups; interviews and focus groups with parents and carers; interviews with a wide range of professionals in health, education and social services; a review of current policy and resources available.

Stage 2 comprised: questionnaires for schools and sexual health service providers and other data-collection.

Stage 3 comprised a study of previous research and presentation of the results back to children and young people.

The audit was undertaken within the context of the following broad points made by practitioners in Bradford about the complex nature of disability:

- Disabled children and young people can have widely differing levels of understanding and development which make the use of conventional age-criteria problematic.
- Disability is often linked to other illnesses or communication needs.
- There are enormous differences between mild disability and moderate to severe disabilities.
- There is a huge range of different disabilities – some physical, some Learning Disabilities, some with complex aspects such as Autism.
- Disabled children are more likely to be cared for and supervised by a range of adults, in a range of settings, respite care, etc., or to require intimate personal care.

⁵ Because of time constraints, nurseries, Children's Centres and colleges were not included.

⁶ The Fraser competencies assess whether or not a person has understanding and ability to give consent.

⁷ See p28 below

- Many disabled children and young people don't have access to the rich background knowledge which other young people gather from media, peers, etc. This means that they need to take longer to explore and build up their own background knowledge as part of their learning.
- Many disabled children do not have access to the network of friends and family support which build self-esteem and provide a protective mechanism for other children and young people.
- There is a need for awareness-raising around the Fraser Competencies and questions of consent for families and professionals.

The years 2009 to 2010 are seeing enormous changes taking place across the Bradford authority and education sector. There is an extensive programme of schools re-building, and most importantly the implementation of changes to provision for disabled children which will see more disabled children entering mainstream schools, with considerable re-organisation of special schools taking place at the same time. This is set against a background of change for local authority and health service delivery as working through Integrated Children's Services and Localities has been developed, and the proposed return of responsibility for managing education services to the local authority in 2011.

This piece of work represents an important and innovatory approach by the Bradford Safeguarding Children Board as little research has been undertaken to look at the subject of sexual health and disabled children and young people with specific regard to strategic planning.

III. National Context

i. National policy framework

The DCSF document **Safeguarding disabled children – Practice guidance** (The Children's Society, 2009) states in its introduction that:

'...disabled children have exactly the same human rights to be safe from abuse and neglect, to be protected from harm and achieve the Every Child Matters outcomes as non-disabled children. Disabled children do however require additional action.' (1.3)

It points out that: *'Research and inspection indicate that disabled children face an increased risk of abuse or neglect, yet they are underrepresented in safeguarding systems. Disabled children can be abused and neglected in ways that other children cannot and the early indicators suggestive of abuse or neglect can be more complicated than with the disabled child.'* (1.16)

It includes a set of specific points about sex and relationships education, with several actions which it invites Local Safeguarding Children Boards to consider:

- Seeking a commitment from mainstream and special schools to ensure the statutory elements of SRE are delivered in ways that are accessible to disabled children.
- Encouraging staff in residential schools, care homes and health settings to promote SRE.
- Promoting the dissemination of information for parents and carers of disabled children about SRE.

The development of high quality SRE and promotion of sexual health for disabled children sits at the core of national policy and priorities. They make a direct impact on all five of the ECM outcomes: Be healthy, Stay safe, Enjoy and achieve, Make a positive contribution, Achieve economic well-being, and constitute a crucial element of the new priority of promoting Well Being and Emotional Health as well as the recent emphasis on universality and inclusiveness of provision.

The strategies which have been identified and recommended by the government as the most important for strengthening preventative services to ensure delivery of ECM are particularly relevant: increased support to parents and carers, positive approaches including early intervention, building effective integration of strategy, processes and accountability, and good training for workers.

See Appendix 1 for more on key national policy

ii. Education and SRE

‘Children with SEN (those with and without a statement) are nine times more likely to be permanently excluded from school than other children.’

(DCSF letter to schools 2009)

8 out of 10 disabled children reported that they had been bullied in a survey by MENCAP

(www.mencap.org.uk 2007)

Good practice –

Oak Field School, formerly The Shepherd School, a special school which has long been a centre of pioneering good practice for SRE

The head, David Stewart, explained how twenty five years ago the school set up a Sex Education Monitoring Group with parents, governors, the community, the university. They have produced booklets for parents and for students and have worked with other organisations such as Brook and the Ann Craft Trust to produce resources. They offer training for schools and have been involved in research.

At the core of their success, he said, is a senior leadership team who have control of timetable planning, and the Monitoring Group. The new inspection priorities and the ECM core areas give extra urgency to schools: *‘If you don’t do good SRE, you will be said to be failing.’*

The school delivers SRE through dedicated time each week, but the head emphasised the difference between teaching knowledge and promoting the ability to make good choices, for instance: *‘Some skills-building has to permeate every lesson.’* SRE teaching begins in the Nursery and runs through to Sixth Form.

He stressed that *‘open and honest discussion’* is crucial. Building good friendships is at the centre of their work. Lacking friends *‘makes you vulnerable and likely to be abused.’* Having physical contact with other human beings, he pointed out, is a *‘fundamental need’*, so to teach that all touching is dangerous is potentially emotional deprivation. *‘If you’ve never been cuddled, if noone’s ever touched you... you are open to abuse.’*

(From an interview with David Stewart, headteacher, for this audit, December 2009)

Educational priorities

The Children and Young People’s Bill which was recently passed by parliament highlights the priorities which have been established within the Every Child Matters agenda. Schools are at the centre of service delivery and partnership working which provides access for the whole community to a range of services, through which families can negotiate the path which suits their individual needs.

Well-being of children and young people is a central concern for government and society. The three broad aims of the National Curriculum for secondary schools, which should inform all aspects of teaching and learning and should be the starting point for curriculum design, are

designed to enable pupils to become:

- *successful learners who enjoy learning, make progress and achieve*
- *confident individuals who are able to live safe, healthy and fulfilling lives*
- *responsible citizens who make a positive contribution to society.*⁸

There is a requirement under the Disability Discrimination Act 2005 for schools to make 'reasonable adjustments' to prevent discrimination against disabled children.

Brian Lamb's report in 2009 called for all school inspectors to receive training on SEN and disability, and for the recruitment of additional inspectors with skills in particular areas, such as teachers of the Deaf (Lamb, 2009). He also called for a major training programme for local authority staff on how to reflect the views of parents and young people in statements. Lamb draws attention to the growing closer scrutiny of provision for disabled children and young people which has been developing over the past years. In response to this report, the new Ofsted duty to inspect on SEN provision was introduced.

School governors have a statutory duty to promote the well-being of pupils and Ofsted inspections currently focus on the following elements amongst others

- The extent to which pupils adopt healthy lifestyles (p9)
- The extent to which the curriculum meets pupils' needs (p10)
- The effectiveness of safeguarding procedures (p10)

No school can now be deemed to be adequate by Ofsted unless safeguarding policies and procedures are in place. (The Framework for School Inspection 2009)

Sex and Relationships Education (SRE)

All schools must have a written policy on SRE. The governing body must decide on the content and organisation of their SRE provision, and inform parents about it.

SRE covers three main areas: Personal and Social Skills, Knowledge and Understanding, and Values and Attitudes. Within these, it includes a range of topics – building friendships and understanding feelings, as well as information about bodily functions and sexual development and teaching on staying safe. Schools have considerable freedom as to which elements they include or which they emphasise. The choices which they make depend on the school, its teaching staff, its governing body and its community.

Teaching about sex and relationships is currently included under Personal, Social, Health and Economic education, though the Science curriculum also includes specific statutory elements. The SEAL programme, for Social and Emotional Aspects of Learning, has been almost universally-adopted in primary schools in particular and provides a framework and ideas for promoting social and emotional skills.⁹ Although SEAL includes many of the elements of primary PSHE, it does not cover certain other essential SRE topics.

⁸ The Rose report recommended extending this to primary schools, but the new proposed primary curriculum was cut from the Children and Families Bill as a casualty of the 'wash-up' as a result of the election.

⁹ Available to download from <http://nationalstrategies.standards.dcsf.gov.uk/primary/publications/banda/seal>

New guidance was issued for consultation to schools on delivering SRE in 2010, covering all aspects which schools need to consider when planning for SRE teaching and including the following point:

'Schools should ensure that SRE is accessible to all pupils including those with special educational needs (SEN).' (2.3).

It notes that:

'Evidence shows that comprehensive programmes of SRE can have a positive impact on young people's sexual behaviour, helping them to make sense of the sexual messages and imagery around them, to understand risks and consequences and to gain the knowledge and skills they need to stay safe and be healthy.' (2.4)

It also includes the following broader comments in the context of the pressures which face young people:

'Far from "destroying their innocence" SRE equips children and young people with the values, skills and knowledge to understand and deal appropriately with these social and cultural pressures.'

SRE makes an essential and significant contribution to safeguarding children and young people during their school-age years and into the future. SRE should enable young people to develop skills and confidence to access professional advice and appropriate health services. It enables children to understand their physical and emotional development and enable young people to take increasing responsibility for their own health and wellbeing and that of others.' (1.3)

Commenting on delivery methods it says:

'Young people have said that the quality of SRE in school is very variable. More than 20,000 young people responded to a survey carried out by the UK Youth Parliament in 2007 and 40% judged their school SRE to be 'poor' or 'very poor.' (2.5)

'Young people consulted by the Sex Education Forum said that teachers must be better trained because they are often embarrassed and un-informed. They said that topics such as puberty and the biology of sex and reproduction are often well taught – but that less factual topics such as skills for coping with relationships were neglected.' (2.5)

It includes a wide range of topics including involving parents, case studies of good practice, comments on sexual, sexist, homophobic and transphobic bullying and advice on curriculum planning.

It passes on the following advice from Ofsted on good practice:

'In school inspections Ofsted have found that standards in PSHE education are improving. In many schools SRE was taught well, but in other schools it was inadequate (ref PSHE Time for Change, 2007). Ofsted advise that:

- *teaching of SRE is at its best when taught by trained and specialised teachers*
- *SRE needs to be planned and delivered within a PSHE education programme which is adequately timetabled and not taught through 'drop-down' days alone*
- *assessment of what children and young people are learning in SRE needs to be improved*

- *more time should be spent helping children and young people to develop the skills and confidence they need to manage the real-life situations they face in their daily lives (2.5)*

(DCSF, Sex and relationships education guidance to schools, Consultation 2010)

Good practice – SRE in a mainstream school in Bradford

Titus Salt Secondary School, Shipley, has Designated Specialist Provision for young people with complex learning difficulties and disabilities within the mainstream school.

The Inclusion Manager, outlined their approach to SRE: *'The general programme is not applicable – it needs to be delivered in a different way, with a range of materials and sources. It is important to structure it and put it in small steps.'*

There is a separate base for the young people with learning difficulties, so that they can attend many lessons in mainstream classes, but have some separately. Besides teaching basics in science, the APAUSE programme is co-taught for Year 9 and 10 students by form teachers and health professionals, and there are follow-up sessions led by trained Sixth Form students.

But for students with learning difficulties, there is *'a fair amount of autonomy – they need over-learning.'* They do lots of work on building relationships, and particularly with Year 8 boys, repeated work exploring questions of public and private behaviour. The school is still exploring how best to deliver work to help with the challenges for young people who have different concepts of time in understanding how to prepare for puberty and menstruation.

The Inclusion Manager has taken the Speakeasy (FPA) course and found it very good for developing her own understanding, but is still seeking appropriate resources – *'Not babyish, but which can be manipulated and adapted... interactive resources and videos for use with interactive whiteboards.'* Many resources, she explained, even those designed for disabled children, say *'Discuss this'* or *'Talk about that'*, but many children are not able to do that and might need visual resources.

(Taken from interview with Inclusion Manager as part of this audit, February 2010)

iii Safeguarding and sexual health for disabled children and young people

'I didn't get Sex education until I was 15 years of age, but I started having sex at about 12 years of age.'

Leonard Cheshire Disability *In Touch* project, response from 18 year old female focus group member

Good practice – Them Wifies presents Josephine – *Let's talk about sex! 'n' stuff*

Josephine is a life-size puppet created by a community arts organisation in Newcastle upon Tyne as a learning resource for women with learning disabilities.

Josephine enables women to explore thoughts and feelings about topics such as personal hygiene, periods, sexual rights and choices. She has a detachable breast which can be felt for lumps, a feelings and thoughts bag, a clitoris that squeaks and a tummy which opens up to show all of her important organs. She is able to share insights through her diary to show how she herself has learned some of the things which it important for all women to know about in order to feel confident and safe. She can lead practical drama workshops in all kinds of settings.

Them Wifies are available for workshops and are looking at ways to develop the model of their work in other areas of the country.

Very little research has been done on sexual health and disabled children and young people. Most of the research on disabled people and sexuality has focused on disabled adults and mainly those with learning disabilities, but some of this gives a perspective on work with children and some important studies are now being undertaken which explore and give voice to young people's ideas too. Some reveal safeguarding issues, some challenge perceptions. It is important to note that the difficulties which adults face are compounded for children and young people, who often have very little scope for autonomy.

