

# Equalities Scoping Study



foundation for  
people with  
learning disabilities

## Introduction

'Valuing People Now' is for all adults with learning disabilities and their families. This means it should be fair for everyone:

- young people and older people
- people of any race or culture
- people of any religion or belief
- gay, lesbian, straight, bisexual and transgender people
- men and women
- people with learning disabilities who have other disabilities or health problems

Alongside 'Valuing People Now' was a report called an 'Equality Impact Assessment'. This looked at the experiences of all the different groups in the list above. It said that things were still not fair for everyone. It said the actions in 'Valuing People Now' should help to make things fairer.

The Office of the National Co-Directors for Learning Disability asked the Foundation for People with Learning Disabilities to see whether things were getting better for these different groups.

The Foundation was also asked to look at what was happening about helping people to develop friendships and relationships. The Foundation was asked to look at:

- articles and reports
- websites
- the Choice Forum, Hidden Loves Network and UK Health and Learning Disability Network.

The evidence we gathered in early 2010 was limited by the short period of time available and we recognise that there may be lots more examples of good things (and bad things)!

We also know that with the current emphasis on personalisation and citizenship there is a lot more that needs to happen to enable people with learning disabilities and their families, with a range of diversity and needs, to engage, feel empowered and receive the services and support they need.

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**Foundation for People with Learning Disabilities**

## How the work was done

Searches were carried out via:

- SCIE Online
- NHS Evidence
- Choice Forum
- UK Health & Learning Disability Network
- PMLD Network
- Hidden Loves Forum
- King's Fund information service
- Valuing People Now website
- Learning Disability Today archive

Topics searched for (all in relation to people with learning disabilities):

- ageing and older people
- gender
- sexual orientation and identity
- religion, belief and spirituality
- race, culture and ethnicity
- relationships, sex and parenting

Period: January 2009 to mid-May 2010

Geographical limitation: England only

## Evidence of action or change since 01.01.09

Valuing People Now delivery programme 2010/11: VPN housing lead to work with National Valuing Families Forum on helping older families to plan ahead

Valuing Older Families Now (2010): workbook for Partnership Boards to check progress and plan improvements

Torbay older family carers initiative, set up by the Partnership Board in 2003, produced a report on its achievements (Feb 2010)

The new Public Health Observatory for learning disability will gather and analyse data that should cast further light on the health of the ageing population

## Emerging issues

Review of research on dementia in people with learning disabilities confirmed evidence of early onset in people with Down Syndrome. Whilst evidence was found of people with learning disabilities receiving medication for dementia, there was very little evidence of non-pharmacological interventions to improve quality of life for people and their families (Strydom et al., 2009). Systematic review of the literature on interventions showed a lack of robust evidence for effectiveness (Courtenay et al., 2010). This suggests that particular attention will need to be paid to ensuring that people with learning disabilities are properly included in the delivery plans for the national dementia strategy

International study of policies on accommodation and support for older people with learning disabilities suggested that neither services for older people nor learning disability services were taking a strong lead on developing appropriate options (Bigby, 2010). Comparison of quality of life of older people with and without learning disabilities in different types of residential settings showed that older people with learning disabilities experienced better quality of life in learning disability services than in older people's services (Higgins & Mansell, 2009). This evidence should be taken into account by councils that are pursuing a policy of putting older people with learning disabilities into services for older people

Evaluation of experiences of older people with high support needs before and after closure of small day service facilities in one area showed that their participation in community activities did not increase (Leyin & Kauder, 2009). Particular attention may be needed to ensure this group is not disadvantaged by such service changes

Review of research on health risks associated with ageing in people with learning disabilities showed that there is a growing body of work on health risks and also health promotion interventions (Haveman et al., 2010; Torr et al., 2010). This confirms that extra care will be needed to ensure that illness prevention and health promotion initiatives aimed at older people include and are appropriately adjusted for older people with learning disabilities

## Good practice

Factsheet from Alzheimer's Society on learning disability and dementia (Factsheet 430, March 2010) <http://alzheimers.org.uk/factsheet/430>

Elders' project (Respond): specialist helpline offering support to older people with learning disabilities and their family carers to address emotional issues related to ageing (e.g. bereavement, awareness of mortality) [www.respond.org.uk/assets/files/elders\\_leaflet.pdf](http://www.respond.org.uk/assets/files/elders_leaflet.pdf)

