

The Sexual Health
Needs of Young People
with Learning Disabilities

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Wellbeing in Sexual Health ●

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Preface

Exploring the sexual health needs of young people is always challenging. This is particularly so for this research as sexual health and wellbeing has not historically been a topic for open discussion with young people with learning disabilities. Although this is generally true for Scotland's young people as a whole, there are additional issues to be overcome for young people with learning disabilities, including a legacy of the past failure to accept their rights to have sex and relationships education and subsequent fulfilling sexual relationships if this is what they wish to pursue.

This briefing paper, which is the culmination of 2 years' work by Health Scotland, brings together evidence on effective and promising practice and highlights the views of young people with learning disabilities. As well as drawing on commissioned research and inputs from practice (together making up the evidence review), this work has been enhanced through the ongoing inputs from an advisory group of key stakeholders as well as from feedback from participants who attended consultation seminars in January, June and November 2007. In addition, Judith Sim, formerly Public Health Advisor with Health Scotland, brought together the findings of the evidence review, identifying key strands and areas for further development as set out in this briefing. Without all of this help, this work could not have been completed.

The final section of this briefing paper identifies a number of potential future actions that, if pursued, will help ensure that sexual health services and sex and relationships education are better able to meet the needs of young people with learning disabilities, as well as those of their parents and the professionals that support them. In turn, this will make the intent and spirit of *Respect and Responsibility*, our sexual health strategy, a reality for all young people, including those with learning disabilities.

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31 December 2007

1 Introduction

This briefing paper summarises the key findings from an evidence review on the sexual health and wellbeing of young people with learning disabilities commissioned by Health Scotland. This review harnessed diverse forms of evidence, including the voices of young people themselves and emerging findings from practice, in what is a very new field. It consisted of three pieces of commissioned research, collectively referred to as the **evidence review**:

Young people with learning disabilities: defining the terms

The report *The Same As You?* (Scottish Executive, 2000a) defines people with learning disabilities as those with ‘... a significant lifelong condition which started before adulthood, affected their development and means that they need help to:

- understand information;
- learn skills; and
- cope independently’

This definition encompasses a broad spectrum of learning disabilities, from mild to severe and profound, and also includes people with autistic spectrum disorders. It does not, however, include those who have highly specific problems absorbing particular forms of information that may inhibit their learning (for example those with dyslexia or literacy problems).

Young people were defined for the purposes of the evidence review as those between 13 and 25 years of age.

- *People Should Tell You Stuff* (Morrison, 2006): a report on a consultation finding out more about what young people with learning disabilities need when it comes to sexual health services – referred to as the **TASC report**.
- *An Analysis of the Published and Unpublished Literature on Sexual Health Policy, Needs and Interventions with Young People with Learning Disabilities* (Burtney et al., 2006) – referred to as the **literature review**.
- *From Evidence to Practice: Case Studies of Promising Practice in Promoting Sexual Health and Wellbeing for Young People with Learning Disabilities* (Burtney and Fullerton, 2006) – referred to as the **promising practice report**.

This work was also informed by a previous study *Sexual Health and Relationships: A Review of Resources for People with Learning Disabilities* (Hasler et al., 2005) – referred to as the **resource review**.

The evidence review was commissioned because of a lack of easily accessible evidence and the increasing recognition that, historically, young people with learning disabilities have not been well served by mainstream sexual health provision. This was highlighted in key Scottish policy documents on sexual health and learning disability, notably *Respect and Responsibility* (Scottish Executive, 2005) and the *The Same as You?* (Scottish Executive, 2000a). The importance of action to address this is reinforced by recent legislation that makes it illegal to discriminate against people with disabilities in providing health and educational services (Disability Discrimination Act, 1995) and by NHS *Fair For All* requirements (Scottish Executive, 2006).

Recent policy documents and the evidence review are based on the premise that young people with learning disabilities have the same rights as all young people to have safe and fulfilling sexual lives. At the same time, they should be given the skills and confidence to recognise potentially abusive or harmful situations. This contrasts with earlier approaches, which viewed people with learning disabilities as asexual 'eternal children', dangerously sexual or predominantly in need of protection from others.

In synthesising the different pieces of research, this briefing paper highlights the emerging findings and remaining evidence gaps. Overall, the evidence review found significant similarities between the documented needs of young people with learning disabilities and those of young people in general. Many initiatives to address the needs of young people with learning disabilities draw on the principles and approaches that inform general good practice in promoting sexual health and wellbeing amongst young people. However, wider evidence on the health of people with learning disabilities indicates that failing to recognise their specific experiences and the barriers they face is likely to compound health inequalities (Health Scotland, 2004). These issues are highlighted here whilst acknowledging the commonalities between young people with learning disabilities and their peers in the wider population. Where points are not referenced, they are taken from the promising practice report.

2 Young people with learning disabilities: their sexual health and wellbeing

The population

The Scottish population of adults and children with learning disabilities is estimated at 120,000 (Scottish Executive, 2000a). On this basis, 20 people in every 1000 of the Scottish population have mild to moderate learning disabilities and two to three have severe or profound learning disabilities.

The population of young people with learning disabilities relevant to this report is likely to be skewed towards boys and young men. More boys are born with learning disabilities than girls because some genetically linked causes of learning disabilities are associated with males (Health Scotland, 2004).