The Leonard Cheshire Disability project called *In Touch* has recently been given an award by Brook as the best sexual health project in the UK. It has collected responses from workshops and approximately 479 questionnaires from disabled young people. Final results have not been published yet, but its Year 2 report shows, for instance, that while more disabled than non-disabled respondents had never received SRE or advice, more than half of those who did receive SRE in school did not find it useful. The disabled young people who took part were overwhelmingly enthusiastic about getting information and a chance to discuss issues around sexual health. In Year 3, the project will develop resources including an inter-active web-site and an inter-active multimedia game which will encourage young people to consider a range of problems to do with sexual health and relationships.¹⁰

A three-year research project led by Leeds-based disability rights charity CHANGE and informed and shaped by the views of young people with learning disabilities, parents and

¹⁰ See the web-site for up-to-date information and sample DVD material: www.lcdintouch.org

teachers, found that young people needed to be better informed about same sex relationships, abuse and the difference between public and private spaces, amongst other topics. The report calls for SRE to be provided at a level that those with learning disabilities can understand and recommends that professionals should be given better training to understand the needs of young people with learning disabilities, especially those with the most complex needs. It calls for more support for young people with learning disabilities in mainstream schools and urges that the topic of pleasure, and not just biological aspects, be included in sex education. (CHANGE, 2010) ¹¹

People Should Tell You Stuff for NHS Scotland reports on a consultation with young people with learning disabilities to find out what would support them in sex, relationships and understanding how their bodies change as they become adults. It aims to be thought-provoking and notes the stereotyping which has surrounded people with learning disabilities as either not sexual or overly sexed, and the fact that people with learning disabilities are more likely to experience violence and abuse including sexual violence and abuse.

Through discussions with young people, the theme of key people or 'gatekeepers' emerges, and the need for services to get to the young people rather than expecting the young people to get to them. The discussions cover topics such as Feelings, Being Gay or Lesbian, Masturbation, Pregnancy, Contraception.

Many of the young people who took part either didn't know about or didn't use the specialist young people's services. What they wanted was somewhere not just for disabled young people, somewhere free, not simply about sexual health, a place where you can get help, advice and encouragement. The report concludes that, in fact, the responses from the young people are very much the same as you would expect from any other group of young people and that they should be seen as young people first, and the barriers which they face in accessing services should be addressed.

The report makes the point that learning the skills for healthy and happy relationships, and accessing services to support this, cannot be effectively done in fixed, time-tabled slots. It also notes the importance of language-use and exploring different uses of vocabulary in different contexts. (TASC, 2005)

Some research has looked at issues of abuse and disabled children and young people. *It Doesn't Happen to Disabled Children* explores the factors which create disabled children's vulnerability to abuse and some of the reasons behind the failures of protective systems:

Barriers to the effective protection of disabled children from abuse are identified at all stages of the child protection process – from referral all the way through to taking action. As the authors [of Chapter 2] explain, sometimes these barriers are organisational, such as the failure to provide the additional time and resources that are often necessary to communicate effectively with disabled children and to carry out high quality assessments. Sometimes, however, the barrier is to be found in the attitudes that professionals bring to situations of suspected abuse. As they write: "We still come across situations where child care professionals do not believe anyone would abuse a disabled child; where the child's pain and distress is not recognised; where abusive practices are seen to be necessary because of the child's impairment. (National Working Group on Child Protection and Disability, 2003)

¹¹ CHANGE has also produced booklets for young people on sexual abuse, safe sex, friendships and relationships, sex and masturbation, and same sex relationships.

In *Disabled Children and Abuse*, David Miller shows that very little research has been undertaken in the UK in respect of abuse and protection with regard to disabled children, that significant numbers of local authorities do not collect data in relation to disabled children who are subject to the child protection process, and that disabled children are over-represented in the population of Looked After children. Miller lists a number of reasons for the increased vulnerability of disabled children, including lack of awareness amongst carers, professionals and the general public of the vulnerability of disabled children and indicators of abuse, lack of comprehensive and multi-agency assessments and planning in relation to need at an early age, lack of effective sex education or safety and awareness work with children. The study calls for key strategies including a national safeguarding strategy to raise awareness, to be developed in the context of the Social Model of Disability, a review of training needs of staff, and the development of sex education programmes with specific relevance to disabled children. (Miller, 2002)

No Sign of Harm: Issues for Disabled Children Communicating About Abuse explores the views of professionals working with children using alternative/augmented communication systems on the issues relating to communication about abuse. It explores the challenges of establishing systems which enable children themselves to communicate abuse, including the children's own ability to understand certain concepts. (Oosterhoorn, Kendrick, 2001)

The need for appropriate training and increased coordination between social work, health and education is highlighted. *Safeguarding Disabled Children in Residential Settings* draws together information from research carried out on abuse and disabled children with particular reference to those in residential homes, and makes a plea for better data-collection and monitoring to support good practice. (Paul, Cawson, 2002)

Safeguarding issues for Deaf young people were publicised in *Sexual Abuse of Deaf Youth and Survey of Deaf People's health habits – British Deaf Association 1995* – which contain data which reveal particularly high levels of risky behaviour and reported abuse in Deaf young people. (Sullivan, Vernon, Scanlan, 1987) A new study looks specifically at SRE for Deaf children and concludes that Deaf children especially require continuous, age-appropriate guidance and support in learning about issues related to growing up. Results show that Deaf children are at an increased risk of being over-protected and missing out on accurate information. The study suggests that parents might benefit from SRE workshops to enable them to become more active agents in their child's sex and relationships education. (Suter, 2009)¹²

Good practice in working with Deaf young people is demonstrated in the evaluation of the Bradford pilot sexual health course for Deaf young people which notes the success which this project had in promoting knowledge and understanding of good sexual health: *'The majority of the young people commented that they now felt more confident in being able to make decisions about sexual health and for some of the young people that they felt more 'in control' and able to negotiate possible sexual relationships.'* The study recommends that the course should continue, with a follow-up to look at learning after six months, and offers other options such as booster sessions and another similar course to be offered to younger people. (Mills, Sugden, Dowling, 2004)¹³

¹² This report is as yet unpublished but more information can be found at www.sre-research.com

¹³ These recommendations were not implemented at the time, but could become part of the wider strategy recommended by this report.

Finally, two books with a broader range. *Sexuality Education: Building a Foundation for Healthy Attitudes (Part 1)* by Terri Couwenhoven offers support to parents of children with Down Syndrome but also gives a wealth of insights for everyone who has contact with disabled children. (Couwenhoven, 2001). *Holding on, Letting go – Sex, Sexuality and People with Learning Disabilities* was written to support parents and carers of people with learning disabilities to feel more comfortable and confident when thinking about sex and sexuality in relation to their son or daughter, and contains a wealth of information and experience gathered from work in this field over a number of years. It contains lots of examples of how people with learning disabilities feel about sex and relationships, and many ways for parents to develop their own thinking and feelings too. It makes a plea that sex and sexuality work with people with learning disabilities should be seen not as a 'luxury' but as a necessity. (Drury, Hutchinson, Wright, 2000)

For more on research into sexual health for disabled adults which highlights issues for children and young people, see Appendix 2.

Good Practice – SRE Curriculum development in Bradford

A newly-appointed PSHE coordinator in a Bradford special school explained how a recent CPD course run by the PSHE Team at Education Bradford had helped her to re-think what they deliver: *'We're not doing what we need to safeguard our children.'*

She now believes that public/private touching, for instance, needs to be taught explicitly, with learning outcomes which can be monitored. *'There's been an acceptance of certain behaviours because a child has a disability, but we're not doing the right thing by them – we're not allowing them to integrate into society.'* Good teaching needs to begin in the early years. Even though the cognitive aspects of the work might be challenging, *'Individual children need to build their routines which are their lifelines, to become less scared of what will happen in the future... If inappropriate touching is happening later, it's as a result of avoidance in early years... We're now developing a new Safe Touch Policy and trying to get parents to agree what is acceptable.'*

She described how she is now working with the school nurse to explore ways to develop appropriate resources for use with children with Autism, using Social Stories, for instance. The SEAL framework which the whole school uses also provides good ideas for developing skills such as building friendships, and for some children these need a huge amount of reinforcement – praise for sharing a piece of puzzle with someone or holding a door open. She also found that the SEAL rules of 'Eyes for looking, ears for hearing, mouth to speak, head to think, hands in lap to concentrate' helped her children to avoid distracting or challenging behavior such as touching a friend or touching themselves inappropriately. For children who cannot understand, positive rules like this are very helpful.

The school has adopted the Equal curriculum, but is planning to adapt the PSHE work: at present, the module on puberty does not come until KS3, but the school now feels that this needs to be begun much earlier to really give children time to explore some concepts such as bodily development.

One of her aims as PSHE coordinator is to *'enlighten'* other staff, to help them to understand how much they already do which they might not have realized is SRE, but also to realize how much more they can achieve with an explicit focus on certain crucial elements of the curriculum.

If these things are not explored in a clear way with children, she believes, *'It leaves them open to abuse.'*

IV. Results of the Bradford Audit

'It's great that you're doing this – you can't hide behind blinkers – if there's any support, lots of parents need it – it would be fantastic.'

Father of one boy with a diagnosed disability and one boy currently being assessed.

i Interviews and focus groups – an overview

This section includes views and opinions from focus groups held with young people, and from focus groups and interviews with parents and carers and with professionals across the district. See Appendix 3 for more about how the work was conducted.

The key questions which were asked:

- What should disabled children and young people know?
- What is the best way for them to learn this?
- What specific challenges are young people and their families facing?
- How can current services be improved?

These are some of the main findings:

- There is a great deal of evidence to show that inappropriate SRE delivery and lack of accessible support to enable young disabled people in the district to develop good sexual health practices can cause them to be extremely vulnerable.
- There is evidence to show that lack of support and help for parents is causing distress to parents and families and to young people themselves.
- While some young people are, as the result of the nature of their disability, extremely vulnerable to abuse, there are others, who, without adequate support and because of the nature of their disability, might be at risk of presenting sexually harmful behaviour. It is clearly essential for all professionals to understand the extremely serious implications of this.
- Very little data is kept to show the issues around sexual health faced by disabled children in the district. At all levels of work within the local authority there has been a lack of priority given to sexual health issues for disabled children and young people. Some excellent work is taking place within the district, but this good practice has not yet been integrated into general practice.
- No parent said that they had been approached in a pro-active manner by the agencies which support their children's needs to discuss the subject of sexual health. They reported that the topic is not raised unless or until there is a problem.
- There is still reluctance amongst some professionals and some parents to engage positively with sexual health issues for disabled children. Many professionals working with disabled

children said that either they or their colleagues lack confidence in dealing with disability issues or in dealing with sexual health issues. Many have had very little training to support their work in one or both of these areas.

- There is currently no dedicated training for sexual health and disability available for staff in residential units or for workers in social care. There is evidence of lack of deaf-awareness in some of the youth services which provide for Deaf young people. One youth club has failed even to provide a visual fire-alarm.
- Increasing numbers of disabled children and young people are entering mainstream schools as the positive result of policies which aim to increase inclusiveness but no training has been delivered to support schools to deliver SRE effectively to them. There are perceptions within some groups that mainstream schools are failing disabled children.
- SRE delivery methods vary widely across schools in the district and this means that some children are getting very little good SRE provision. It is usual for SRE to be delivered in fairly large mixed-ability groups in mainstream schools, and there is evidence that some disabled children are withdrawn from these lessons because they would not be able to understand, though alternative provision is not offered. Curriculum content is frequently not appropriate and some SRE delivery methods used are not accessible for disabled children in terms of teaching methods used or in terms of the time allowed for embedding knowledge.
- Although it is acknowledged by parents and by health professionals that establishing good habits of sexual health from an early age is particularly important for some disabled children, very little support is offered to parents with young children. This is possibly because SRE and sexual health topics are still generally seen as only becoming an issue at puberty, but this is much too late for disabled children.
- The circumstances surrounding sexual health and Deaf young people require specific and urgent consideration. It was suggested that a separate piece of work should be undertaken to explore this.
- Evidence suggests that there are additional challenges faced by LGBT disabled children and young people and that schools are not providing adequate support for these young people. There is a need for further information in this topic.
- There is a lack of appropriate resources for some groups eg Deaf young people who use BSL.
- There is a need for specific consideration of the subject with regard to certain communities, such as the South East Asian communities, and a need for on-going dialogue with faith groups.
- Different cultural contexts can create different issues: disabled young people in South East Asian communities, for instance, might be allowed less opportunity to socialise outside the family, but might be expected to marry if they are able to carry out what are seen as the functions of marriage; in other communities, they might have more freedom to socialise, but there might be less expectation that they will build long-term relationships or will marry.
- Evidence suggests that establishing sexual health services which could go out to places used by disabled young people might be one of the most effective ways of delivering.

Good practice – Teen LifeCheck in Bradford

A dozen notebook computers have been bought by the Health and Equality Team in Bradford to give young people easy access to the national NHS Teen LifeCheck which will help young people to find out more about health and personal issues including sexual health.

A senior manager from Integrated Youth Services explained how, by using a medium which young people are familiar with, and being able to go out to events such as large-scale city-centre events where young people are, they are *'opening some of those doors to accessibility.'*

Although the Teen LifeCheck might not be easy for many disabled young people to use without help, the flexibility of this idea suggests how information can be made more accessible for them.

ii. What the children and young people said

Compiled from initial interviews with disabled children and young people

Focus groups were held with 39 young people between the ages of thirteen and eighteen in schools and youth settings. The design of sessions for all groups was the same, though they were adapted according to the young people's abilities and needs. A small research project was also set up to look at accessibility of sexual health advice centres.

The sessions were designed to give the young people the opportunity to take a lead in the audit by defining the issues which they thought were important and making suggestions about good practice and improvements. They aimed to:

- Explore the young people's own knowledge as a context for the discussion
- Find out what they felt it was important for young people to know about in the area of sexual health and how they thought these things should be taught
- Find out what problems they knew about which young people similar to themselves were experiencing and where they felt would be good places to go for help or advice
- Set up a small action research project where the young people could explore how it felt to use some of the sexual health services already in place.

All the young people involved were extremely helpful and many of them were admirably honest and forth-coming. They all made an important contribution.

It was felt that, given the scope of the present work and the constraints on time, it would not be realistic to attempt to work with young people with extremely challenging communication needs: it has to be acknowledged that this requires time and relationship-building. This acknowledgment itself makes an important point about good practice. There were also some students within the groups who were able to communicate in limited ways only or who

demonstrated little understanding of the subjects discussed, so the responses recorded tend to represent the views of more articulate groups and individuals.