Guidance from British Psychological Society/Royal College of Psychiatry on assessment, diagnosis, treatment and support of people with learning disabilities who develop dementia [www.rcpsych.ac.uk/files/pdfversion/cr155.pdf](http://www.rcpsych.ac.uk/files/pdfversion/cr155.pdf)

Mutual Caring project (Foundation for People with Learning Disabilities, 2010): suite of materials to raise awareness about the interdependence of people with learning disabilities caring for older family members and to provide practical advice [www.learningdisabilities.org.uk/mutual-caring](http://www.learningdisabilities.org.uk/mutual-caring)

The project found a continuing need for services to collaborate better: learning disability, older people's and carers' services

## Evidence of action or change since 01.01.09

The new Public Health Observatory for learning disability will gather and analyse data that should cast further light on any differences in service usage or recorded experiences (e.g. of employment) by gender

## Emerging issues

Some studies have focused on the intimate relationships and sexuality of either men or women (Rogers, 2010; Carson & Blyth, 2009; Yacoub & Hall, 2009), but these have not suggested any advantage or disadvantage experienced according to gender. For example, lack of information or support and over-protective attitudes were described by both men and women

A study of carer knowledge and experiences with menopause in women with learning disabilities showed that awareness of the issues was good but there was poor availability of accessible information (Willis et al., 2010)

A study of risk and protective factors in relation to the mental health of women with learning disabilities showed that a range of staff had an understanding of the increased risk of mental ill health and also the protective factors (Taggart et al., 2010). The results suggest that more could be done to promote good mental health in this population

Research on contraception and women with learning disabilities showed that there was poor access to information, insufficient attention to confidentiality and consent, and questionable use of depot injections (McCarthy, 2009). This raises questions about choice and control for women; such questions are becoming more important as support grows for people with learning disabilities to be supported to develop intimate relationships

See also section on sex

Gilmore & Chambers (2010) surveyed learning disability staff and leisure workers about attitudes to sexuality: they reported generally positive attitudes, but:

- thought men had less self control than women
- were more protective about women in relation to sexual freedom

Concerns remain from anecdotal evidence about the experiences of women with learning disabilities who are mothers, including those in contact with the criminal justice system. No new studies of their circumstances were identified

## Good practice

Work to improve women's access to health screening (e.g. breast screening in Wolverhampton, cervical screening in Leicester) and men's health (prostate and testicular cancer; men's health group in Oxford)

## Sexual orientation and identity

### Evidence of action or change since 01.01.09

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CQC Count Me In census: support materials for providers include help to ask service users about their sexual orientation

### Emerging issues

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Research with men with learning disabilities showed that many encountered negative attitudes from family and support staff towards homosexuality and were not supported in their wishes to explore or express their sexual orientation (Carson & Blyth, 2009; see also Blake, 2010). Negative attitudes towards disabled men were also found in the gay community (Blyth, 2009). Such attitudes leave LGBT people with learning disabilities at risk of missing out on fulfilling lives, if their sexuality is suppressed, and also at risk of placing themselves in vulnerable situations through lack of information and support

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A study of cross-dressing and gender dysphoria in people with learning disabilities showed a similar range of issues to those found in the non-disabled population. However, people with learning disabilities may need longer assessments, exploration of the issues and therapeutic interventions. Complex ethical dilemmas are raised for people who lack capacity to consent (Parkes et al., 2009)

### Good practice

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Report and easy read books (CHANGE, 2010) on lesbian, gay, bisexual and transgender sexuality

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Growing Friendships campaign led by Learning Disability Today, which includes the importance of recognising and supporting diverse sexual identities (see e.g. Stevens, 2010)

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Hidden Loves electronic forum, hosted by the Foundation for People with Learning Disabilities. Messages in the period reviewed include, for example:

- lists of LGBT support organisations
- information about gay groups in London

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Guideposts 'Interact' service in Gloucestershire provides consultancy, workshops and a social group for LGBT adults with learning disabilities

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SCIE Social Care TV film about working with lesbians and gay men with learning disabilities (SCIE, 2010)