There is little published material on the sexual health and wellbeing of young people with learning disabilities, and even less that is directly relevant to this population in Scotland.ⁱ Historically, data on sexual health outcomes or service use have not been routinely collected by disability which limits what we can know in these areas.

However, we know more about the needs and experiences of some young people with learning disabilities than others. For example, more is known about those with mild to moderate learning disabilities than about those with more severe learning disabilities. Finding appropriate methods and ethical frameworks for carrying out such research remains a challenge.

Additionally, young people with learning disabilities are as heterogeneous and diverse in terms of culture, ethnicity, faith and sexual orientation as the wider population of which they are a part. There is little known about the experiences of young people with learning disabilities in Scotland from minority ethnic or particular faith communities.

Some causes of learning disability are associated with physical disabilities and sensory impairments (Health Scotland, 2004). This means that a number of young people with learning disabilities can have complex needs and face multiple barriers in accessing health services and sex and relationships education (SRE).

The TASC report is one recent attempt in Scotland to find out directly from young people with learning disabilities about their experiences (Morrison, 2006). Although it involved small numbers, its findings reinforce those of similar initiatives elsewhere in the UK (Craik, 2002; Simpson et al., 2006). A comparison of the views of young people with learning disabilities with those of a general sample of young people was achievable given that the TASC Agency had previously carried out equivalent research for Healthy Respect, the national health demonstration project on young people's sexual health and wellbeing (TASC Agency and Healthy Respect, 2005). Both groups wanted strikingly similar services (described in Section 4). This study, some promising practice case studies and other published work all emphasise that

ⁱ We cannot necessarily directly transfer to Scotland findings from countries where histories of care, education and attitudes towards people with learning disabilities, or general approaches to sex and sexuality, may be very different from those locally. Similarly, we must be careful in assuming that research carried out with older UK populations can be applied to contemporary young people; older people may have grown up under educational and health systems that may be very different to those of today's young people with learning disabilities.

young people with learning disabilities have feelings, hopes and aspirations in common with many of Scotland's other young people (Simpson et al., 2006).

However, there are also differences between young people with learning disabilities and their non-disabled peers. Many of these arise from the nature of particular learning disabilities in combination with societal barriers and stigma faced by people with learning disabilities. The evidence review found that the following specific issues significantly shape the sexual health and wellbeing of many young people with learning disabilities:

- being regarded by parents and carers as asexual 'eternal children' who need to be protected from the world of sex and sexuality (Health Scotland, 2004)
- having a well-documented vulnerability to abuse and violence, which often results in those around them feeling protective (Beail and Warden, 1995; Sequeira and Hollins, 2003)
- having a greater dependence on parents and carers and spending a longer time living at home than many young people (Stalker, 2002)
having less time than other young people to socialise alone with friends (Stalker, 2002)
- having ways of communicating that may not be easily understood by others, and difficulties with reading and writing for many (Scottish Executive, 2000a; Health Scotland, 2004)
- being confused about conventions and expectations about sex, and about interpreting media representations of sex and sexuality
- having patterns of cognition which mean that facts and information are not necessarily easily absorbed at first hearing (Scottish Executive, 2000a; Health Scotland, 2004).

These factors combine to limit the access of young people with learning disabilities to the advice, information and help that they need from formal services, and to the informal channels through which many other young people learn about sex and sexuality, and behaviours that are appropriate or inappropriate in public.

Additionally, the TASC report found that finding trusted adults to discuss issues of sex and sexual health with was an issue for many young people (Grigg, 2001; Swann et al., 2003), and was a particularly significant issue for young people with learning disabilities. For example, although some young people with learning disabilities were able to talk to others in their family (particularly their mothers) about their concerns, including those around sexual health, for many discussing sex was completely 'off limits', even with those they were close to. There was a sense that some young people wanted to protect their families from their own developing sexuality. Along with research reported in the literature review (Craik, 2002), the TASC report also found that fearing the consequences of being 'found out' in relation to sexual feelings or expressions of sexuality loomed particularly large in the lives of many young people. Key workers were identified as the adults who they would most likely to talk to about sexual health matters and this was reinforced by the findings underpinning the Healthy Woman's Project, which examined the uptake of cervical screening (Levi et al., 2006). This suggests that those paid to provide direct care, for example care assistants from the voluntary or statutory sectors, were far more likely

than family carers to see women with learning disabilities as having a sexual identity and being in need of sexual health services.

The TASC report comments:

‘ . . . our view is that when considering the needs of young people with a learning disability, we need to see them as young people first then we, as educators or sexual health service providers, need to address the barriers that have been put in place which prevent them from accessing the information, help, support or services they need. This is our responsibility.’

Consistently running through the evidence review were the particular difficulties surrounding same sex relationships. Being gay or lesbian elicited negative responses from young people. In some cases, the TASC study participants did not know what the terms meant but associated them with negative connotations. The literature review found that young people found it difficult to get help or support in discussing homosexuality, that it could be threatening to discuss with friends, that it may exclude them from friendship groups, and that some would find it difficult to meet other gay or lesbian people (Abbott and Howarth, 2005; Dickey, 2005).

Some of the conflicting findings in the literature review on how much young people understand about sexual health may stem from the different tools used by various researchers.

In particular, there can be a lack of consensus on the relationship between concepts and use of language for this group. For example, although some argue that understanding lags behind awareness of language (Konstantareas and Lunsky, 1997), others suggest that, although terminology might not be accurate, the concepts behind many aspects of sexuality and sexual health can be understood by people with learning disabilities (Craik, 2002; Grant and Fletcher-Brown, 2004).