As in any research, it is important to be aware that some answers might reflect a sense of what the young people believe are the 'right' ones. Occasionally this seemed to conflict with what might be a realistic response: one group of young women, for instance, said that they would go for help to the police if someone asked them to get into their car. As it is unlikely that they would actually have the number for the police, or be able to contact someone easily, this shows the difficulty of distinguishing between what young people think is a correct response and evidence that the skills are in place to avoid risk.

Given the constraints on the work, it was felt to be unrealistic to expect the young people to reveal some of the more personal issues around relationships and feelings which professionals have said cause worry to the young people they meet.

Case study –

An eighteen-year-old young woman with learning disabilities revealed during the focus group sessions some of the extremely serious risks which disabled young people are dealing with.

She included the following on her list of the things which she felt that young people should be taught about: Keeping safe eg from getting pregnant, touching, infections, rape.

She said that she also felt that they should be given support to make *'relationships – good ones, not violent ones'*.

Some of the problems which she said, in her experience, young people faced were: *Getting pregnant, Getting beaten up, Not being let out of the house, Boyfriends cheating on you, Being out and about – men only wanting three things – sex, money and to get you pregnant.*

When asked about SRE she said that she had had *'nothing'* in her previous school. Since then, at her current school, she has been given time and a great deal of support and is now able to speak confidently about many sexual health issues and her own needs.

(This young woman had been raped when she was younger and was clearly still distressed about some of the things which had happened to her.)

Brief summary of results:

Of the young people who were able to respond, given the constraints of the work:

- Most felt that all young people should be given a broad knowledge of sexual health issues.
- On the whole, they felt that this should be taught in school.
- Knowledge of key factual information about sexual health topics from the SRE curriculum was good for some students with learning difficulties and mild learning disabilities.
- Most of those students knew of places and/or people to go to outside their family for help or advice, though there was a sense with some that they were giving the answer which they knew was the 'right' one and they might not actually be able to access this help.
- For students with moderate to severe learning disabilities knowledge was limited.
- There was evidence to suggest that even where factual knowledge is in place, the skills and understanding which prevent risky behaviour are lacking.

- There was evidence, from the problems which the students listed, to suggest serious safeguarding issues.
- There was evidence to suggest that some schools are delivering useful SRE lessons while others might not be.
- It was difficult in such a short time-span to talk about really private issues – very little discussion was had about learning how to build good relationships, for instance, or worries about finding a girl-friend or boy-friend, which are some of the key issues which were noted by professionals who work with young people.
- The problems of communicating with some of the students highlight the challenges of providing accessible SRE and sexual health provision. Although some students appeared chatty and knowledgeable, they did not know the meaning of words such as ‘vagina’ and ‘menstruation’. The specific challenges of communicating with Deaf young people and especially those who use British Sign Language to communicate are dealt with below.
- Advice centres which sign-post to sexual health services which cater for young people are accessible to these young people in some important ways, in their friendly atmosphere for instance, though there is no evidence that disabled young people would have found their way there without being taken as part of this project.
- Within the advice centres, although staff were very welcoming, there was very little awareness of the type of support which these young people would need in order to be able to access services. The young people reported that staff spoke too fast, and that the leaflets had too many words. Facilitators noted too that individual young people were not offered time to sit down and really explain what they wanted, and were mainly directed to leaflets or given printed information.

What young people should know and where should they learn it:

All of the young people spoke with expectations of having girlfriends or boyfriends or married relationships. Some were already sexually active and one young woman was engaged and planning for her marriage.

Generally, the young people felt that it is important to know about a wide range of the topics which are covered by the SRE curriculum – including keeping safe, puberty, periods and erections, contraception, pregnancy and married relationships. The general opinion was that Year 5 or Year 6 would be the best time to learn about most of these things, though this might be because they themselves had covered these topics then.

Most of the young people felt that these things should be taught in schools, but in single sex groups or possibly in small groups. One young Asian woman described a science lesson dealing with periods in a mixed sex group: *‘It was so embarrassing we felt like walking out.’* In a group of younger Muslim boys, some felt that it is not important for boys to learn to look after babies. Some said that they would prefer to learn from mums or siblings, or from friends for some things. Some would like a professional to come in, but when asked if the school nurse could do this, two groups said that they had never seen the school nurse.

Some had clearly enjoyed their SRE lessons and one small group had been shown how to do a urine test for Chlamydia. A great deal of the success of these lessons seems to have been to do with individual teachers. One boy had given a presentation on testicular cancer in science.

For others it had not been so positive. One young woman said: *‘At my old school I got nothing.’* She felt that this had put her at risk.

One young man commented on the total lack of information about same-sex relationships and LGBT issues in his lessons: *'The Pope thinks it's evil ... you can't help your feelings.'*

Problems and safeguarding issues:

Staying safe and using contraception was seen as the most important problem in many groups. The reality of having sexual intercourse and knowing what to do was a *'big worry'*.

There were a whole range of other very real worries such as how to tell your mum that you've started your period, how to tell her you've had sex, worries about how your body looks or about what someone might say about you after you've had sex with them, whether to use condoms and pressure from partners or local 'culture' not to do so, at-risk behaviour caused by drink or drugs, getting STIs, getting testicular or cervical cancer, hygiene questions.

In three groups abortion was seen as an important issue, and one girl explained that *'They say it doesn't happen in Asian communities ...'* but she and her friend agreed that it does.

Some of the more serious problems which were presented were rape, being beaten up, being frightened to get married because of the possibility of violence, being exploited by an older or more persuasive partner. One young woman repeatedly insisted that if an attractive man drove up in a car, she would get in and go with him if he asked.

Where to find help:

The person or place they would go to for help varied according to the issue. Either mum or a GP were most frequently mentioned.¹⁴ In the most vocal and street-wise groups, several knew about local clinics. One knew about the Information Shop for Young People in Bradford. Some would ask teachers – this depended on their previous experiences: one group had clearly respected and liked their teacher, but some said *'Don't trust them'* and *'They'd blab to other teachers.'* One group was adamant that they would not go to their dad; *'Don't see him,' 'Don't live with him,' 'Too strict,' 'It's not what you talk to him about.'* One boy said; *'Sometimes parents can't talk to their children – not a lot do – they're too embarrassed.'*

Some young people clearly had good practical knowledge eg if you think you might be pregnant *'You can get a pregnancy test from the chemist for about £10 or go to the doctors' or Health Centre.'* They could talk knowledgeably about the cap, the coil, injections, implants and some had personal experience of using these. Many had good networks of support including sisters, aunties, or social workers. Others either had misunderstandings (that *'pee'* rather than sperm comes out when you masturbate) or were not able to articulate their views.

There was evidence that some young people have been scared by information which they have been given by parents, about catching diseases or about the law and under-age sex, for instance, and have been unable to have a discussion with anyone to resolve their fears.

¹⁴ Though the Scottish survey People Should Tell You Stuff found that most young people with a learning disability were actually unlikely to go to their GP alone (TASC, 2005)

Deaf young people:

45.8% of deaf girls and 42.4% deaf boys exposed to unwanted sexual experiences.

49% didn't tell. 11% were not believed.

(Kvam, 2004)

The issues for Deaf young people whose first language is BSL are particularly challenging. Some do not have adults at home who sign, some have families who speak little English. But more than that, there is a barrier because the signing for communicating around sexual topics is quite graphic, which can make communication with a parent or other adult challenging. This might also make it hard for young people to understand conceptual differences between medical or generally accepted vocabulary and signing equivalents.

The small group of Deaf young men aged 16-plus who took part in the focus-group suggested that there is a high level of sexual activity amongst Deaf young people from all communities and they mentioned a high conception rate too.¹⁵

Some of the young men had a good factual knowledge of technical aspects of sexual health such as how to use condoms, body parts, menstruation, which they had learnt at school. They all felt, however, that teaching in school had not been adequate to equip them for a healthy sexual adult life. There had not been enough time, and one young man emphasised the need for reiteration to enable young people to keep exploring the relevant issue at different stages of their development. They had been left with unanswered questions with nowhere where they felt safe to ask.

One young man described the difficulty of communicating useful information to Deaf young people. He had seen posters in English at the youth centre about free contraception, but he explained that most Deaf young people would either misunderstand or ignore them as they weren't powerful enough to catch their attention.

They felt that Deaf young people would be unlikely to go to a clinic for advice. They described the lack of trust which many Deaf young people feel for those who are hearing and do not use BSL. In order to communicate they would need an interpreter, but to get somebody they could trust when they want to discuss personal or confidential matters would be difficult and could cost money.

They were adamant that they would not discuss sexual matters with their parents. One young man explained that he is not allowed to talk about these things, and another explained that his family is strict and over-protective, so he wasn't allowed to know about these topics. He talked about the difficulty of trying to explain to parents that they need support to deal with these cultural differences. One young man whose factual knowledge seemed to be less, explained that because he doesn't know about things, he does not feel confident.

Certain important things emerged from the discussion. There were serious gaps in their knowledge and understanding and there were things which they worried about. What might

¹⁵ Although a focus group was planned in one school for Deaf young people, it was unable to take place because parents failed to return permission slips. This failure might have been because of concern over what would be discussed; it might relate to the culture of the majority of parents, and specific issues around delivery of SRE; there might be other factors.

have been helpful was the opportunity to discuss and explore these issues in a free and open way, but, for various reasons, this was not being offered to them in a way which was accessible.

They emphasised that the best way to learn about things for them would be through a sexual health adviser running sessions at the youth club, and possibly using a DVD and with one-to-one sessions on offer.

Test the Service - young people's research findings:

The young people carried out three small research projects to find out how accessible sexual health services were for them. The results below are a combination of the young people's own experiences with the observations by the facilitator.

1. Test by 18 year-old young woman with moderate learning disabilities from a special school who rang a local advice centre for young people –

- She was able to explain that she wanted advice about 'keeping safe' and that she was from a special school.
- She was invited to go in and talk to someone.
- She was given instructions which she could understand about where to go.
- She was offered leaflets and face-to-face advice about keeping safe.
- She was given the opening times, but could not write them down.

Her comments:

It was helpful that *'They said Hi and what's your name? Where do you come from?...They said thanks'*.

It was not helpful that she had to wait for a while to be passed from one person to another and that *'They talked too fastly.'*

Would she feel ok about going there? *'Yes.'*

2. Test by a group of twelve Year 11 students with learning difficulties and mild learning disabilities in mainstream school who visited an advice centre for young people in central Bradford.

Students were given a scoring sheet and could award a maximum of three dot-shaped stickers for each category: Can I get there? Can I make an appointment? Do staff make me feel welcome? Is it confidential? Do they listen to my problems and give useful advice? Do they say or write things in ways which I can understand? Do I feel comfortable there? What would make it better?

The advice centre in central Bradford scored highly in almost every category. But there were concerns about the question 'Do they say or write things in ways that I can understand?' where three students gave low scores. Comments included the following:

'I don't think it need to be better. I think it's good. Also I think they're lovely people.'

'I don't think it could be better, but could make it easier to understand.'

'Simpler leaflets.'

Although some students collected leaflets, it was done in a random way and it seemed unlikely that they would actually read them later.

3. Test by a group of three 18-year-old female students with moderate to severe learning disabilities from a special school including one wheel-chair user who visited a local advice centre.

Again the lowest score was for the question about whether services gave spoken or written information in ways which students could understand', although two students scored low for feeling comfortable in the place. Comments included: *'Give me some more information about it [in accessible form], 'More pictures and more understanding – better writing, less words.'*

Students responded very positively to the services on the whole, though they had not been taken to the venues as part of their SRE work and only a very small number had already visited the services, so they might not have found their way there on their own.

In all cases staff were friendly and helpful. It was clear, however, from the students' comments and from facilitator observation, that the real needs of this group of young people were not being fully met. They were not invited, for instance, to sit down and take time to explain what they really needed when they first went in, although staff at the central Bradford service later offered one-to-one time to discuss Chlamydia testing. The young people were directed to leaflets or given written information about session times but although they collected lots of these, many of them were clear that they would not actually read them, and one group gave all of theirs to the facilitator when they had left.

Overall conclusions from the young people's responses:

Most of the young people had expectations or hopes about being involved in sexual relationships. Some had clear ideas about sexual health and what it is helpful to know.

Some young people had good levels of factual knowledge and this probably reflects either good teaching or good talking at home. But what was clearly lacking was the skills and development which would enable them to practise good sexual health into adulthood. In some cases there was evidence suggesting that this made them extremely vulnerable.

Sexual health services are offering the right type of service for some, but staff would benefit from training to support them to identify clients with disabilities who might need extra help. There is also a need for appropriate, accessible resources and for a more flexible service to meet the needs of those who, for various reasons, would not be able to or choose to visit a clinic.

Myths and prejudice – Children’s Learning Disability Nurse, Leeds

‘There are still lots of myths around disabled children – that they are victims, predatory, or animalistic. We want equity – not just for ticking boxes. Disabled young people are twice as likely to suffer from low self-esteem. SRE covers the whole identity and being of an individual.

Lots of people get stressed about pre-pubescent girls coming up to menstruation – putting them on Depo-Provera because they think they can’t cope. It’s bad practice – there’s evidence from other countries of a link with obesity and depression.

People have low expectations – the first time [young women menstruate] they might struggle, but people expect them to learn straight away and if they don’t they think they can’t cope... It’s the start of womanhood! People [ie parents/carers] struggle with it emotionally – too many professionals let that cloud their judgement.’

The Children’s Learning Disability Nursing Team has produced a resource Puberty and Sexuality for Children and Young People with a Learning Disability which is designed to support National Curriculum objectives, but which is also an extremely valuable resource for use by all professionals working with disabled children and young people.