**Religion/  
belief/  
spirituality**

**Evidence of action or change  
since 01.01.09**

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The new Public Health Observatory for learning disability will gather and analyse data that should cast further light on any differences in service usage or recorded experiences (e.g. of employment) by gender

**Emerging issues**

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Interviewees in a study in one London borough (Nadirshaw & Sowerby, 2009) pointed to a range of ways in which support could be improved to enable them to explore and express their religious and spiritual identities

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A South Birmingham relationships course (Ogi et al., 2010) found that some people with strong religious beliefs were reluctant to talk to people who did not share those beliefs

**Good practice**

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A new book on religion, belief and social work includes a chapter on people with learning disabilities and recommends that social workers should pay attention to religion and belief in order to meet their professional responsibilities (Furness & Gilligan, 2010)

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Sheffield Health & Social Care NHS Foundation Trust offers chaplaincy for patients with learning disabilities

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The Bag Books charity is developing a story about a profoundly disabled Muslim person celebrating Id-ul-Fitr

## Race/ culture/ ethnicity

### Evidence of action or change since 01.01.09

DH funding to Princess Royal Trust for Carers/Crossroads Care is being used in part to commission a 'how to' guide from Inspired Services on reaching out to 'seldom heard' family carers

The Valuing People Now delivery plan for 2010/11 includes an ethnicity work programme:

- scoping work around advocacy
- work with black carers' organisations
- national awareness raising events
- regional race equality training
- revision of the Framework for Action
- attention to race equality in Valuing Employment Now

The National Advisory Group on Learning Disability & Ethnicity (NAGLDE) worked with the Office of the National Directors on an ethnicity work programme. Valuing People Now supported NAGLDE, the Learning Disability & Ethnicity Network and the Ethnicity Training Network

An Ethnicity Adviser was appointed to the National Directors' team

Some Partnership Boards are establishing action plans to improve support for people from BME groups (e.g. Buckinghamshire, Leicestershire, Telford & Wrekin, Midland Mencap). Some councils are establishing posts specifically to reach out to BME families (Puri, 2010)

The new Public Health Observatory for learning disability will gather and analyse data that should cast further light on any differences in service usage or recorded experiences (e.g. of employment) by ethnic group

### Emerging issues

A study of ethnic variation in use of CAMHS and other services by children/young people with learning disabilities found significant differences:

- use of respite was highest for Black and White European and lowest for South Asian families
- use of community based social services was highest for Black and lowest for South Asian people
- use of CAMHS was lowest for South Asian people

The authors raise questions about the reasons for variation, including family structure and parental belief systems (Durà-Vilà & Hodes, 2009)

A study of BME people with learning disabilities and family carers in one London borough showed that many of their views were similar to those that would be expressed by other service users and families – concerns about communication, appreciation of specific support. However, both service users and family carers raised specific concerns about lack of adequate support in respect of language, culture and religion/belief. Many wanted access to staff from the same ethnic background as themselves (Nadirshaw & Sowerby, 2009). This raises questions about cultural competence of services and staff. Speaking at a Royal Society of Medicine event on ethnicity and intellectual disability, Mir noted that training could improve the cultural competence of staff and that the role of interpreters should include translation of cultural concepts, not just strict interpretation of words (Mir, 2009)

Review of the inclusion of people with learning disabilities from ethnic minority groups in mental health research and service provision showed that 'double disadvantage' persists and that the resulting exclusion can lead to increased mental health problems (Singh & Orimalade, 2009)

A study of the perceptions of majority and minority ethnic family carers showed that minority ethnic families were still more likely to report negative experiences (Hatton et al., 2009). Two self advocates interviewed by Learning Disability Today felt that "things are changing less for us than they are for other people", although "Valuing People Now is taking us seriously" (Learning Disability Today, 2009)

An unpublished review of ways of developing effective engagement with BME communities (personal communication, 2010) shows that there is a range of promising approaches (based on community development), but no quick fixes

### Good practice

The Foundation for People with Learning Disabilities was awarded a DH TSIP grant for a 3 year project on reaching out to BME families (started 2009/10)

ARC/BILD/Mencap secured a grant for a project to develop a 'Charter for Inclusion' for BME people with learning disabilities and their families

The Race Equality Foundation published a briefing on race equality in advocacy services, focusing on people with learning disabilities (Fulton & Richardson, 2009)