Future work could build on the innovative methods used by TASC and other initiatives, which have worked hard to forge common words to discuss sexual health and wellbeing that young people understand and are comfortable with. Although this is key for all young people, it is particularly so for those with learning disabilities. Issues of language and methodology are described in more detail in Sections 3 and 7 on SRE and on involving young people respectively.

The sexual health and wellbeing of young people with learning disabilities: a summary

<p>We know that:</p>	<ul style="list-style-type: none"> ● young people with learning disabilities have many of the same experiences, needs, hopes and aspirations as other young people ● they face a number of specific barriers of access to the education, information and services that they need ● these barriers must be tackled if health inequalities are not to be compounded.
<p>We need to know more about:</p>	<ul style="list-style-type: none"> ● effective methods for finding out more about their views on sexual health.

3 Sex and relationships education

The McCabe report (Scottish Executive, 2000b) on SRE for young people in Scotland highlighted the importance of providing accessible school-based SRE for those with learning disabilities in both special and mainstream schools. However, there is currently no comprehensive picture of SRE provision for young people with learning disabilities in Scotland. The TASC report found that there are some young people who have never been given any SRE, and the literature review indicates that there is a lack of consistency in providing SRE to those with learning disabilities (Watt et al., 1997; Paul et al., 2004).

It proved much easier to collect information about dedicated or community-based initiatives relevant to the sexual health needs of young people with learning disabilities than it did about how effectively mainstream provision met their particular needs. The latter may exist but has not been well documented. Additionally, evaluations of general SRE interventions do not routinely include their impact on young people with learning disabilities, thus further limiting our knowledge. Some additional information about the provision of SRE in special schools should become available when Health Scotland's commissioned review of secondary school SRE programmes is published at end March 2008.

In the past, raising issues of sex and sexuality was frequently seen as encouraging sexual activity, and remaining silent on these issues was seen as protective for young people. When SRE did take place, it was largely concerned with redirecting or containing young people's 'inappropriate' behaviour, with little consideration for long-term education (Paul et al., 2004).

Promising practice case studies highlight the positive steps taken by mainstream, special schools and community settings to pioneer ways that recognise the rights of young people with learning disabilities to have safe and fulfilling sexual lives. The points below, drawn from promising practice case studies, also reflect general effectiveness evidence or accepted good practice:

- linking education and services, an important principle in *Respect and Responsibility*, is particularly important for young people with learning disabilities, who may be particularly unaware of the services available to them and who need support in using them
- flexibility is key: SRE delivered in fixed, timetable slots to groups of young people with different needs and levels of understanding is difficult in any class (Henderson et al., 2007) but is particularly inappropriate for young people with learning disabilities
- proper procedures should be in place to deal with potential disclosure during SRE provision (Sex Education Forum, 2004)
- SRE should sensitively address lesbian, gay and bisexual issues, often hidden for this group
- start SRE early and repeat often to make sure that young people understand and retain what they have learned.

Specific ways of adapting SRE to the limited abilities of many young people with learning disabilities to help them absorb and retain information include the need to:

School-based SRE for young people with learning disabilities: evidence from the literature

In Australia, Johnson et al. (2001) recommended that, when developing curriculum for adolescents with mild learning disabilities, teachers build on students' existing experiences, break activities into discrete tasks, provide opportunities for students to apply or transfer previous learning, help students generalise by providing multiple examples, and present learning in short periods of time.

In USA, the findings from a rigorously evaluated community-based sex education programme suggest that the programme materials and the techniques used by educators are as important as the information itself. Plunkett et al. (2002) argued that the techniques should incorporate visual, auditory and tactile methods. For example, the use of anatomically correct dolls could be used to initiate conversation and to assess the knowledge base of students. Techniques such as role play, modelling, videos and group work allow students the opportunity to hear information repeated in different ways throughout the session.

Some of these points are reflected in a factsheet which offers guidance on SRE in an English context (Sex Education Forum, 2004). These are incorporated into the Scottish SRE programme, SHARE, a generic programme enhanced for use with students with learning disabilities in mainstream schools.

- allow plenty of time
- have booster sessions
- deploy the increasingly innovative methods available for encouraging young people to explore issues of sexual health and wellbeing: these include those described opposite on school-based SRE for young people with learning disabilities and in some promising practice case studies – some are starting to incorporate methods for providing SRE to those with profound learning disabilities (Sex Education Forum, 2004)
- recognise that young people with learning disabilities may need input which particularly emphasises handling relationships and the emotional complexity that is involved in developing and sustaining adult relationships (Townesley, 2004).

Good practice relies on multi-disciplinary working between schools and external agencies. However, it is not enough to rely on these agencies alone to deliver SRE in school settings (Burtney et al., 2006). This can isolate SRE and detract from the need to consider the whole-school ethos and trust in teacher–pupil relationship as the basis for good SRE (Bucknall, 2005). Findings from the TASC report reinforce this, suggesting that the basis of trust was undermined if teachers shouted or appeared to lack understanding. The Caledonia Youth promising practice case study emphasises that trust has to be built up before raising sexual health issues (Burtney and Fullerton, 2006).

The lack of appropriate resources was raised as a challenge in the literature review and promising practice report. Both highlighted examples in which resources are being developed or adapted for use with young people with learning disabilities. Health Scotland's resource review has publicised those resources that are available together with a series of leaflets on a range of topics adapted for people with learning disabilities (Hasler et al., 2006).