(From an interview as part of this Audit, March 2010)

What the parents and carers said

Compiled from initial interviews and focus group discussions with parents and carers

'In this present age, knowledge is power. The sooner you give your children knowledge, the sooner they can come to terms with things which they will be facing.'

Father of a 7 year old disabled boy

All parents and carers who responded, through interviews, group discussions and more casual chats, were keen for their children to get the best and most effective information to help them to maintain sexual health and to protect themselves. They would welcome teaching about safe and appropriate behaviour as part of SRE in school.

Findings from focus groups and interviews

- Very few parents or carers were able to say that their children had definitely been taught SRE at school.
- None had been approached pro-actively on this topic by any of the organisations which support them and very few said that they had received support around sexual health issues.
- The topics which they felt were most important for children to know about were: puberty, inappropriate touching, keeping yourself safe, feelings, hygiene. Most felt that children should be taught about these things in primary school.
- Many stressed the need for very early teaching about appropriate and inappropriate touching to establish good habits, from the start of school.
- One issue which united all the women in the mothers' focus group was wanting to see more positive views of disability promoted. Concern was also expressed about the way in which teaching about abortion can have a negative impact on perceptions of disability and on disabled children if not done sensitively.
- Most of the parents were clear about what would be a good service to support them in this area: a place or organisation where there is regular contact so that they and their children could build up a relationship with staff; where experts would sign-post them; where staff would be non-judgmental.
- All of the parents said that they would like more partnership with schools.
- Some parents were very happy about the partnership which they have with their child's school to support behavioural and friendship issues.
- Many praised the Speakeasy courses organised by the Down Syndrome Support Group.

Many parents spoke of their concern that good positive habits should be put in place from an early age. With many disabled children still needing help with toileting and hygiene at a much later age than other children, parents were aware that their children find it difficult to develop the concept of what is private and therefore what constitutes inappropriate behaviour in public. The point was made again that, although development might be slightly later for some disabled children, it is important that issues around sexual health are considered much earlier in some cases.

Generally, the parents interviewed felt that there is a lack of awareness of the importance of sexual health for disabled children and young people and lack of attention given to some things which can cause considerable stress and distress to families and children. The comment was made by one dad that although the family have had regular appointments with a paediatrician, no question had ever been raised about sexual health issues.

Parents were keenly aware that lack of understanding or appropriate knowledge could make their children very vulnerable to risk, either of abuse or of bullying by peers.

Case Study –

One father explained that he is the sole carer of his fifteen-year-old daughter who needs help with mobility and with all areas of personal care. He had been offered no support in the area of sexual health, and had been waiting for six months for an assessment promised by the Special and Complex Needs Team which would assess her requirements for personal care.

He emphasised that, although his daughter is mentally and physically immature in many ways, she has periods and is going through all of the typical emotions which teenagers experience. He felt that it is an area in which he would welcome support: *'Even just a leaflet to read – awareness would help. Being a male...knowing what sort of help is out there.'*

He knows that his daughter has an awareness of gender and sexuality because she responds in a sexually aware way to a male teacher.

Parents' views of schools and SRE

Most parents with children in mainstream schools welcomed the recent moves to increase provision for disabled children in mainstream schools and felt that this is the right place for them to be. Many said, however, that they felt that their children needed more than the school was offering in order for them to understand good sexual health. Some parents felt concerned that the specialisms which special schools offered can be lost in the move to mainstream school. With SRE taught as a mixed ability subject in mainstream schools, disabled children with learning difficulties can be effectively excluded.

One parent with an older child explained that though the boy had had a talk from the school nurse on puberty, *'... None of it went in – it needs reinforcing more. From one talk, they might come out with one fact.'*

Many parents felt strongly that their children needed a chance to work separately in smaller groups for this subject, so that they could explore more. One mother said that her son, for instance, took longer to develop understanding even of vocabulary – but it was crucial for him to have understanding of the words which other people are using, including the slang words used by peers, where possible, to avoid being taunted.

The question of time came up repeatedly. One parent emphasised the need for things to be '*specialty tailored*.' He has realised that learning about some things take longer for his son than other children, but things also need to be started earlier so that the child can approach learning ready and prepared.

One parent expressed concern that now that fewer statements of special educational need are being issued, there is no guarantee of the quality of support which children receive. Funding goes directly to schools, but parents were not always sure that they receive the best quality service and one parent reported the use of Support Assistants who he understood are unqualified.

Many parents felt that SRE for disabled children, just as for other children, should involve a joint approach with parents and schools together. The most satisfied parents were those who were able to work with schools to enable their children to build social skills and to develop appropriate behaviour with other children which would benefit them in later life.

Challenging issues

One father was very keen to say that in his opinion, and speaking as a committed Muslim, nothing in Islam prohibits disabled children from being given as much knowledge as is appropriate for their age. He commented on the vulnerability of disabled children. Another Muslim father wanted the connection between RE and SRE to be explored more fully in schools: '*There's a link that can be made – I'd like extensive education about what it's all about – how you make decisions.*'

Good practice – An Islamic perspective on puberty and Autistic Spectrum Condition

Working in partnership with Bradford District Autistic Support Group, Barnardo's set up an information session for Muslim parents in 2009, inviting a respected Imam and primary school teacher, who is fluent in both English and Punjabi, to give advice and answer questions about puberty and sexual health for disabled children from an Islamic perspective.

Parents had expressed concerns over certain issues in this area, and were invited to prepare questions in advance, or to ask during the session. The BDASG data-base was used to contact parents and the session was set up to take account of cultural sensitivities.

Questions covered a wide range of topics, from the problem of a disabled child who keeps interrupting a parent who is reading the Quran, to others more directly about sexual health such as when it is essential for a disabled child to complete faraz ghusal (showering for purification after acts such as sexual intercourse, wet dreams, menstruation, childbirth).

Responses from the Imam were practical and showed understanding of the realities of life. Of masturbation, for instance, the advice was to explain that it is *Haram* or forbidden, but '*If they are unable to understand, then Allah is most forgiving.*' Parents who took part found it extremely valuable and reassuring.

(From unpublished report – Barnardo's, Bradford)

Parents spoke of a range of issues which are challenging for them, including finding the confidence or the right way to talk to their children about bodies and puberty, finding ways to behave with their children which allow autonomy and do not patronise, ensuring that peers or teachers behave in appropriate ways, without patronising or inappropriate hugging, dealing with toileting and hygiene issues with older children, coming to terms with the fact that their child is growing in to an adult with new needs, dealing with issues in a way which is appropriate to their culture, inappropriate behaviour such as teenagers taking clothes off in the living room.

What would help?

'Make sure that there is somewhere to go if parents are struggling... It would be nice to ring somebody up if we were in a dilemma – to have a chat.'

One service which was providing support in a different area was recommended as a model of good practice because they built a good relationship with both parents and the child, and: *'They kept providing different things for us to try... they would ring us, for a chat.'*

One father commented that, although he had not found many areas of support for his particular issues, one service had been good because they had *'taken the time to listen, to understand what we have to say... They referred us to other professionals.'* He valued that fact that this service had an open-door access and also that they were able to deal with the same person every time.

The Speakeasy course, provided through the Down Syndrome Support Group working in partnership with the Sexual Health Team, was mentioned with enthusiasm for the insight and understanding which it gave.

What the practitioners said

Compiled from initial interviews with practitioners working with disabled children and young people in the Bradford district

'It's not about demonising sex with young people, it's about giving information and power.'

Professional practitioner in Third Sector

Good practice in Bradford – partnership working

The Down Syndrome Support Group organises and runs a range of courses for parents and other adults, to enable them to build the skills and understanding needed in order to support children and young people with Down Syndrome.

They recently worked in partnership with the Sexual Health Team to deliver a Speakeasy SRE course and feel that there is a *'massive need'* for courses like this. *'People travel from Manchester and Hull to attend training courses and group sessions,'* Dr Uttley, joint facilitator on the course, explained.

The confidence of the parents attending increased hugely over the weeks. By the end they were able to discuss most topics with ease. It also gave them insights and new ways of seeing some of the safeguarding issues around sexual health for disabled children.

One teaching assistant from a primary school also attended and concluded: *'It's worth putting this into schools for all staff working with SEN children... It's vital... [SRE] needs to be small steps – it's all thrown at them in Year 5. Schools have to reinforce it, even if parents are doing it – right from reception.'*

The current course could be adapted for use by other groups who deal with different disabilities or to be used directly with groups of young people. It combines excellent and up-to-date information on sexual health with extra information which comes from personal experience and thorough research. Dr Uttley is keen to trial a course where adults and young people could initially spend time learning in separate areas, and then come together for a structured chat session so that adults could practise some of the skills which they have learnt.

(Taken from interviews as part of this Audit, November 2009)

Key people in the field were contacted across a range of services. Many of the professionals who took part in the discussions said that there has been a failure to face up to the reality of sexual relationships and disability, which leaves children at risk. One described increasing numbers of parents of children with learning difficulties coming to their service to discuss their worries about children and young people who are *'displaying dangerous levels of unawareness about the situations they're in.'*

Sex, Sexuality and People with Learning Disabilities - A Policy and Guidelines for Staff and Carers in Bradford was produced in 1999 to provide support and a framework to enable staff to

deal with some of the issues which arise was in the process of being re-written as this audit was being carried out.

The main issues which practitioners see in the area of sexual health and disabled children and young people, explored in more detail below:

- Providing accessible SRE and sexual health services for young people has not been a **strategic priority**
- There is a need for awareness-raising to promote positive **attitudes to disability** and to sexual health for disabled children and young people
- There is a need for greater understanding amongst some parents and carers and many workers of the **safeguarding** issues around disabled children and sexual health
- There is a lack of **accessible services, support and resources**
- There are **work-force development needs** for professionals who work with disabled children
- **SRE delivery in schools** is frequently not accessible or appropriate
- There is a lack of good communication and **partnership working** across organisations to utilise expertise and resources
- Certain groups of young people experience additional risk or might need **special provision**.

1. Strategic priorities

One senior manager within Children's Social Care explained:

'For Looked After children, the partners have accepted their shared responsibility for parenting...' but perhaps shared responsibility for disabled children has not been accepted in the same way. 'We should make sure that at a strategic level, the needs of disabled children are given a high priority - within all council policies and procedures, there should be a recognition of their impact on disabled children, recognising that they might need something extra.'

There is currently no monitoring system in place in Bradford to collect data on the numbers of disabled young people who access various services, nor is the information from the QOF on patients with learning disabilities from GP practices shared with Community Health Services. Currently no data is collected from Children's Services or Education Bradford on disabled young people's sexual health.

There are currently no figures on numbers of disabled children and young people with different disabilities within the authority. There is a Bradford-wide data-base on children with special needs, but data is entered only on a voluntary basis. Although data is kept to show how many children in care are disabled or have a statement of special educational needs, no amalgamated

records show how many disabled children and young people need support around issues of sexual health.

The point was made that professionals, including GPs and those in schools, are often not confident in assessing the learning needs of some young people.

The lack of strategic priority given to sexual health and relationships for young disabled people was repeatedly mentioned. There is little, for example, to support the cross-agency work and networking which is essential in this field. The point was made by some practitioners that successful and innovative work, such as the Show Me project which provided outreach work to young women and their families, and the Deaf Youth Club project, has not been supported by policy development at the highest levels of senior management. Both have failed to find further funding.

2. Attitudes to disability

Children and young people with disability are, in Bradford as elsewhere, more likely to have a complex variety of issues to deal with which might be likely to cause low self-esteem or depression. The point was made repeatedly that bullying is a big problem faced by disabled children and that internalised prejudice against disability can manifest in a range of behaviours which make it more difficult for them to build good relationships.

Many professionals reported that for some parents or carers, there is a tension between the rights which disabled children and young people have and some of the safeguarding and protection issues which might be present because of the nature of their disability. This creates a fear that giving information or advice to disabled children, even more than to any other group, will encourage promiscuous or undesirable behaviour.

One practitioner was concerned that there is still a '*knee-jerk reaction*' to disabled young people who show sexual behaviour. This might not be the same for other young people and can create problems where perhaps there are none, and can in turn lead to restrictive measures being put in place. She gave the example of a young woman who adores boys and sexual touching. A plan was made to send her to live in house with girls only, rather than to enable her to learn a variety of appropriate ways to express and enjoy her sexuality as other young women might: because the young woman is disabled '*Everybody is judging...*'.

There was evidence of a lack of understanding of the Social Model of disability and of a low awareness amongst some staff of the issues around this.

Some professionals were concerned about the enormous impact which worries about sexual health issues can have on the well-being and thus the behaviour of disabled children and young people if they are not dealt with.

3. Safeguarding

The point was made repeatedly that those young people with mild to moderate disabilities, who are able to go out independently in the world, are ironically therefore some of the most vulnerable. It was suggested that Deaf young people are one of the most vulnerable groups.

Professionals frequently spoke of the vulnerability of the children with whom they work or described examples of children and young people in situations of risk. There is no provision in

Bradford for young people who demonstrate inappropriate sexual behaviour but who do not have a mental health issue, unless/until they become harmful to others and come into conflict with the law.

The safeguarding issues have not yet been acknowledged nor is suitable provision available to support these young people, interviewees said. One professional, with a great deal of experience of working with young people, referred for support around sexual health issues explained that many of these young people are sexually active though *'they don't even understand the biology'*, and are presenting with STIs, with experiences of rape, sexual assault, under-age sex. *'They can't negotiate the sort of sex they have, so they have risky sex and no say in it.'*

A gap was identified in provision to act in a preventative way to positively promote sexual health and to support those young people currently 'in need', in order that they should not become 'at risk'.

Several professionals mentioned their concern that the system of Direct Payments to families and disabled young people for services will impact negatively on sexual health: it is essential, it was pointed out, that provision should include a programme of awareness-raising, to ensure that important areas like sexual health advice are included in packages of support.