Advance made a DVD, involving tenants and service users, about race equality "Care About Racism"

The Race Equality Foundation (REF) and CHANGE are working together to redesign REF's parenting manual to make it accessible to parents with learning disabilities

In Barking & Dagenham the 'Carers Friendship Map' is making particular efforts to engage family carers from Black and Asian communities



**Evidence of action or change since 01.01.09**

Some Valuing People Now regional newsletters report projects on relationships and two regions (South West and North West) chose relationships as a priority for their regional delivery plans

Human rights training materials published by DH (Northfield, 2010) cover relationships

**Emerging issues**

Concern about reported exploitation of people with learning disabilities by 'friends' (e.g. Steven Hoskin) led to ARC starting the 'Safety Net' project to explore the issues

Continued concerns are expressed about the loneliness experienced by many people with learning disabilities and the lack of support for people to develop friendships and other relationships (Carson & Blyth, 2009; Holman, 2010)

Concerns continue to be raised about the appropriateness or otherwise of paid staff becoming friends with those they support and/or becoming members of circles of support. Strong views are expressed on both sides (as shown in posts on the Choice Forum, UK Health & Learning Disability Network and Profound & Multiple Learning Disability Network during 2009/10). In summary the arguments put forward are:

- people paid to be in your life can (and should) be allies, but that is different from friends
- someone who has been paid but has left and wishes to continue as a friend should not be allowed to do so unless through a formal befriending scheme (with CRB checks) to avoid allegations of exploitation and to protect the service provider against safeguarding concerns
- whether refusal to allow such continuing contact amounts to deprivation of liberty and whether Mental Capacity Act guidance is being followed in supporting individuals to make their own decisions about keeping in touch
- whether 'best interests' decision making processes can help in situations where the person lacks capacity to decide whether they wish to stay in touch

**Good practice**

Learning Disability Today magazine and Stars in the Sky started a 'Growing Friendships' campaign to raise awareness of the importance of friendships and relationships and promote good practice

Hidden Loves electronic forum, hosted by the Foundation for People with Learning Disabilities. Messages in the period reviewed include, for example:

- lists of LGBT support organisations
- information about gay groups in London

Psychologists in South Birmingham recognised that many people in the area were not only lonely but also found aspects of relationships difficult to understand. They set up a relationships course; the group produced a booklet to preserve the learning for themselves and also to share with others (Ogi et al., 2010)

Dorset People First work with Dorset V (young volunteers) and other local organisations to offer a wide variety of opportunities through a Friendship Club (Kerr, 2010)

A research project has started on the importance of friendship in the lives of adults with profound and multiple learning disabilities (Hughes, 2010)

A research project has started on what is happening to support people to develop and keep friendships and relationships (Gore, 2010)

The Life in the Community project from the Foundation for People with Learning Disabilities showed that community connecting approaches can help to link people with others in their communities and that this can form the basis for developing friendships: [www.learningdisabilities.org.uk/publications/life-in-the-community/](http://www.learningdisabilities.org.uk/publications/life-in-the-community/)

Solihull Care Trust produced a series of easy read booklets on friendships and relationships

## Relationships/ sex/ parenting

### 02 Intimate relationships and sex

#### Emerging issues

A study of the sexual lives of men with learning disabilities found that some felt pressured into sex and some reported unsafe sex, despite being aware of risks. However, they felt that services were shifting from being paternalistic about sex to being more supportive (Yacoub & Hall, 2009). Similarly Carson & Blyth (2009) reported that the participants in their research had had little or poor support in the past, but some felt that they were beginning to notice more positive attitudes

A small programme of individually tailored sex education for 4 adults resulted in improved capacity to make sexuality-related decisions (Dukes & McGuire, 2009)

Research on contraception and women with learning disabilities showed that there was poor access to information, insufficient attention to confidentiality and consent, and questionable use of depot injections (McCarthy, 2009). This raises questions about choice and control for women; such questions are becoming more important as support grows for people with learning disabilities to be supported to develop intimate relationships

Rogers (2010) discussed sexuality and relationships of young people with learning disabilities from the perspective of their parents

Discussion on the Hidden Loves forum about supporting men who express interest in attending strip clubs, lap dancing clubs