Discussing sexual health issues with young people with learning disabilities

The TASC Agency worked with young people to create a cut-out character who they could talk about during the sessions without feeling that they were put 'on the spot'. They could also use it as a tool to help them to choose and use the words that they all understood and with which they felt safe in discussing sex and sexuality.

The Josephine Project works with women of all ages, predominantly in community settings, through drama and story-telling, using a life-size, anatomically correct cloth doll called Josephine. Through Josephine and the diary she keeps, women explore thoughts, feelings, keeping well and safe, the services available to them and how their bodies work (Burtney and Fullerton, 2006).

The potential of symbols, increasingly used to aid communication with people with learning disabilities, has not been explored in relation to sexual health and wellbeing. The TASC report identified this as an area for future exploration. However, the fact that there is currently no one recommended system of symbols for use within the NHS or across different sectors in Scotland is likely to limit immediate developments in this area (NHS QIS, 2006).

Limits to young people's understanding of abstract representations represent a challenge and mean that materials occasionally have to be graphic and explicit. This can pose problems for professionals, such as not feeling comfortable using such materials and having concerns over the responses of parents and carers. This reinforces the need for support and education for teachers, the involvement of parents, and policy and guidance, which are discussed in Sections 5, 6 and 8 respectively.

Finally, as SRE for people with learning disabilities is a relatively new area, there are few evaluations. Only a few initiatives moved beyond descriptive research to employ robust designs and outcome measures to ascertain the efficacy of different approaches.

It is difficult, therefore, to assess the relative effectiveness of particular SRE models. However, such models for the general population of young people in the UK have not been sufficiently rigorously evaluated to enable comparison with those for young people with learning disabilities (Grigg, 2001; Henderson et al., 2007). General initiatives to evaluate SRE could usefully include its impact on young people with learning disabilities.

SRE for young people with learning disabilities: a summary	
We know that:	<ul style="list-style-type: none"> • linking education, advice and services is particularly important for young people with learning disabilities • SRE needs to start early and be revisited regularly and often • agreeing language that young people understand and feel safe with is essential for effective SRE for this group • good SRE depends on the involvement of professionals from a variety of agencies and young people themselves, with policy supported and implemented across institutions and areas.
We need to know more about:	<ul style="list-style-type: none"> • the relative effectiveness of different models, techniques and settings • the nature of effective symbols to use in SRE.

4 Providing sexual health services

Improving primary care for people with learning disabilities

In Scotland, primary care practices are now required to establish, under the Quality Outcomes Framework, registers of those aged over 18 with learning disabilities and to provide annual health checks.

Those participating in the Directly Enhanced Service for people with learning disabilities are also required to make links with community groups and others to identify barriers of access to primary care. We know little yet about how these initiatives can incorporate sexual health and wellbeing.

Knowledge about the uptake of sexual health services (or any health services) by young people with learning disabilities is limited as their use is not monitored by disability. Recent Scottish evidence suggests that fear of stigmatising people has prevented diagnosis of learning disability and communication needs being recorded routinely in medical records (Wood and Douglas, 2007). This means that people cannot easily be targeted with the care, materials and information that they need. However, the situation could change where directly enhanced services are provided in primary care settings (see box opposite). There is also an increasing amount of good general guidance available both on identifying people with learning disabilities using NHS services and on providing accessible services for them (Scottish Executive (2002b; NHS QIS, 2004 and 2006).

Young people with learning disabilities – and some of their parents and carers – generally have a very low level of awareness of the sexual health services available to them, even when specialist services are targeted at meeting their needs (Craik, 2002).

The young people involved in the TASC report stressed that they wanted to use mainstream services rather than special services. They articulated a vision for an ideal sexual health service which had much in common with that of their non-disabled counterparts – for example services that are local, friendly and anonymous and which offer the opportunity to see a practitioner of the same gender as themselves. Assurances of confidentiality, key for all young people, were particularly important.

However, these young people drew on their previous experiences of using health services and some of their everyday experiences of having a learning disability to highlight particular features that would make services easier to use. They wanted staff who understood what it might be like to have a learning disability, who did not stigmatise them and who did not expect them to be able to read easily or to fill in forms.

Many of these points are mirrored in and supplemented by findings from the literature review, and in more general findings about barriers of access to health services for people with learning disabilities, which include:

- flexible appointment systems
- short appointment times

- reliance on ability to read
- reactive delivery of health-care systems, which depend on people coming forward to ask for help
- physical access barriers, which can be significant as many people with a learning disability also have a higher than average level of physical disability (Health Scotland, 2004)
- poor co-ordination of information between services and agencies
- institutional discrimination (Lennox and Kerr, 1997; Powrie, 2002; Wood and Douglas, 2007).

The Feeling Good clinic at the Sandyford: a promising practice case study

The Sandyford is a Glasgow-wide initiative in sexual and reproductive health. Its Feeling Good clinic aimed to help generic services respond to the health needs of people with learning disabilities. With no initial funding, the Sandyford-based nurses worked together with local learning disability specialists, learning from each other as they went. A dedicated point of contact was established for people with learning disabilities and professionals working with them.

Via the Glasgow Learning Disability Partnership in each community healthcare partnership, six “dedicated” staff are facilitating 'relationship groups' for people with a learning disability. These staff will link with Sandyford community 'hub' staff to ensure mutual support and appropriate referrals to Sandyford services.