4. Accessible services, support and resources

Some of the services which might be accessible for other young people are not necessarily so for disabled children. Some might be unable to visit clinics or GP surgeries alone, some might need extra time to make appointments, to sign in or to make their requirements known. There is no dedicated support for positive sexual health for young disabled people:

'It's very hard if you're in a wheelchair and you're thinking of having sex... there are practical considerations...' (Community paediatrician)

There is currently no service in Bradford to provide support for dealing with sexually inappropriate behaviour which could at a later stage bring young men into conflict with the law, but one practitioner reported that this is one of the issues most frequently presented to him.

Although health and teaching professionals reported receiving frequent requests for support from parents, there is no specialist support for sexual health for disabled children and their parents/carers offered through the Bradford authority.

There are particular needs relating to specific communities, the language needs of some parents from South East Asian communities who cannot understand 'difficult' Urdu, for example, or the taboos which limit discussion in some communities.

Although inclusion has become a higher priority and socialising and building friendships has been shown to be crucial for well-being, there is no tracking mechanism to show the regular attendance of disabled young people at activities. Costs, for an interpreter for deaf young people, for instance, can be difficult for projects with a small budget. One practitioner who delivers training courses for disabled young people which include relationships and sexual health elements noted that fewer of these are being funded in Adult Education in recent years.

The implications of creating accessible resources would be huge, one practitioner explained. Stickers, text messages and posters which might be good ways of contacting many young people might not work for many disabled young people.

5. Workforce development needs

At present there is no dedicated training for sexual health and disability being delivered to staff in social services or education by Children's Services. There is a Disability Working Group which operates across the whole of Integrated Youth Services and disability training is on offer for staff, but some evidence suggested that for the last two years there has been no take-up. One senior manager explained that an important part of their job is to build self-esteem through activities and to put health practitioners into youth provision in order to provide information and support in ways which are accessible to young people.

Currently ten more disability inclusion workers are being recruited to the Integrated Youth Services, and there is a disability action plan which includes targets on SRE and sexual health. There was some concern, however, that implementation of the plan depends on priorities within localities and decisions by individual managers, and that localities working might mean a lack of cohesion across the whole of the authority so that services are not deployed where they are needed. It was mentioned that there is greater pressure within Integrated Youth Services to complete on other targets, and that the impact assessment which the disability action plan requires has not been completed.

There is also a lack of clarity for some staff about skills such as the intimate personal care which might be needed to work with disabled young people, and some reluctance to deal with the realities of the sexual health needs of some disabled young people eg inappropriate touching of oneself.

It was repeatedly stressed that awareness in this area should be part of core training for all staff, and included in initial degree courses for teachers, social workers and police for instance.

A scoping exercise has recently been completed to address workforce development needs in the district, and this has revealed gaps in areas of sexual health for disabled young people. Plans are being made to begin to address some of these.

There is under-capacity in the School Nurse team, and some evidence that, although the support which they provide is very much valued by many schools, they would benefit from training to build confidence specifically in dealing with disabled young people. School Nurses in Special Schools often have their time taken by care plans, which leaves no opportunity for promoting good sexual health. There is a serious lack of men in the nurses' team to provide positive role models.

6. About SRE in schools

'We hear stories all the time about the vulnerability of the young people.'

Teacher describing the challenge of enabling some disabled children to understand how to protect themselves when they are in the community

'I don't think teachers know what they're allowed to say and what they're not allowed to say.'

Teacher in primary school describing her dilemma in talking to children about topics to do with sexual health

Many practitioners made the point that an appropriate SRE curriculum for disabled children requires flexibility and lots of repetition as well as specialised content. It was stressed that some disabled children might need one-to-one sessions and a curriculum tailored especially for their individual needs. There is currently very little provision in mainstream schools for this and it is not prioritised.

There is a lack of clarity in some cases about the difference between SRE, PSHE and SEAL so that while many schools do very good work on building good friendships and other elements which come into the SEAL and PSHE curriculum, they omit some of the specific SRE topics needed by disabled children such as inappropriate touching.

Lack of understanding of safeguarding issues and those particularly relevant for disabled children, means that key elements of SRE are not taught until Year 5 or 6 in many schools. Feedback from parents and many practitioners suggests that children need to be taught certain elements of SRE, such as body parts and concepts of public and private touching, from a very early age in an age-appropriate way.

Some schools and especially special schools, deliver SRE throughout the year and 'as and when'. Evidence shows that a large number of mainstream primary schools run SRE sessions at the end of Year 5 or 6, and that many secondary schools deliver in 'drop-down days', and that both often deliver in large, mixed ability groups. Evidence from schools and from school nurses shows that in many cases, nurses are brought in to 'do' the challenging parts of SRE, frequently at the end of the school year and in a way which is not an integral part of the taught curriculum. It was pointed out by several specialists that delivering in a one-off session has been shown by Ofsted to be poor practice and offers little or no opportunity for reinforcement or for children to ask questions and explore in a way which would support good learning for disabled children.¹⁶ There was some suggestion that even in some special schools, SRE is ignored until there is a crisis.

Many professionals across the spectrum spoke of their concern for the vulnerability of disabled children within mainstream secondary schools in particular, where the larger size of the school community might be difficult for them, and where neither children nor parents can be offered the same tailored support which special schools have traditionally offered.

¹⁶ (Ofsted, 2002)

Some teachers mentioned the lack of appropriate resources, DVDs with sub-titles for deaf children or materials suitable for children on the Autistic spectrum, for example, and appropriate DVDs about STIs. Some mentioned the lack of good training locally for staff and the prohibitive cost of travelling to London, for instance, for courses.

Key features of an accessible SRE curriculum for disabled children and young people:

- Teaching should begin as early as possible (ie from toddlers upwards) and might need to go on for longer than for other groups of children.
- Content might need to cover some extra topics or to cover some things in more explicit detail (eg public and private space, appropriate touching, dependency on others for intimate care, etc.)
- There will need to be lots of repetition and reinforcement
- There will need to be a great deal of emphasis on building self-esteem and confidence
- Content and teaching strategies will need to be tailored to suit individual needs
- It will need to be taught in the context of a positive perception of the capabilities and rights of disabled children and young people
- Teaching will need to prioritise the development of skills and understanding which prevent vulnerability to risky behaviour
- There will need to be an emphasis on developing appropriate vocabulary and terminology
- Parents/carers should be involved in planning
- A system of monitoring should be in place to ensure that good teaching and learning is taking place

Summarised from discussion with children, parents and professionals as part of this audit

One interviewee said that as some disabled children and young people are unable, because of the nature of their disability, to read other people's behaviour well or to understand some of the boundaries of acceptable behaviour which are set by our society, they therefore act unknowingly in ways which cause difficulty or embarrassment for others, or which put themselves at risk. *'This can posit SRE as a 'problem' for society, carers, parents, and workers'*, she explained, which prevents openness in dealing with issues in a helpful way.

The Sexual Health Team, funded through the PCT, is currently working with school nurses and PSHE consultants from Education Bradford to review and re-design the APAUSE Programme, a peer-education SRE programme which they have been training students to run. Concern was expressed about low up-take by schools, with only five of the thirty secondary schools currently signed up for this programme.

Some interviewees had questions about the way in which many schools use the school nurses, and the fact that the work which they do is not fully integrated in to the school curriculum but is used as an add-on. Professionals from organisations working with young people in the district reported that even though they might be working on safeguarding issues with young people who attend certain schools, they are not allowed to work within the schools; in some schools or in some cases, they are not allowed to discuss sexual health in the school itself.

Most professionals who took part in interviews felt that more support was needed in order to enable parents to play a bigger role in SRE for their children.

7. Partnership working

It was emphasised repeatedly that the services which deliver should be working in a more collaborative way with parents and schools to raise awareness and identify need.

The importance of support groups such as those held by the PCT for parents and carers was emphasised, especially as the networking opportunities which special schools provided is now being lost for many parents.

A large number of professionals said that they would welcome the chance to network with others.

8. Special provision

Certain groups of disabled young people are under-represented in numbers of those accessing services. Disabled girls and young women from South Asian communities are less likely to access services providing social activities or to be referred to some services which support young people at risk from sexual exploitation. They might benefit from differentiated support.

Other groups such as young gay men and trans-gender young people are particularly vulnerable as they are more likely to experience bullying which affects school attendance and their opportunities to build good friendships and relationships, but also because they are frequently struggling to come to terms with their own identity and might put themselves at risk. They might benefit from improved staff training for workers in both specialist and universal services.

Some professionals noted that there is a need for greater provision for dealing with those young people experiencing serious risk.

iii. Questionnaires

Responses from the schools' questionnaire

'Nobody has ever asked me where SRE fits into the School Improvement Plan.'

PSHE teacher in a special school on the low priority given to this subject

A total of 40 responses were received from management and teaching staff in schools to a questionnaire asking about the provision which they have in place for SRE for disabled pupils. Schools in all localities across the district were targeted to ensure a fair representation.¹⁷ Responses came from a balance of primary, secondary and special schools. Some questionnaires had incomplete responses which affected the data analysis.

There appears to be a misunderstanding in some schools of the term 'disabled children' and the social model of disability which it implies. This might have affected the responses. Some schools thought that this term refers only to physical disabilities; more than one school thought that it is a term of disparagement; one school was *'not comfortable using it as a formal classification'*; one teacher referred to *'handicapped children'*. The most common way of referring to children's learning in education has conventionally been in terms of whether the child has a Statement of Educational Need. The term 'learning difficulties' is also used.

Who teaches SRE, what training have they had and how do they feel about it?

Most schools have a staff member with specific responsibility for SRE, but only half of those who responded said that this staff member is at Senior Leadership or Middle Management.

Over half of those primary schools who responded said that SRE is taught by all class teachers with some outside support. In secondary schools, there was more likely to be a dedicated team. Most teachers who responded to the question on training which they have had within the last two years to deliver SRE, appear to have received little specific SRE training. PSHE Coordinators were more likely to have had Continuing Professional Development with the PSHE Team in Education Bradford, a course with a focus on organisational issues within PSHE rather than classroom-based SRE work. A few were confident that they had had *'lots'* and mentioned the APAUSE programme or Speakeasy.

Over half of schools who responded said that in the past two years, staff have had no training in working with disabled children. Staff at other schools had received training in broader aspects of working with disabled children. No respondents mentioned training which combines SRE and implications and issues for disabled children.

The majority of teaching staff who responded said that they feel confident about teaching SRE for disabled children, but a sizeable number either did not complete this question or said that

¹⁷ All schools in the district were invited to take part via email, but response was low. Questionnaires were then sent to targeted schools in localities and the questionnaire was publicised through the Education Bradford portal. Among responses, two schools were unable to complete the questionnaire as they were revising their policy; two were unable to complete due to staffing constraints.

they did not feel confident. Approximately sixty per cent of respondents said that they felt that SRE is taught *satisfactorily* for disabled children in their school. Thirty per cent said that teaching is *very effective*, and a small number said that it is *not effective*.

A small number of staff were clearly very unsure: *'Not sure what is required for Year 5 – relationships are taught but not sex education'*, *'Not confident in teaching/delivering in this area. Don't know how parents would react.'*

When is SRE taught and who for?

Over half of the schools which responded said that they teach SRE to all years and the most favoured way of delivering in primary schools was combining work across the curriculum with blocks or topics. The amount of time which children can expect to receive for SRE varied: across primary and secondary sectors, some schools said between 1 and 4 hours per week, while others offered between 2-3 hours to 6-10 hours per year.

It was not always clear, however, when schools described their teaching, whether they referred to broader PSHE work or SRE specifically. At early years and primary level in particular, most SRE would be about building self-esteem and skills to make friends. This fits with the SEAL work and Circle Time activities which were frequently mentioned.¹⁸

What strategic planning does your school have in place for delivering appropriate and inclusive SRE for disabled children and how are you evaluating and monitoring teaching and learning?

There was little evidence that schools have clear strategies and systems to make sure that their SRE curriculum is appropriate and inclusive for disabled children or for monitoring the quality of teaching and learning taking place in SRE with regard to disabled children. One school was able to say that *'Year 6 Designated Special Provision children would be included after discussion with parents/carers and appropriate support/adaptations.'*

One school stated clearly that they do not have any strategies in place to ensure quality delivery of SRE for disabled children. Others referred to some of the frameworks which they use, such as Healthy School work, SEAL, and in one case *'PSHE Assessment to match ECM framework'*, or to one-to-one work. There was little evidence that clear monitoring systems are in place, though one school mentioned the use of subject-based systems.

Teaching staff gave a low response to the question about monitoring and one could only say that *'We haven't had any negative feedback.'*

Working with partners

Out of the partners which schools use, school nurses were recommended by the highest number of schools, though there were also reservations about some aspects of their work (see criticism on page 46 below of the lack of good resources which are used by nurses). Also mentioned were Bradford and Airedale Health Teams, the PSHE Team and the team providing support for working with Autism, both from Education Bradford, and Step 2, a Third Sector young people's sexual health project.

¹⁸ What the questionnaire did not measure is whether schools are tackling some of the important safeguarding issues in PSHE which are not part of the SEAL curriculum.

Planning with children and parents

No school said that they plan with children, although one school wrote that they discuss on a *'one-to-one basis with individuals and their families'*, and another referred to a Parents/school liaison worker. One school said that parents are able to view materials at parents evening and to discuss issues with the school nurse.

What issues and challenges arise in schools?