CHANGE's project with the University of Leeds on sex and relationship education involved work with young people, parents of young people, and schools. Issues identified were:

- lack of accessible information (or lack of awareness of what is available)
- very limited and patchy availability of opportunities to socialise and form friendships and/or sexual relationships
- lack of information and support for parents to help them address sex and relationships issues with their sons and daughters
- the same issue for teachers

Whilst some parents were reluctant to consider their sons' or daughters' sexuality, many were positive about this but wanted more support (Garbutt, 2009)

The Ann Craft Trust and the Judith Trust are conducting research into the issue of people with learning disabilities being forced into marriage

Gilmore & Chambers (2010) surveyed learning disability staff and leisure workers about attitudes to sexuality: they reported generally positive attitudes, but:

- were more cautious about parenting
- thought men had less self control than women
- were more protective about women in relation to sexual freedom

Clarke & Cropley (2010) found that paid support staff were more open towards the sexuality of people with learning disabilities than family carers were. Participants in the research highlighted the need for more education and training

A mother who talked to newspapers about her efforts to support her son to lose his virginity provoked mixed reactions. A documentary on Channel 4 ("Can we get married?") also explored the mixed reactions from families and supporters to people with learning disabilities who wish to have sex and/or get married

#### Good practice

Life Support Productions published two sex education DVDs in 2009 – 'Kylie's Private World', aimed at girls and women with learning disabilities, and 'Jason's Private World', aimed at boys and men. Both cover consent

Dorset People First are doing work on a project 'Love, Sex and You'

People in Partnership project (Birmingham) are doing a project on training for young people on safe relationships, sex and parenting

CHANGE did research with University of Leeds and published a report on sex education and a range of easy read booklets about sex and relationships (CHANGE, 2010)

The Learning Disabilities Federation (North Tyneside) runs the Guy project for men and the Josephine project for women, exploring relationships and sexuality

The Family Planning Association ran a strong campaign on sexuality and people with learning disabilities in 2008; their website offers a range of resources for people themselves and for staff. The Pearl sexual health service in London has produced easy read information and adjusted its services to be welcoming to people with learning disabilities (Giraud-Saunders, 2009). On the Isle of Wight the sexual health service offers a specialist service (the SHIELD) programme (Hardy, 2010). Hertfordshire has a Sexuality Support Team

Some areas are emulating Stars in the Sky and setting up local dating agencies (e.g. Mates to Dates in Birmingham)

Guideposts (Gloucestershire) runs 'Interact', a service focused on supporting vulnerable adults with relationships and sexuality issues

Jo-Jo Mind and Body is a Merseyside social enterprise that provides emotional and sexual health education for people with learning disabilities

**Evidence of action or change since 01.01.09**

The Valuing People Now delivery plan for 2010/11 included:

- work with DCSF to raise awareness of the issues
- work with DCSF to publish and disseminate new commissioning guidance
- exploration with other Govt departments on advocacy for parents
- action to improve data about parents from Partnership Boards
- a new webpage on parenting

The South East Valuing People Now webpage lists a range of parenting projects and resources

**Emerging issues**

Continued concerns about lack of support for parents with learning disabilities, e.g. Choice Forum messages posted by advocate (April 2009) and friend (May 2009)

A review of the information available for parents with learning disabilities found a range of resources, though a minority were designed to be accessible. There was little information about parenting children over the age of 5. The authors found that parents wanted a wider range of information in a wider range of formats, including DVD and audio options on websites. Few parents knew of the information that was available (Marriott & Tarleton, 2009)

Concerns remain from anecdotal evidence about the experiences of women with learning disabilities who are mothers, including those in contact with the criminal justice system. No new studies of their circumstances were identified

**Good practice**

The Race Equality Foundation (REF) and CHANGE are working together to redesign REF's parenting manual to make it accessible to parents with learning disabilities. This is part of REF's 'Strengthening Families, Strengthening Communities' programme

'Supporting parents with learning difficulties and disabilities: stories of positive practice' published by the Working Together with Parents Network (2009)

A request from an advocate on the Choice Forum (April 2009) elicited examples of good practice, such as:

- a weekly drop-in for parents with learning disabilities in Peterborough, run by a community learning disability nurse, advocate and Portage worker
- parent support service run by Options for Life (Sandwell)
- person centred approaches and tools from Circles Network
- London network for parents, run by the Elfrida Society