Having an established specialist point of contact has increased the number of young people with learning disabilities using the clinic.

Many young people with learning disabilities are unable to use health services on their own. However, there is evidence that suggests it is a matter of pride for some to do so (Levi et al., 2006). This lack of autonomy raises issues of how to create space for young people to talk freely to health professionals about matters that they may not want their parents or carers to know about whilst at the same time depending on parents and carers for communication and other support – for example getting to clinics.

The promising practice case studies highlight how the balance between ensuring confidentiality on the one hand and protection from abuse on the other – an issue in providing services for all young people (Morrison and McCulloch, 2004) – is particularly complex for those with learning disabilities. This suggests the need for clear guidance and policy. Encouragingly, there is increasingly detailed guidance on these issues for health professionals working with young people with learning disabilities.

There are some emerging models of sexual health service delivery that focus on enabling access for people with learning disabilities. All those highlighted in the promising practice report are based in mainstream care, which accords with what young people want, but with specialist clinics or points of contact within them.

Promising practice case studies highlight the following as important:

- a 'whole clinic' approach with training provided for all staff, including reception staff, on meeting the needs of people with learning disabilities
- the availability of materials and information that are appropriate for people with learning disabilities and the need to involve users in developing or adapting materials; using others as proxies for what people with learning disabilities understand is no substitute for this
- extended or repeat appointments depending on the needs of the individual
- the potential for sexual health and wellbeing to be built into generic anticipatory care initiatives for people with learning disabilities.

Providing sexual health services for young people with learning disabilities: a summary	
We know that:	<ul style="list-style-type: none"> ● awareness of sexual health services is likely to be low unless the services actively promote themselves to young people with learning disabilities at regular intervals ● most young people with learning disabilities prefer to use mainstream services; specialist clinics or points of contact facilitate their use of mainstream services ● sexual health services can draw on generic research findings on ways of improving access to health care.
We need to know more about:	<ul style="list-style-type: none"> ● the optimum ways of ensuring a balance between confidentiality and protection ● how specific provision for young people can incorporate the needs of those with learning disabilities; most promising practice case studies featured generic adult health provision, whereas young people wanted access to the same services as their peers ● the extent to which arrangements for supporting young people's transition to adulthood include raising awareness of and support for using sexual health services.

5 Supporting professionals

There is no comprehensive picture of how those responsible for providing SRE and sexual health services for young people with learning disabilities are trained for and supported in their role. The literature review and the promising practice report indicate that:

- many staff lack confidence and feel ill-equipped to provide SRE and services that are in keeping with recent thinking about sexual health and learning disability (Watt et al., 1997; Stevens, 2004; Bucknall, 2005)
- there can be tensions between protection and empowerment (Hingsburger, 1995)
- lack of training and back-up compromises their abilities to support young people (Watt et al., 1997; Paul et al., 2004; Stevens, 2004).

There is a need for training for all staff with a role in supporting young people with learning disabilities, including those providing direct everyday care, such as key workers and other carers. The latter are sometimes neglected as most education and training opportunities are directed at those working in management or professional capacities (McConkey and Ryan, 2001; NHS QIS, 2006). This is particularly significant given the TASC report's findings on the importance of key workers as confidantes for young people.

Some specific areas in which staff need support were identified. For example, staff can be concerned about negative parental reactions to the provision of SRE and sexual health services for young people, and this can inhibit them (Craik, 2002; Bucknall, 2005; Wheatley, 2005). The literature review also found that staff were particularly concerned about tackling lesbian, gay and bisexual issues with young people with learning disabilities (Abbott and Howarth, 2005).

Staff regretted the lack of clear guidance available to them on these and other issues (Craik, 2002; Wood and Douglas, 2007). This highlights the importance of detailed organisational policy to support staff (and keep them legally safe). Section 8 describes some of the good examples being developed in this area. There are also established examples and emerging promising practice in education for staff, for example those provided by the websites of the Simply Being Me and the Me and Us initiatives. General effectiveness literature and accepted good practice indicate that:

- Education may be more effective if it incorporates the opportunity for staff to explore their own values and attitudes to sexuality and those of people with learning disabilities in particular
- Involving people with learning disabilities in providing such training can be a powerful approach to learning as it gives professionals an opportunity to hear, first hand, what it is like to use services from a users' perspective. This is further detailed in Section 7
- It is important to ground education and professional development for staff in real-life situations, keeping it practical and user centred.

Support networks for staff in Surrey

Staff from Surrey Oaklands NHS Trust and Croydon Social Services Department agreed to work together to make sex and sexuality part of everyday planning for people with learning disabilities. They have created an active support network that provides mentors for service users, parents and staff. Trained by project co-ordinators, these mentors provide advice and help in action planning. At the heart of the network is a workbook, People, Friendship and Sex, which the mentors work through with users, encouraging discussion and exploring ideas.

Creative practice in education and support for staff other than formal ‘training’ is emerging. The promising practice report suggested that allowing time for networking, intensive joint working and reciprocal ‘shadowing’ can help mainstream sexual health service staff and help learning disability specialists feel more confident in addressing the sexual health needs of young people with learning disabilities.