Very few mainstream schools responding indicated that they found any challenging issues which arise for disabled children around SRE.¹⁹

One headteacher wrote: *'A fairly high proportion of Autistic and Aspergers – needs careful planning'*, and another specified *'Appropriate touching.'* One school wrote *'Children with Autism/Aspergers Syndrome have difficulties relating to other people. This affects their social relationships.'* Two other schools indicated challenges which they face in this area: *'Assessing levels of understanding'*, *'Small groups to develop skills or to support learning.'*

When asked about issues, one teacher commented: *'The vulnerability of the children is always considered. We take great care in ensuring 1-1 needs are met with a special focus on esteem and follow-up.'* Others mentioned concern about when a child is unable to communicate, and the need for extra support. One wrote: *'Children with autism have a lack of social awareness and sometimes behave inappropriately towards others.'*

What do schools think would help?

When asked specifically about help, more up-to-date resources came top of the list. One teacher commented that *'The nurses often arrive with a very mixed bag and rely on talking and a few simple pictures.'* There is a strong sense from many schools that they are making efforts to adapt and to design an appropriate curriculum: *'We need SRE aimed at children with autism that takes into account their difficulties.'*

The next most frequent request was for training. One senior manager commented on the challenge of combining the skills and knowledge of health professionals with the classroom management and teaching skills of teachers so that young people with learning difficulties are able to access material. He would welcome a course on delivering SRE for students with learning difficulties run by education professionals: *'I would send all my people straight away.'*

The school nurses were frequently recommended as providing positive support, though one school commented that *'The school nurses and external professionals tend to come in and deliver SRE'* which suggests that in some cases there is not a real partnership with school nurses and teaching staff working together. Barnardo's and the National Autistic Society were also recommended.

¹⁹ This could be interpreted in a variety of ways: because they are doing a great job and there are none, or because they do not recognise the issues, or because they are not willing to share the fact that there are challenges.

Responses from the Questionnaire for providers of sexual health services or SRE other than schools

'Delivery of Sexual Health services to individuals with disabilities, particularly young people, is something we take seriously as a service. We have very skilled and compassionate staff who are able to deliver tailored services, perhaps even on an outreach basis, however, environments and resources need to be more appropriate to enable this to happen effectively.'

Senior Manager

The questionnaire was sent to organisations which provide sexual health services and/or deliver SRE provision.²⁰

The main points from the questionnaire responses were:

- In spite of some excellent work taking place, accessible and appropriate services are still not being provided for disabled children
- No data is being kept on up-take of services by disabled young people, and there is very little monitoring of this specific work
- Children and young people and parents and carers are not involved in planning or monitoring of services
- There is a need for good and accessible resources
- There are workforce development needs around sexual health for disabled young people
- There is a need for further improvement in partnership working, particularly between providers of sexual health services and schools, and between mainstream and Third Sector service providers, including opportunities to share experience, information and resources.

What data do you collect? Who is responsible for delivering? What training have you had?

It is noticeable that no organisation systematically collects data on the up-take of services by disabled young people, though one said that they collect information on numbers of people under 25 years old who use their services.

Very few organisations have a specific staff member with overall responsibility for making their service accessible to disabled young people, though some have staff with an interest in or experience of working with disabled young people. One team said that this is 'a *generic responsibility for all staff to consider.*'

²⁰ The number of responses was small, from four key teams, but this represented larger numbers of people as questionnaires had either been completed by one person for a team or by managers. Some smaller organisations and individuals had already given time to be interviewed so quite reasonably declined to complete the questionnaire.

Very few staff who deliver SRE or sexual health services, excepting of course the Disability Nurses, have received CPD in the past two years specifically to support their work with disabled children or have specific qualifications in this area.²¹

Many staff who said that they have received CPD to support their work on SRE and sexual health with young people said that they have completed or are completing the PSHE CPD Certification course run by Education Bradford which was praised as *'very effective'* or the Added Power and Understanding in Sex Education (APAUSE) training. In one large team *'All staff have attended study related to sexual health in the last two years.'*

What strategies are in place?

When asked about strategies to ensure that their service is accessible for disabled children and young people, two teams said that they use an Equality Impact Analysis or Assessment to look at the impact which they are having on communities, including disabled people in those communities. Two teams mentioned You're Welcome which has been implemented across the district and provides a framework and a self-assessment tool to support organisations in making services accessible to young people. Nevertheless, one manager of a large, district-wide team wrote: *'Disability should be an integral part of service delivery equality. However, I would question whether staff are fully equipped to answer this confidently.'*

Who are your partners? Who do you plan with? How do you evaluate and monitor?

Most teams who listed schools when discussing working with partners, said that working with schools was *'satisfactory'* (this was used several times by different respondents, no-one described partnership with schools as either *'excellent'* or *'poor'*), one said: *'New schools planning – well'*, one said that working with partners is *'effective when delivered'*. One large team delivering public health has not yet developed formal partnership links with other agencies.

No organisation said that they have any systems currently in place which provide real opportunities for parents/carers or disabled young people to be involved in planning services. Most responded to *'requests'* or *'referrals'* and one respondent said *'None systematically although some indirectly through working with the Bradford Leaving Care Team.'*

Monitoring and evaluation of the work was described as follows: *'Verbal feedback from teachers'*, *'Evaluation and feedback from children'*.

What issues for disabled children do you find?

Issues for disabled children and young people around sexual health and/or SRE which teams noted included the following: *puberty, period control, relationships; lack of resources specifically to help reinforce explain issues; parents/ carers lack of awareness of where services are and what they provide and offer; exclusion from the planning processes in services and education; parent or carer might occasionally refuse permission.*

One team wrote that *'People [not] agreeing the child has the right to services/education'* occurs *'frequently'*.

²¹ Questionnaires were completed with whole-team responses so data on individuals is not available, but it seems that only two staff had recent training or have qualifications.

One respondent wrote of the issues which his team sees:

'The most frequent is of over-protection from parents and carers in particular to do with sex & relationships, most young people have sexual experiences and make mistakes from which they learn, most often disabled children are protected from these mistakes and consequently end up with impoverished notions of what sexual lives can be like.

In addition staff and carers often only take the initiative to deal with sex and relationships when they become problems by which time behaviour is more difficult to deal with.'

What challenges do you face and what might help?

Challenges which the organisations themselves faced included the following: *finding resources which really are accessible or which are sensitive to the needs of local communities; access to targeted training; lack of agreement with partners, which related specifically to schools; services for boys; tailoring services to the specific needs of the child; some rooms poor for wheelchair access (although more recent buildings more appropriate); couches for examination not easy to use.*

One response included the following:

'In common with much of SRE education there is a lack of understanding by services of what it entails and a lack of skills in the workforce. Especially within learning disabilities services, sexual health is often only addressed when it becomes seen as a problem: e.g. with inappropriate sexual behaviour; the services then quite often come looking for answers to the specific problem rather than investing in ongoing education which could have avoided those behaviours. Many young people will tend to be chaperoned by carers which may prevent easy access to such 'confidential' services.'

One senior manager wrote: *'I think that we need to address this whole area as we are not meeting the needs effectively'.*

Suggestions around partnership working included the following: *a coordinated approach across organisations, including 3rd sector; the development of 'champions' within organisations; a strategic steer; revival of Sexual Health Forum for learning disabled young people specifically employing a worker to convene it and support its development so that it can be a focus for training and policy development; a Directory of Services which could be accessed/delivered by specialist disability practitioners/expert service users and third sector groups; a dedicated team to develop resources.*

Requests were for: *accessible resources; good quality staff training.*

Other suggestions included: *more explicit role for a school to enable young people generally to access sexual health services as part of curriculum teaching; more school-based health services generally; explicit role of school nurse in secondary schools to include basic sexual health service provision; time to access parent/ carer groups; involvement with this client group to help improve our service.*

Snap-shots – GP practices

This was added as it was felt that GP practices had been under-represented in the previous data-collection. It is based on a quick 'snapshot' survey carried out through telephone interviews with either GPs, Practice Managers or Reception staff in ten GP surgeries across the district selected at random.²²

Out of ten practices interviewed, two had very little to offer in their responses. No practice collected data specifically to monitor up-take of sexual health services by disabled young people. One practice said that staff have had training in working with disabled people, one had had training in safeguarding and diversity, and one is already working with Bradford People First, an organisation run by people with learning disabilities, to improve accessibility. None had had staff training specifically around sexual health for young disabled people, but three offer services specific to young people and one has a sexual health lead and sexual health clinics. When asked about what they have in place to support young people to access sexual health services, responses ranged from '*Treated like everyone else*', '*posters*', '*leaflets*', to a practice which has a book with Maketon. One practice offered a separate room for parents and carers to wait in when patients visit the nurse so that the patient can have a '*full and frank discussion*.'

Several practices discussed the challenges of contacting disabled young people. One practice with a student patient-base carries out out-reach, through its web-site, in GPs' surgeries, and through school visits to contact young people and accepts patients aged 12-19 who do not have to be registered with the practice. They noted, however, that they have a very small number of disabled students registered. They felt that disabled students probably had better opportunities to know about the services they offer, however, than other disabled young people as they are able to network with other students.

One Practice Manager explained that although there are posters in the reception area offering Chlamydia testing, they have to be sensitive to their patient population by being 'a little less overt' than other practices might. They work with the Chlamydia testing team and the Genito Urinary Medicine (GUM) clinic and have GPs trained in sexual health, and she felt that whereas lots of disabled youngsters might be '*invisible*' in the area of sexual health in other practices, their staff are very aware of the issues. Because this practice is family-centred, however, and many young people have attended through childhood, probably with family, one challenge is to make young people aware that a sexual health service is there for them at their GP surgery. She emphasized the need for partnership working: schools and colleges need to really promote the service and encourage disabled young people to go for a check-up, showing that '*This is cool, this is normal*.'

Two managers mentioned the challenge of getting feedback from disabled patients, suggestions about what would be helpful. One said that they have targets in their development plan to engage with patients, but '*in inner city Bradford, a diverse population with different problems – people with learning disabilities don't always access services because they're scared or because of stigma... They don't come to us through the usual channels*.'

When asked what might help GP practices to deliver good sexual health services for young disabled people, one Practice Manager said '*We could do with more support – there's not a lot*

²² More than 20 practices were contacted by phone. It is possible that the ones which made the effort to respond were more positive about the subject, or more likely to be pro-active.

of training – it's quite a specialist service. I'm conscious we could do more... There's some information about access, doors, desks, but not about them accessing services.'

Raising awareness is needed, another manager said: *'Clinicians and managers are always good at telling people what's good for them – coming at it from a completely different angle... the best people to ask are the patients themselves.'* She also mentioned the challenge of assessing learning capacity: *'Some labels are out-of-date – based on IQ score. Some doctors feel that's not correct, but where do you go for advice? You need a forum to discuss and share – localized for inner city.'*

One GP said: *'We would love a teenage health suite with a separate entrance... This is a training practice – it's important to make doctors aware of the issues'.*

Good practice – Sexual Health Services for people with learning disabilities

The Pearl Service in Hammersmith and Fulham is the only integrated dedicated service in the country providing sexual health services for people with learning disabilities.

They began to develop the service when they discovered that difficulties in negotiating the Call Centre were preventing disabled people from accessing their service and that key-workers did not know about the Sexual Health Clinic. Ceri Evans, the senior sexual health adviser, explained that *'We've been horrified at the level of resistance to people with learning disabilities having healthy sex... The up-take is still relatively small but the need is far greater than we can ever deal with.'*

Other clinics who want to develop a similar service or to build on their experience can book a visit from The Pearl Service and can have access to the resources which they have developed.

For more information – www.chelwest.nhs.uk

Good practice - Partnership working in Dumfries & Galloway

Dumfries & Galloway's sexual health strategy stresses the importance of partnership working. It is led by a steering group which involves representatives from a number of different agencies, including health services, local authority, voluntary agencies and service users. There is also a Young People's Sexual Health Steering Group which has recently taken on new members to give wider representation. Financial support is provided by the local authority to a number of groups who contribute to sexual health, including South West Rape Crisis and Sexual Abuse Centre, Wigtownshire Women's Aid, Age Concern, Couples Counselling and D&G Coalition of Disabled People.

There is also strong partnership working with the area's GPs. Locally enhanced services (LESs) have been agreed under the new GP contract so that GPs are paid a fee for inserting intra-uterine devices (IUDs) with 19 out of the area's 34 GP practices taking part. A LES for Implanon insertion has also been agreed and 14 GPs in 11 practices in nine towns have been trained.

The use of link workers, most of whom are nurses, is also being pioneered. These workers actively promote the area's sexual health services by going out to different groups, including LGBT, looked-after children, homeless people, prisoners, substance misusers and people with mental health problems. *'We want our services to be accessible and welcoming to everyone,'* says lead clinician Dr Maggie Gurney. *'But if people aren't accessing our services we want to make sure we are meeting their needs by going to them.'*

(The Scottish Health Directorate, 2008)

V. Recommendations in full

The data collection revealed some broad results which have informed the recommendations. While important moves towards equality and inclusiveness have been made, there is still evidence of a reluctance to deal with some of the complex issues around sexual health for disabled young people, including some of the safeguarding implications and the crucial contribution which sexual health makes to health and well-being at all levels.

The importance of SRE as part of good practice for all young people's health is not generally being acknowledged, nor is the fundamental contribution which it makes to the delivery of all outcomes of ECM. Without the active promotion of good SRE and active engagement with it, other initiatives cannot succeed.

In some areas there is evidence of a lack of understanding of the Social Model of disability, which is now accepted as the 'gold standard' of best practice.

At the strategic level, there is a need for systems and structures which could ensure the promotion of sexual health among disabled young people. Sometimes when systems are in place, they are not actively used. For some practitioners, the lack of positive engagement might stem from a need for awareness of issues around disability or a thorough understanding of what good sexual health practice includes.

In some cases there is a disparity between what disabled young people need and say they would like, and what they are being offered by schools and services.

There is also evidence of a disparity between what parents say they want and what they are being offered.

It is extremely important to note that much of the data collected with regard to schools has implications which are relevant for the delivery of SRE for all children and young people, not just for disabled children.