A documentary maker is planning a film about parents, hoping to show that positive support can keep families together (Choice Forum, April 2010)

James (2010) argued that community learning disability nurses are well placed to support parents, working in partnership with others

### **Emerging issues**

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Posts on the Choice Forum and Profound & Multiple Learning Disability Network during 2009/10 raised questions about the appropriateness of touch between supported and supporters, for example:

- a support worker wondering whether it is OK to kiss people with learning disabilities on the cheek or forehead as a greeting, as might be done with co-workers
- a parent concerned that their daughter's support workers feel inhibited (because of POVA) from comforting her by holding her hand or giving her a cuddle when she is upset
- another parent who worked 'unofficially' with her daughter's staff to overcome these inhibitions but was worried this left them vulnerable

Solutions proposed by other contributors included:

- using robust person centred planning (involving everyone who knows the person best) to discuss and agree what kind of touch is liked/disliked, how consent may be indicated, in what circumstances touch may be appropriate, and to explore risks and safeguards
- a 'circle of consent' and personal policy/guidelines to help with safeguarding

### **Good practice**

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As a result of the questions raised through the forums (see 'emerging issues'), the Social Care Association agreed to run a series of workshops to help service providers and their staff redress the balance between appropriate touch and safeguarding policies

## Comments

### Age

Some of the issues raised highlight a dilemma: to what extent should older people with learning disabilities be included in older people's services? And what reasonable adjustments would be needed to such services in recognition of the different life experiences that people with learning disabilities may have had?

It seems likely that the policy of some councils (moving people at age 65 from learning disability services to older people's services, with a resulting reduction or change in support) will be open to challenge on grounds of age discrimination. Other key issues include:

- the importance of planning ahead with older families
- ensuring that policy on older people (including dementia care and future funding of social care) is sensitive to the specific needs of older people with learning disabilities and older family carers

### Gender

Very little was found about discrimination on grounds of gender. Some stereotypical attitudes about sexual relationships persist; these may result in:

- increased risk for men of being seen as a risk to others
- increased risk for women of over-protection

### Sexual Orientation and Identity

It is encouraging to note a growing range of research and resources on sexual orientation and identity, indicating increasing interest and awareness. However, it is likely that this is not yet reflected in the day to day experiences of most people with learning disabilities and continued efforts will be required to tackle discriminatory attitudes both in communities and in support services

### Religion/belief/spirituality

Very little was found to indicate whether or not people with learning disabilities are being supported to explore and express religious beliefs or spirituality, or whether they are experiencing any difference in discrimination on grounds of religion or belief

### Race/culture/ethnicity

It appears that people from minority ethnic groups still experience comparative disadvantage, although a range of initiatives now under way may be expected to achieve improvements. Continued effort will be required to address this disadvantage

# Relationships/sex/parenting

## 01 Friendship

The Growing Friendships campaign clearly responded to increased awareness about the loneliness experienced by many people with learning disabilities and the patchy support available to help people develop and sustain the social networks that most people take for granted

Despite some examples of good practice, efforts to improve opportunities are being hindered for many people by:

- lack of clarity about whether it is the job of services to support friendship
- tensions with approaches to safeguarding

There will also be concern that one effect of the public sector recession may be to limit support for activities seen as 'optional'. Addressing these issues will be vital if the 'social capital' component of personalisation is to be taken seriously

## 02 Intimate relationships and sex

It is encouraging to note a growing range of research and resources on sex and intimate relationships, indicating increasing interest and awareness. However, some stereotypical attitudes persist, in relation to both gender and disability, and it is likely that increased awareness is not yet translating into increased opportunities for most people with learning disabilities. As with the note on gender stereotyping, it may be that women and men experience different risks in this area of life.

## 03 Parenting

Again, it is encouraging to note a range of examples of good practice. However, significant change will not happen until attitudes to sex and intimate relationships change. There will also be concern that one effect of the public sector recession may be to limit support for parents, if fostering or adoption of the child(ren) is seen as cheaper

## 04 Touch and safeguarding

This specific issue was not included in the original brief, but is clearly related to the issue of human relationships. Whilst respondents on the forums had good suggestions, it is not clear that these are being widely applied

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