Through a mutual ‘shadowing’ initiative, sexual health staff at Glasgow’s Sandyford Initiative began to feel more confident working with people with learning disabilities, and community learning disability staff began to feel more confident about sexual health and wellbeing issues. Information from monitoring and evaluation of the effects of formal and informal training initiatives on practice is needed. Knowledge of resources to support sexual health of young people with learning disabilities is increasingly being addressed, for example through Health Scotland’s resource review (Hasler et al., 2006).

Supporting professionals: a summary

<p>We know that:</p>	<ul style="list-style-type: none"> ● sexual health staff need education and access to resources for working with young people with learning disabilities ● learning disability staff need education on sexual health and wellbeing ● staff can learn from each other in ways other than formal ‘training’, for example by mutual shadowing ● all staff potentially in contact with people with learning disabilities need education on how to meet the needs of this group ● staff need clear guidance on providing sexual health services and SRE for this group.
<p>We need to know more about:</p>	<ul style="list-style-type: none"> ● the needs of staff providing direct care to young people – for example key workers – for education and support ● the relative effectiveness of existing forms of education and support for staff.

6 Involving and supporting parents and carers

Supporting parents through Growing Up Aware: evidence from the literature

This is a rare example of a programme evaluated for its effectiveness through a well-designed randomised controlled trial (Ballan, 2004). Based in the United States, it aimed to demystify sexuality and learning disabilities; increase parental acceptance of sexuality; improve parental communication skills about sexuality; and increase children's awareness through parent education.

The author argued that the success of the programme lay in the identification of parents' support needs through focus group discussion and in eliciting their views on programme delivery (for example programme format, group membership, meeting times, childcare, etc.). Throughout the programme, parents were viewed as experts on their children while the facilitator's role was to focus on enhancing parents' adaptive capacities and coping skills.

The care taken to develop and pilot the programme was a further important factor in its success.

The literature review suggests that, although parental involvement in and support for SRE is important for all young people and adds to its effectiveness (Grigg, 2001; Swann et al., 2003), it is particularly so for young people with learning disabilities, given the key and prolonged role of parents and carers in their lives. The same principle applies to health services: promising practice case studies such as the Feeling Good clinic at the Sandyford highlighted that, given their role as 'gatekeepers', it is particularly important that services which aim to include young people with learning disabilities address the experiences of their parents and carers.

Information about the specific needs of parents and carers of young people with learning disabilities is limited. However, there are parallels between parents and carers of young people with learning disabilities and other parents. This includes a lack of adequate knowledge, a lack of confidence, and their need to be supported to enable them to talk to young people in a meaningful way as it does not necessarily happen 'naturally' (Cheng and Udry, 2003). However, it is also clear that they have additional concerns. These include the sometimes overprotective approaches previously outlined in Section 2, and a fear amongst some that sexual health knowledge might increase the potential for the sexual abuse of young people (Swain and Thirlaway, 1996).

Potential ways of effectively supporting the parents and carers of young people with learning disabilities include:

- involving carers in SRE and service provision (Plunkett et al., 2002)
- involving them early in a child's life and on a continuous basis to avoid contact only when a crisis develops
- developing materials and information that specifically address their concerns (Ballan, 2004).

Some organisations, such as Barnardos Connect, have been developed specifically to meet the support needs of parents of children with learning disabilities. There is some limited evidence that the provision of training to professional carers alongside provision of training for parents and people with learning disabilities improves the sexual health knowledge and outcomes for people with learning disabilities and their parents and professional carers (Plunkett et al., 2002).

Involving and supporting parents and carers: a summary	
We know that:	<ul style="list-style-type: none"> ● parents and carers of young people with learning disabilities have a 'gatekeeping' role in relation to SRE and sexual health services, and that it is particularly important to address their concerns ● parents need support to acknowledge their offspring as sexual beings ● it is important to involve parents and carers from the start.
We need to know more about:	<ul style="list-style-type: none"> ● the detailed needs of the parents and carers of young people with learning disabilities for support and information.

7 Engaging with young people

Encouraging young people's participation in improving their sexual health was a theme across the promising practice case studies. This reflects a wider acknowledgment of young people's rights to participate in decisions affecting them (UN Convention on the Rights of the Child). It also reflects the growing influence of the self-advocacy movement for people with learning disabilities, which promotes their rights to speak for themselves. This contrasts with a ready acceptance in the past of others to speak for people with learning disabilities and by proxy to assess their needs and experiences. NHS Quality Improvement Scotland (NHS QIS) has made the involvement of people with learning disabilities central to the standards it has set for health service delivery to people with learning disabilities and to the guidance it produces for staff (NHS QIS, 2004 and 2006). It has also produced a report on involvement in collaboration with people with learning disabilities (NHS QIS and Scottish Consortium for Learning Disability, 2006), which provides clear pointers for health service providers.

The benefits of encouraging the participation of young people in promoting sexual health and wellbeing are highlighted in the promising practice report. These include:

- the increased acceptance of courses and resources when the target group is involved in shaping the production
- the rich perspective people with learning disabilities can give when they are involved as co-trainers or when they relate their own experiences, in contrast to training carried out only by professionals who can only guess at what it is like to receive services
- the wider benefits for young people of using their skills and resources to promote their sexual health and wellbeing, for example the benefits of the shared experiences of talking and reading together about sexual health and relationships can remain after the activity or intervention has been completed.

The Healthy Women's Project: participation in producing materials

A 3-month consultation was held with women with learning disabilities on a range of health-related materials in preparation for producing cervical screening materials. This intensive work highlighted in detail words, pictures and symbols the women understood and those that confused them. The latter included the 'thought bubbles' which are commonly deployed in materials for people with learning disabilities but which were understood only by the most able women (Levi et al., 2005).