Recommendations at the strategic level

A commitment was made in the Bradford JAR report in 2008 to ensure that '*all partners understand and carry out their responsibilities for improving sexual health*'. Within the Bradford Children and Young People's Plan one of the priorities is promoting '*healthy life-style choices*', which includes sexual health. The Children's Trust partnership has the statutory duty to promote equality and well-being.

Given all of these and the overwhelming evidence which shows that children are currently being put at risk, this report recommends that the Bradford Safeguarding Children's Board take urgent action to influence the Children's Trust Partnership to implement the following:

1. Strategies for promoting good sexual health for disabled children and young people should be established within the Children and Young People's Plan across the authority at the highest level and that implementation of those strategies should be prioritised.

2. In order to ensure this, an existing member of each of the ECM Outcomes groups be appointed to adopt the role of Champion to promote and take forward good practice in delivering sexual health services to disabled children and young people.
3. A request to the Young People's Sexual Health and Teenage Pregnancy Board to develop a policy for promoting good sexual health for disabled children and young people which will sit alongside the Sexual Health Strategy, and which is owned and acted on by all across the Trust. They should also be asked to support and performance manage policy delivery.
4. A review of systems for gathering and analysing data on sexual health and disabled children and a framework should be established for doing this with reference to the Teenage Pregnancy Unit and Public Health Observatory.
5. All organisations who work with children should undertake an annual audit of how their current services promote sexual health for disabled young people, with reference to the policy above.
6. The Safeguarding Disabled Children multi-agency training should include an element on promoting positive sexual health for disabled children and young people.
7. Every agency should evidence how they have involved young people and parents/carers in planning at all levels, using the successful Aiming High model of involving key stakeholders in the design of accessible services.
8. Bradford Parenting Board should be asked to consider the development of training for parents and carers to enable them to support their children in having good sexual health. This training should be promoted through targeted interventions in localities and schools. [This should apply equally to parents and carers of disabled and non-disabled children]
9. Bradford Safeguarding Children Board should re-launch an up-dated version of the Safe Parenting Handbook, with a section on sexual health and SRE. This handbook should be promoted through the Children's Information Link.

Workforce development

10. Basic training in promoting sexual health for disabled children should be developed and included in the Workforce Development Strategy, for all teams who provide services to children, with additional training for all staff who work directly with children.
11. A short-term multi-agency task-force should be established to design and deliver such training for work-force development initially, which will then become mainstream.
12. The training should include the following:
 - Awareness-raising about the safeguarding issues around disability eg appropriate touching, how to develop curricular content to include this.
 - Awareness-raising about the importance of this subject for well-being and positive health for disabled young people.
 - Awareness-raising to provide positive images of disability.
 - Basic SRE understanding

13. Multi-agency training should be established to promote good partnership working.
14. A regular forum should be established which would include teaching and support staff, as well as staff from other services, to promote collaborative responsibility across services.
15. Training should be provided for PSHE consultants within Education Bradford to enable them to deliver good quality training for teachers to promote good sexual health for disabled children and young people in schools as part of SRE.

For Education Bradford, Children's Services and Learning Services

16. Nurseries, children's centres, schools and colleges should be required to include reference to their provision for SRE for disabled children within their statutory Disability Equality Scheme as well as within their SRE policies, including reference to the following: systems for consulting and planning with parents (all) and pupils (secondary), and staff development and monitoring to ensure that good teaching and learning is taking place.
17. The Strategic SRE Group should be asked, as part of their current remit, to lead on the design and delivery of training for schools, to enable them to design and deliver good quality SRE for disabled children and young people, including training for head teachers and governors and for staff in schools on SRE and their duty within the ECM framework.

For Education Bradford

18. Schools should be supported to develop and implement policies, in line with their ECM and Equality duties, to deliver accessible SRE for disabled children as part of a whole-school approach to safeguarding. This should be included in statementing processes.
19. Awareness-raising training should be undertaken with School Improvement Partners about the safeguarding issues and the importance of this work, and the key contribution which it makes to children and young people's attainment, so that this can be included in School Improvement Plans.
20. Training should be offered for school governors to give them good understanding of issues around SRE delivery and around disability, to enable them to understand their duty to deliver in these areas.
21. Schools, nurseries and localities should be offered training to enable them to design an appropriate SRE curriculum for disabled children, with particular regard for the needs of Deaf children.
22. Work should be set up with SENCOs to establish the Social Model of disability within schools.
23. NQTs, who will have had modules on SRE in their training, should be supported to promote the delivery of high-quality SRE for disabled children.
24. Schools should be supported to develop effective monitoring systems for teaching and learning in SRE for disabled children and young people in line with new Ofsted requirements.

25. Each locality should establish a list of good resources for schools and some of the more expensive resources should be available for them to borrow.
26. Where special schools have moved to share sites with secondary schools, establishing TicTac centres should be a priority.
27. The rights of LGBT children and young people should be recognised and included in the SRE curriculum.

Schools

28. Schools should set strategies in place to promote closer working between parents/carers and schools in this area eg the establishment of Parents' Champions.

For the PCT

29. Flexible and accessible delivery methods of sexual health services should be developed to promote good sexual health for disabled children and young people and to respond to the needs of specific groups or individuals; a forum be established to share good practice.
30. The central contact and information service should develop expertise in providing accessible support for staff, for disabled young people and for parents/carers (including accessible leaflets and other resources) and which would be able to provide information and to sign-post them to other appropriate organisations.
31. The Strategic SRE Group should look at provision of SRE for disabled children and young people within the PCT with a view to addressing any gaps.
32. Training should be provided for GPs, staff at GP practices and other health providers to support good practice when working with the sexual health needs of disabled young people eg accessibility issues, questions of consent around contraception, in line with the You're Welcome requirements.

Health

33. An audit tool should be commissioned to enable all providers of sexual health services to review the resources and communication systems which they use to ensure that they are accessible for all service-users.
34. Specific strategies of flexible delivery of services should be developed in partnership for those groups who are either most vulnerable or most lacking in support currently eg mobile young people with mild to moderate learning disabilities, LGBT young people, Deaf young people, parents and carers who themselves have a learning disability.
35. The current clinic-based service should be developed in line with the Transforming Health Services, to ensure that highly-skilled practitioners are able to be more responsive in meeting actual demands eg running sessions in partnership with Integrated Youth Services, for workers in organisations, for health promotion, in individual homes if necessary.

36. That a central contact and information service be established with expertise in providing accessible support for young people and parents/carers and information about district-wide resources to which they could be sign-posted.
37. The various aspects of the role of school nurses should be clarified and appropriate training should be given to enable a dedicated team to promote sexual health for disabled children and young people in schools.

Localities

38. Each locality should establish a list of good resources and some of the more expensive resources for schools to access.

Colleges

39. Modules on SRE for Disabled Children and Young People should also be included in Initial Teacher Training.

Parents and carers

40. The Parenting Strategy within Localities should establish training sessions for parents/carers, using the Speakeasy training materials²³ to raise awareness of some of the issues and to offer skills and strategies.

Integrated Children's Services

41. The current Disability Action Plan should be reviewed and implemented as a priority.
42. An accessible system of support for young people and parents/carers should be established which might include the following: phone-line for help for young people or parents, drop-in centre where disabled young people can go for expert advice and support, a team of qualified staff to respond to needs, on-going support as needed, further development of the current parents' forum.
43. A central focus across localities and systems for networking for professionals should be established.
44. Teams working to support Transition should review the systems for working between schools and adult services in order to promote sexual health for disabled young people.
45. Innovative and flexible ways of delivering sexual health services should be established to support the sexual health needs of disabled young people eg a team trained in delivering sexual health services to disabled young people to deliver across the district in youth centres.
46. Male staff should be recruited to support boys' health issues in primary schools.

²³ Produced by Family Planning Association

47. Suitable resources should be provided which are accessible to those groups of professionals who provide SRE. This might include support in the form of a web-site.

Further work

48. A further piece of work should be undertaken to look at the issues to do with disabled children and young people who present or likely to present sexually harmful behaviours.

49. Further work should be undertaken to look at safeguarding issues for Lesbian, Gay, Bisexual, Transsexual and Questioning (LGBTQ) disabled children and young people.

50. A further piece of work should be undertaken to look at issues for Deaf children and young people in view of the high risk factors which have been identified in relation to this group and the specific communication and learning needs which they have.

51. A piece of work should be set up to look at the specific needs of some communities and to make recommendations about appropriate support.

VI. Resources

Organisations offering advice and resources on-line:

www.bash.nhs.uk

New web-site for Sexual Health Services in Bradford – zappy, teen-friendly design. Includes information on Ur Choice peer education programme for schools.

www.ncb.org.uk/sef

The Sex Education Forum at the National Children's Bureau – the leading authority on SRE in England – offers information for professionals including factsheets on topics such as sex and relationships education for children and young people with learning difficulties and a list of resources which is regularly up-dated.

www.fpa.org.uk

Resources and information including a section of resources for parents and professionals to use with young people with learning disabilities and the Speakeasy handbook for facilitators to run a course to help parents to talk to their children about sex and relationships. Offers training courses and can deliver locally.

www.brook.org.uk

Sex and relationships information for young people including a section of resources for disabled young people and booklets and posters *Young disabled people can... have sex and relationships*.

(www.brooklondon.org/youngdisabledpeople.htm for web version)

www.anncrafttrust.org.uk

The Ann Craft Trust works with staff in the statutory, independent and voluntary sectors to protect people with learning disabilities who may be at risk from abuse, as well as providing advice and information to parents and carers.

www.nspcc.org.uk

Includes a range of resources including *All Join In – a SEAL resource for Foundation and KS1 teachers*; *Worried? Need to Talk?* - booklets to support young people with a link to Child-line; *Safe – Personal safety skills for deaf children*; *Take Care!* – self-awareness and personal safety issues in the primary curriculum.

www.nas.org.uk

The National Autistic Society includes information and resources – eg *Girls growing up on the autism spectrum*; *Making sense of sex – a forthright guide to puberty, sex and relationships for people with Asperger syndrome*.

www.healthscotland.com/wish

Sexual health and Relationships – A Review of Resources for people with learning disabilities – reviewed 2008 NHS Scotland – an excellent list of resources and comments from users.

www.sexualhealthsheffield.nhs.uk

Sheffield Primary Care NHS Trust - Centre for HIV & Sexual Health web-site – offers training nationally and has delivered a 1-day course on Sex and Relationships Education for Young People with Special Needs.

'Promoting positive, holistic sexual health and well-being and reducing health inequalities' – provides good information through a newsletter and very positive web-site.

www.baseuk.org – The British Association of Sexual Educators – offers information for professionals, promotes ‘*healthy, pleasurable and fulfilling sexuality.*’

www.outsiders.org.uk –

‘The Outsiders Club is a vibrant social and peer support network of disabled people. We are many different things to our many different members. Most are hoping their personal dreams will come true and, for those who make the effort, they usually do.’ Has a Sex and Disability Helpline and also runs SHADA, the Sexual Health and Disability Alliance, consisting of professionals who concern themselves with the sexual wellbeing of their disabled clients, patients, residents and students, and aim to inspire their peers to do likewise.

www.bild.org.uk

British Institute of Learning Disabilities offers training a range of issues to professionals working with disabled people

www.lanarkshiresexualhealth.org/disability

Information on sexual health for disabled people taking a rights-based approach. Includes Lanarkshire Sexual Health Strategy and Action Plan, 2005-2008, which aims to promote positive sexual health, in all its dimensions, in a way that is equitable and non-judgemental, and sensitive to individual needs.

www.disabilitynow.org.uk

Includes a personal ads section – pushing the boundaries – an article on cross-dressing, a writer of eroticism who is a wheel-chair-user, and a Civil Partnership.

www.mcks.scot.nhs.uk

Enormous source of useful resources compiled by NHS Edinburgh and Lothian, including practical guidance for workers including issues to do with masturbation, and support which is available.

www.enable.org.uk

Campaigning charity run by people with learning disabilities – includes *Surviving Sexual Abuse: an easy-read guide.*

www.sexsupport.org

Susan’s Sex Support site covering a wide range of topical issues on sexual health and relationships for disabled people, including a quiz to take if you are considering having sex, and frank discussion.

www.wheelchairpride.com

For young people - includes a beauty contest for wheelchair users.

www.themwifies.org.uk

Them Wifies presents *Josephine – Let’s Talk about SEX! ‘n’ stuff* - a community arts organisation based in Newcastle Upon Tyne – a learning resource for women with learning disabilities, exploring a range of sexual health issues including breast awareness and sexual rights and choices.

www.apda.org.uk – Asian People with Disabilities Alliance provides broad support for these communities.

For SRE in schools

Assessment, evaluation and sex & relationships education: a toolkit for those working with children and young people. 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. Blake, S, and Mutton, S. (2004) for the National Children's Bureau.

Organisations specific to Bradford, some of which are able to provide support or advice on sexual health

Bradford Parents' Forum - an established support group for parents of children with special educational needs – contact Nageena Khan n.k19@hotmail.com

www.badasg.org.uk - Bradford and District Autism Support Group - promotes independent living for children and young people aged 5 -18 living with autism. Offers social skills training for children aged 11 - 18, parent support groups, Asian parents support group, and help and guidance with benefits.

www.downsupportbradford.uk.com – support, training and activities for young people with Down Syndrome and their parents and carers

www.homestead.com/awareuk - Airedale and Wharfedale Autism Resource (AWARE) supports parents, carers, siblings, professionals and interested parties in the care and support of those with an autistic spectrum disorder.

Bradford Parent/Carer Participation Service – run by Barnardo's – a parent participation service for parents/carers of disabled children

www.snoopisfun.org.uk – special needs childcare offering activities and life skills for children and adults with learning disabilities

Access to Information for Minorities (AIM) Project – media project which supports disabled young people to develop media skills to produce their own resources eg Keep An Eye on Your Balls dealing with testicular cancer - 01274 848150

Advice on sexual health and information about services available in Bradford can be accessed through the central contact for Sexual Health Services 01274 200 024

Resources for use with disabled children and young people

Puberty and Sexuality for Children and Young People with a Learning Disability – produced by The Children's Learning Disability Nursing Team for Leeds NHS 2009 – a resource-book for schools and other organisations covers a range of topics and includes a session on Arousal, Masturbation and Dignity, and one on Testicular and Breast Care - www.leedssexualhealth.co

Safe: personal safety skills for deaf children - a group-work programme on DVD-Rom designed to help give deaf children the knowledge, awareness and language they need to stay safe and make better informed life choices - NSPCC (Kovic, Y, Lucas-Hancock J and Miller D)

All about us - a self-study learning tool to explore sex, sexuality and relationships, which can be used by someone with learning disabilities on their own or to complement other learning. Also available from the Family Planning Association are a range of books for professionals and parents - www.fpa.org.uk

CHANGE – the national equal rights organisation led by disabled people and based in Leeds has booklets on Abuse, Contraception, Masturbation, Friendship, Being Gay or Lesbian - www.changepeople.co.uk

Picture Yourself 2 - One of a range of resources for SRE including SRE and Learning Disability - by Hilary Dixon and Ann Craft with illustrations by David Gifford (updated 2002) - www.me-and-us.co.uk

Leaflets and short films using vision and sound about sexual health issues and aimed at younger people - www.easyhealth.org.uk

Excellent booklets on women's health issues eg *Cathy has Thrush* - www.elfrida.com

Leeds Animation Workshop are producing a DVD for 2010 to help people with learning disabilities, their families and people who work with them to feel more confident about relationships with friends and partners – proposed sections on sex and contraception, meeting and getting close to people - www.leedsanimation.org.uk

Let's Do It – creative activities for sex and relationships education for young people and adults with learning disabilities by Image in Action (168 pages, A4) including ideas of how to adapt the activities for different groups' needs. *Let's Plan It* is a companion resource with detailed planning guide for course preparation - www.brook.org.uk

Books Beyond Words is a series of books for people with learning disabilities produced by the Royal College of Psychiatrists using visual ways to explore some health topics such as going to the doctors, going for a Cervical Smear Test, speaking out about sexual abuse - www.rcpsych.ac.uk/bbw

GetYourHeadRoundIt - Using 'cool' puppets to give young people a voice about PSHE issues – '*Accessible, Inspiring and Interactive Social Education.*' Includes a DVD on *Emotional Well-being* for KS2 and one on *Sexual Health and Relationships* for KS3,4 - www.getyourheadroundit.co.uk

You, Your body and Sex – SRE DVD resource for people with learning disabilities and special needs – Kylie's Private World and Jason's Private World – covers issues including Self-examination, Consent, Love and Affection in relationships, Where to get condoms and advice - www.lifesupportproductions.co.uk

Feeling Grown Up - Oakfield School, Nottingham (formerly the Shepherd School) – a series of very simple illustrated booklets on subject such as menstruation, using public toilets, etc. New school web-site www.nottinghambsf.co.uk

'*How it is*' - an image vocabulary for children about: feelings, rights and safety, personal care and sexuality. Produced by Triangle and down-loadable from NSPCC <http://www.nspcc.org.uk/inform/howitis>

Growing up, sex and relationships – one booklet for young disabled people, one booklet for parents/carers and families and one for teachers - www.cafamily.org.uk

Information about a range of resources for use with people with Learning Disabilities is available through Glasgow Public Health Resource Unit - www.phru.net

Teaching Children with Down Syndrome about their Bodies, Boundaries and Sexuality – This book for parents blends factual information and practical ideas for teaching children with Down syndrome about their bodies, puberty, and sexuality. It has been used locally in Bradford to support the delivery of Speakeasy courses for parents run by the Down Syndrome support group. Terri Couwenhoven, Woodbine House 2007.

Challenging homophobia and heterosexism for people with learning disabilities and the people who care for them, and booklets exploring issues around lesbian and gay relationships - David Abbott and Joyce Howarth – www.bristol.ac.uk/norahfry/resources/online

Generic information on sexual health for young people

Educational site for 11 to 14 year-olds includes sex and relationships information - www.lifebytes.gov.uk

A guide for teenagers includes contraception, pregnancy and 'love bugs' - www.likeitis.org.uk

Information about sexual health and relationships aimed at young people - www.ruthinking.co.uk

Sexuality and Disability not aimed at young people

Holding on, Letting go - Sex, Sexuality and People with Learning Disabilities. Lots of information to boost confidence of families and carers. Drury J, Hutchinson L, Wright J. (2000). Human Horizons.

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Appendix 1- National policies

Every Child Matters provides the framework within which work with children and young people takes place, seeking to strengthen preventative services by focusing on four main themes: increasing support to parents and carers, ensuring that necessary intervention takes place before a crisis point is reached, addressing some of the underlying problems of weak integration and poor accountability, and ensuring that people working with children are valued, rewarded and trained.

Its five outcomes are the core of all work with children:

- Be healthy
- Stay safe
- Enjoy and achieve
- Make a positive contribution
- Achieve economic well-being

The DCSF document *Promoting the emotional health and well-being of children and young people – Guidance for Children's Trust partnerships, including how to deliver NI 50, 2010*, highlights the importance currently placed on well-being and personal development and the ways in which these are connected to achievement and success in life. The document points to the centrality of emotional health to ECM outcomes and how its promotion helps authorities to meet other priorities in the local area agreement.

It identifies good relationships as being amongst those protective factors which ensure that young people sustain good emotional health, and lists among 'risks' such factors as: learning difficulty or disability, academic failure, communication problems, specific developmental delay.

The document draws attention to the need for staff to change from seeing their role as 'remedial' towards using positive approaches (6.10). It also notes that the staff with the least experience of emotional health issues often spend the most time with vulnerable children and proposes that their capacity be developed (6.13).

In the summer of 2009, the DCSF published *Safeguarding disabled children – Practice guidance*, which, read alongside the statutory document *Working Together*, and the *Framework for the Assessment of Children in Need and their Families*, provided clear guidance and information for professionals working with children across all agencies. Besides highlighting the greater vulnerability of disabled children, the Guidance is clear that there might be factors which

professionals are not consciously aware of, which might make it more difficult for them to attribute indicators of abuse or to take action in the case of disabled children. It is the combination of the greater vulnerability of disabled children with surrounding factors which affect adults' responses, which can make dealing with sexual health and relationships issues with disabled children both particularly challenging and particularly important.

The Children's Plan: Building Brighter Futures set out targets for Children's Trusts to have in place by 2020, and government strategy emphasised integration of services as the key to successful delivery, describing the elements as being like layers of an onion: Inter-agency governance, Integrated strategy, Integrated process, Integrated front-line delivery, Outcomes for children and young people/Parents/Families/Community.

The aim is to develop a flexible, responsive service 'organised around the child, young person or family rather than professional boundaries or existing agencies', with Local Authorities playing a key role in driving the processes of change through their local Children and Young People's plans. Certain strategic aspects are particularly relevant for the present report: universality and inclusiveness, the connection between health and safety and thriving, the aim of narrowing a gap between disadvantaged children and their peers, and the emphasis which is placed on supporting parents and carers.

The Children's Plan sets out the expectation that by 2010 all schools will provide access to core specialist services such as sexual health advice. The tool which will support this is the Common Assessment Framework or CAF, a standardized tool used to conduct an assessment of a child's additional needs.

Appendix 2 – Research into sexual health issues for disabled adults

Some of the work on adult experiences of sexual health issues points up the importance of good practice to empower children. *Making the Links – Disabled women and domestic violence* includes experiences of the disabled women who make up 7% of the women who use domestic violence services and looks at the provision which is available to support them, with recommendations for good practice. It includes the following comments: '*Sexual violence appeared to be more common for disabled women than for non-disabled women*', '*Disabled women who reported abuse were often disbelieved, not taken seriously, or made to feel guilty, ungrateful, or unworthy of any relationship.*' (Women's Aid, 2008)

Two studies have looked at the sexual health needs of disabled people and some of the reasons why their needs have not been met. *Sexual health for people with intellectual disability* concludes that people with intellectual disability experience the same range of sexual needs and desires as other people. However, they experience many difficulties meeting their needs, might be discouraged from relieving sexual tension by masturbating, face a high risk of sexual abuse, and are likely not to be offered the full range of choices for contraception and sexual health screening. Poor education and social isolation may increase their risk of committing sexual offences. However, with appropriate education and good social support, people with intellectual disability are capable of safe, constructive sexual expression and healthy relationships, she suggests. (Eastgate, G, 2008)

Providing such support is an essential part of supporting people with intellectual disability. *Sexuality and personal relationships for people with an intellectual disability* is a two-part study, with service-users and with professionals. It found that service users, especially those over the age of 18 years, had an understanding of their sexual rights but also identified a number of social and cultural barriers that they felt prevented them from achieving sexual autonomy. Those under the age of 18 years had only rudimentary knowledge of sexuality issues, for example pregnancy and sexual anatomy, but aspired to relationships and marriage similar to those over the age of 18 years. The study concludes that provision of sex education training and promotion of positive attitudes towards appropriate sexual expression is critical to the realisation of sexual autonomy for people with an ID. It recommends providing staff and family carers with opportunities for dialogue and ongoing training in the area of sexuality. (Healy E, McGuire BE, Evans DS, Carley SN, 2009)

Enhancing capacity to make sexuality-related decisions in people with an intellectual disability shows how individually-tailored sex education modules twice-weekly for ten weeks and tailored sexuality education can improve capacity to make sexuality-related decisions. *Sexual relationships in adults with intellectual disabilities: understanding the law* shows that there is a very limited understanding amongst adults with intellectual disabilities of the laws around sexuality which might protect them. The study suggests that there is a need to educate people with Intellectual Disabilities about the laws relating to sexuality and stresses how important it is for people to understand the law and, given the high rates of sexual abuse perpetrated against people with ID, how essential it is for them to benefit from the protection the law affords. (Dukes E, McGuire BE, 2009; O'Callaghan AC and Murphy GH, 2006)

Two studies which explore the practice of health professionals around 'sexual expression' with regard to disabled people demonstrate that, while factual information about medication, etc. is more straightforward, the areas which might be felt to be important by service users are often challenging for health professionals. The studies call for change to '*encourage recognition of the sexual needs and desires of people with disabilities and provision of support for sexual health through committed and competent teams.*' They also look at some of the barriers which can prevent health professionals from dealing well with broader sexual health issues and suggest good practice (Couldrick, Sexual expression, physical disability and professional practice, 2008, 12(4); Couldrick, The Recognition Model: a new sexual health mode of practice for use by disability teams, 2009, 13(2))

Challenges which staff experience and the need for appropriate training are explored in two further articles. One looks at penile hygiene and suggests that supporting men and boys with an intellectual disability to meet their penile hygiene needs is perhaps one of the least acknowledged but most confronting issues facing care staff. It makes the point that the delivery of intimate hygiene can be a challenging topic particularly as it has been drawn into the emerging sexuality discourse and the ongoing abuse narrative. Compounding this challenge is the lack of guidance in intimate care for support staff. In addition, whereas males with an Intellectual Disability outnumber the female, female care staff greatly outnumber male staff. The second article looks at staff experience in dealing with sexual incidents and finds that nearly 50% of staff identified more training and clear policy guidelines as the two means of increasing their confidence in dealing with issues of client sexuality. These results highlight the need for staff training that spans agencies and results in common approaches to client sexuality. (Wilson NJ, Cumella S, Parmenter TR, Stancliffe RJ, Shuttleworth RP, 2009; McConkey R, Ryan D, 2008)

Appendix 3 - Methodology, Focus Groups and Data collection

Stage 1

The young people

Focus groups were set up with thirty-nine older young people in nine groups, three in youth service settings, two in a special school and four in mainstream schools. The ages of the young people ranged from thirteen to early twenties. There were almost equal numbers of males and females, and a mix of ethnicities with a balance of White British and Asian/Pakistani heritage. Three young people were Deaf and one was a wheel-chair user. Of the others, some had severe to moderate Learning Disabilities and some had Learning Difficulties.

The central questions which they were invited to explore were: What things should young people know about? Where is the best place for them to learn these? What issues are young people like yourselves facing around sexual health? What is the best place or person to go to for help and what would improve things? A framework of topics from the National Curriculum for SRE was used for facilitators to assess how much understanding the young people had of key areas.

Small research projects were also set up for the young people to give feedback on their direct experience of contacting advice centres for young people which offer sexual health services.

Working with parents and carers

Focus groups were set up with eleven mothers and telephone interviews were held with seven fathers of disabled children, drawn from the groups who had already taken part in workshops or activities through Barnardo's. There was a balance of ethnicity. Besides this, discussions took place as part of interviews with professionals who were also parents, and within three visits to the Speakeasy for parents of children with Down Syndrome.

Parents/carers were asked: Has your child had any SRE at school? If so what have they learnt? What would you like your child to know? What issues do and your child face in this area? What support have you already received? What would be helpful?

With professionals

Interviews were carried out with almost one hundred professionals, mainly on an individual basis, but occasionally in teams, who work in a variety of settings and at various levels across the Bradford district. Some of these were selected because they were thought to be key professionals in their area of work, others because they work with children or young people in some capacity.

They were asked: What data do you keep with reference to sexual health and disabled young people? What training have you had to support delivery of services to disabled young people? What issues do you see young people experiencing? What do you have in place to support sexual health for disabled young people? What might help?

Stage 2

In the second stage, questionnaires were sent to schools and to other organisations across the district who work in this area. Initial responses were poor, so a follow-up was done by phone, and an extra 10 'snap-shot' phone interviews were done with GPs and practice staff, and with youth workers.