The report identifies that young people with learning disabilities can participate in the promotion of sexual health at different levels through:

- involvement in their own individual care and learning, for example Caledonia Youth
- helping to shape services and training others: for example, the Scottish Consortium for Learning Disability (SCLD) is one of a number of projects that involve people with learning disabilities in training professionals; Simply Being Me in Fife is an innovative project that supports lesbian, gay, bisexual and transgender (LGBT) people with learning disabilities in taking an advocacy role to raise awareness of the double challenge facing them, and assists carers to support them.

- involvement in policy-making: for example, the development of the *Making Choices, Keeping Safe* policy in Lothian included consultation with people with learning disabilities.

The promising practice report also highlighted a number of challenges to encouraging participation in sexual health, and ways of overcoming these:

- people with learning disabilities often like to please others in their responses; in involving and consulting them, therefore, it is crucial to probe sensitively beyond their immediate statements
- linking with advocacy projects can be a productive way of engaging young people in sexual health issues
- establishing the genuine participation of young people with learning disabilities takes time and resources – for example to build relationships between all those involved with, and build the involvement of, people with learning disabilities; the practical implications of arranging transport, venue and timing should also be taken into account.
- abstract notions such as advisory or reference groups can be difficult to grasp for people with learning disabilities; these need to be made concrete and tangible to be real
- providing accessible information and materials and structuring meetings so that they are accessible are key to establishing participation.

Projects committed to participation produced easy-read versions of relevant documents. They also used the Speakeasy system for recording meetings.ⁱⁱ

Engaging young people in their sexual health and wellbeing: a summary	
We know that:	<ul style="list-style-type: none"> • involving young people in their sexual health and wellbeing can bring benefits to the work and boost their self-esteem • establishing genuine participation needs time, resources, accessible materials and attention to practical issues such as transport and timing • collaborating with advocacy organisations can enhance the involvement of young people with learning disabilities.
We need to know more about:	<ul style="list-style-type: none"> • effective ways of involving young people in their own sexual health and wellbeing • involving young people with more severe disabilities and those from minority ethnic or faith communities.

ⁱⁱ In this context, Speakeasy refers to a way of simultaneously recording proceedings using a combination of simple words, pictures and symbols.

8 Developing local policies

National policy on learning disability and sexual health [notably *The Same as You?* (Scottish Executive, 2000a) and *Respect and Responsibility* (Scottish Executive, 2005)] has provided both a solid direction for work on sexual health and learning disability and the impetus for policy development at local level. Each NHS board, together with their local authority and other stakeholder partners, is required to produce a local sexual health strategy. A number of these address learning disability and, in some cases, a specific policy on sexual health and learning disability has been produced, with associated guidance for staff.

Previous sections of this briefing paper have highlighted the importance of local policy and guidance, and the vulnerability experienced by staff in its absence (Craik, 2002; Finnegan and Clarke, 2005; Wood and Douglas, 2007).

Organisational ethos is a significant influence on the attitudes of individual staff (Christian et al., 2001; Allen, 2006) and evidence suggests that, in the absence of specific policy, staff are more likely to rely on their own values, leading to a haphazard approach to promoting sexual health and wellbeing (see the Norah Fry Research Centre website). This suggests the need for considered local policy and guidance to support staff in working to the agenda set by wider national policy. This is needed at different levels, for example within particular institutions and services as well as at NHS board and local authority levels. Practitioners need policy support in providing SRE, dealing with sexual incidents or supporting lesbian, gay or bisexual young people, for example.

In some cases, local areas have started from scratch in developing policies and in others they have adapted them from elsewhere. The promising practice report outlines the pros and cons of each approach. Generally, the advantages of adapting policies that have been developed elsewhere include being able to preserve local resources for roll-out and implementation but this can come at the cost of loss of ownership and understanding of the issues that have to be addressed when a policy is developed from scratch.

The following key points underpin successful policy development and implementation:

- Providing young people with learning disabilities with the opportunity to access policies that have an impact on their lives [the literature review notes that an encouraging number of recent policies include an easy-read version: the development of picture banks by organisations including CHANGE and the Norah Fry Research Centre should facilitate the process of developing easy-read publications]
- Using accessibly produced policies as a resource through which support workers can help to explain relationships and sexual wellbeing to people with learning disabilities
- Achieving integrated partnerships within and across agencies in both policy development and implementation
- Promoting ongoing training programme to support workers at ground level in understanding and taking ownership of the policy

- Ensuring robust monitoring and evaluation of existing policies to ensure their currency and responsiveness to ongoing issues

Developing local policies: a summary	
We know that:	<ul style="list-style-type: none"> • detailed and clear guidance and policy for staff in this sensitive area is crucial • national policy has provided an impetus for increasing policy development at local level in Scotland • increasingly such policy is developed through multi-agency groups and involves people with learning disabilities and their carers • an increasing number of Scottish policies are available in easy-read format.
We need to know more about:	<ul style="list-style-type: none"> • how practice has changed as the result of recent policies on sexual health and learning disability.

9 Actions and next steps

National approaches aimed at redressing health inequalities are directed at building the needs of specific groups into mainstream health and educational provision, with specific initiatives to supplement this or to enable groups bearing the brunt of inequalities to access mainstream services. This is an approach broadly supported by the evidence review.

Key policies in sexual health and learning disability – *Respect and Responsibility* and *The Same As You?* – are implemented through national ‘overseeing’ groups and by various local groups in each NHS board and local authority area. These national and local groups are key vehicles for ensuring that the sexual health and wellbeing of people with learning disabilities is built into the implementation of both policies.

The options for potential further work recognise that each local NHS board and local authority area will differ in how the policies are implemented. This is because, within the overarching framework of national policy and standards, each area has its own way of providing and co-ordinating sexual health (included SRE) and learning disability services. Each area also differs in its geography and in the size and nature of its population of people with learning disabilities. In a number of cases, it makes more sense to recommend actions that apply to the general population of people with learning disabilities rather than make specific recommendations for young people within this population.

Although seeing local work as crucial to improving the sexual health of young people with learning disabilities, the following also recognises the importance of enhancing this through appropriate national support and initiatives to promote the sharing of good practice across localities.

1 Overall co-ordination and sharing of good practice in the field

The interest amongst practitioners in the results of the evidence review, and in particular the promising practice case studies, suggests the importance of building on this through the establishment of an ongoing forum for sharing emerging practice and new evidence.

Potential future action could include:

- The development of a web-based forum dedicated to improving the sexual health and wellbeing of people with learning disabilities aimed at professionals and agencies that support young people and their parents/carers.

2 Assessing the needs of young people with learning disabilities for SRE and sexual health services

Although little work has been carried out in the UK on the sexual health needs and experiences of young people with learning disabilities specifically, there have been two substantial pieces of research on the needs of adult communities. Both of these broadly reflect the findings of the TASC report, which did focus specifically on the needs of young people.

Potential future action could include:

- Assessments by local areas of the sexual health needs and experiences of their own communities of young people with learning disabilities, drawing on diverse sources of evidence. These could include, as a priority, the views of young people themselves, supplemented by the views of parents and carers and of health professionals.
- National support for local work of this nature produced in the form of a brief guide to ways of assessing need, drawing on material from the evidence review. This would supplement the existing NHS QIS guide to involving people with learning disabilities in health services, and focus on the specifics of how to engage with young people with learning disabilities in the sensitive area of sexual health.

3 Sex and relationships education

It proved easier to assess SRE provision for young people with learning disabilities in special schools than it did in mainstream schools. More specifically, although SHARE has been enhanced to support teachers in delivering SRE for young people with learning disabilities, we know little about how it is being used in mainstream schools. Information on this may indicate wider issues about barriers and facilitators to SRE for this group in mainstream schools. We also know little about how SRE is incorporated into support for the transition to adulthood for young people with learning disabilities.

Potential future action could include:

- Incorporating SRE provision for pupils with special needs in prospective national or local research commissioned on SRE in primary or secondary schools.
- Developing a supplement to existing materials for those providing SRE on ways of introducing the topic to parents/carers. Although SRE outcomes for young people with learning disabilities are likely to be broadly similar to those for all young people in terms of skills, confidence and knowledge, those providing SRE may need particular support in communicating these to parents.
- Assimilating monitoring quality of the provision of SRE for pupils with learning disabilities into mainstream mechanisms – for example through local authority Quality Improvement Officers or Her Majesty's Inspectorate for Education (HMIE).

4 Providing sexual health services

Potential future action could include:

- Producing a guide to providing user-friendly sexual health services for people with learning disabilities, incorporating a set of standards. This should draw on material from Health Scotland's evidence review and local and national expertise in the area.
- Having appropriate references and images for people with learning disabilities in local authority and NHS board generic publicity and information materials on sexual health. This would support 'myth busting' in relation to sexuality and young people with learning disabilities.

5 Support for parents/carers

Addressing the needs of and providing support for parents and carers emerged as a key issue in the literature review, and discussions as part of its dissemination have made clear that this is a main concern amongst professionals.

Potential future action could include:

- Developing resources to help parents and carers talk to young people with learning disabilities about sexual health and wellbeing. This should make explicit the risks of abuse that young people are exposed to if they are not supported by those around them to explore and develop confidence around issues of sexual health and relationships.

6 Support for professionals

We know little about how equipped health professionals are to promote the sexual health and wellbeing of young people with learning disabilities.

Potential future action could include:

- Assessing how well equipped NHS staff are to meet the sexual health needs of people with learning disabilities in NHS boards' training needs analyses. Inter-agency sexual health groups and community planning mechanisms are potential ways of extending such analysis to other groups of professionals.
- Evaluating training, education and professional development to assess its usefulness to practice (rather than simply how useful the training/education events themselves were).
- Promoting expertise amongst those working in sexual health and learning disability through relevant local sexual health improvement and learning disability groups and networks.

7 Policy

Although national policies on learning disability and sexual health are robust, there is scope for improvement in how they integrate at local and national levels.

Ensuring implementation of policy on the sexual health and wellbeing of young people with learning disabilities – and the general population of people with learning disabilities – remains a challenge.

Potential future action could include:

- Scrutinising mechanisms for implementing both policies in NHS boards and local authority areas and for meeting the needs of people with learning disabilities – for example through managed clinical networks for learning disability (where they exist) and through performance management systems – by integrating sexual health and learning disability into them.
- Providing details in annual progress reports on *Respect and Responsibility* by NHS boards and their stakeholders/partners of how the sexual health and wellbeing of people with learning disabilities is being promoted.

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