Valuing People Now

‘Making it happen for everyone’

Equality Impact Assessment
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<th>Policy</th>
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<td>HR/Workforce</td>
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Document purpose Policy

Gateway reference 10531

Title Valuing People Now: a new three-year strategy for learning disabilities

Author Department of Health

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Target audience PCT CEs, NHS Trust CEs, SHA CEs, Care Trust CEs, Foundation Trust CEs, Local Authority CEs, Directors of Adult Ss

Circulation list Medical Directors, Directors of PH, Directors of Nursing, NHS Trust Board Chairs, Directors of HR, Directors of Finance, Allied Health Professionals, GPs, Directors of Children’s Ss, Voluntary Organisations/NDPBs

Description Valuing People Now sets out the Government’s strategy for people with learning disabilities for the next three years following consultation. It also responds to the main recommendations in Healthcare for All, the Independent Inquiry into access to healthcare for people with learning disabilities

Cross reference Valuing People (2001); Valuing People Now: The Delivery Plan: Making it happen for everyone (2009); Summary of responses to the consultation on Valuing People Now: From progress to transformation (2009)

Superseded documents Valuing People Now: From Progress to Transformation (2007)

Action required N/A

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For recipient use
Valuing People Now

Making it happen for everyone

Equality Impact Assessment
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Introduction

The Department of Health, like all other public bodies, has a legal duty to promote equality and eliminate discrimination. It is also legally required to foster positive relationships between different groups of people, eliminate harassment, and involve people in decisions regarding their health and social care and their access to services.

“The NHS of the 21st Century must be responsive to the needs of different groups and individuals within society and challenge discrimination on the grounds of race, gender, age, ethnicity, religion, disability and sexuality. The NHS will treat patients as individuals, with respect for their dignity. Patients and citizens will have a greater say in the NHS, and the provision of services will be centred on patients’ needs”. (NHS Plan, DH 2000)

Equality impact assessment is the process by which the Department seeks to meet its legal requirements in conjunction with the DH Single Equality Scheme. It is also how the Department seeks to narrow the health inequalities that exist in England between people from different ethnic backgrounds, people with disabilities and non-disabled people (or between people with different disabilities), men and women (including transgendered people), people with different sexual orientations, people in different age groups, and people with different religions or beliefs. Policymakers must screen all new (and eventually, all existing) policies for their impact on people from each of these groups.

The Department of Health exists to improve the health and wellbeing of people in England. The NHS is a universal service, and social care is available to all based on identified need. However, equity of provision does not mean that people are able to access health and social care equally. There are recognised inequalities between

- women and men,
- disabled and non-disabled people,
- people from different ethnic backgrounds,
- people with different sexual orientations,
- people of different ages, and
- people with different religions or beliefs.

To ensure its policies are effective in improving health and social care, the Department needs to understand the effect its policies has on all these groups. For this Equality Impact Assessment, the impact on people with learning disabilities will be assessed against each of these areas.

Additionally this Equality Impact Assessment recognises the fact that there are inequalities between family carers and the general population, and there is also some evidence (from stakeholders) that inequalities exist between long-term carers (e.g. parents of people with learning disabilities) and those who care for a short term only. Therefore this assessment will also cover the impact on family carers of people with learning disabilities.

What is an EqIA?

Like all other public authorities, the Department has a legal duty to conduct and publish equality impact assessments (EqIAs) of all its policies and programmes in relation to disability, ethnicity and gender. The Department has also decided, as a matter of policy, to
take a similar approach with regard to the other equality ‘strands’ of age, sexual orientation, and religion or belief.

Equality impact assessment considers what effect the Department’s activities have on:

- eliminating unlawful/unjustifiable discrimination and harassment;
- promoting equality; and
- fostering positive relationships between different groups of people, thereby improving community cohesion
- promoting positive attitudes towards disabled people, and taking account of someone’s disabilities even where that involves treating them more favourably than other people; and
- involving people in decisions regarding their health and social care, and their access to services.

Stage One: Initial Screening

Title and short description

Valuing People Now – A New Three Year Strategy for People with Learning Disabilities *(Making it Happen for Everyone, DH 2009)* sets out the Government’s commitment to ensuring that the Valuing People policy (DH 2001) is implemented more fully, and impacts on those groups of people with learning disabilities which, to date, have benefitted least from its policy objectives. These are:

- people with more complex needs (The Story so Far, DH, 2005a)
- people from black and minority ethnic groups and newly arrived communities *(op cit)*
- people with autistic spectrum conditions (anecdotal evidence)
- offenders in custody and in the community (anecdotal evidence)

It also recognises that family carers, including carers with learning disabilities, have not benefited fully from its policy objectives.

Valuing People: A New Strategy for Learning Disability for the 21st Century (DH 2001) was the first Government policy aimed specifically at people with learning disabilities, and highlighted the inequalities they face in key areas of life. It provided a vision for the lives of people with a learning disability and their families based on the four principles of Rights, Independence, Choice and Inclusion. It set out the Government’s commitment to improve the lives of people with learning disabilities and to tackle those inequalities.

Valuing People Now is explicit in its aim and commitment to redress the balance for all people with learning disabilities, who as a generic group are still one of the most excluded groups in society in terms of access to mainstream services, such as healthcare, post-16 education and training, employment, housing etc. (evidence cited below).

It sits firmly within the current social policy context of:

- The transformation of social care and the personalisation agenda set out in Putting People First (DH 2007)
- The Independent Living Strategy (ODI 2008)
- The National Carers' Strategy, Carers at the Heart of 21st Century Families and Communities (HM Government 2008)

Additionally this strategy:
- addresses what people have told us about the support people with learning disabilities and their families need
- reflects the changing priorities across Government which impact directly on people with learning disabilities
- sets out the Government’s response to the ten main recommendations in Healthcare for All (2008), the report of the independent inquiry into access to healthcare for people with learning disabilities, chaired by Sir Jonathan Michael
- provides a further response to the Parliamentary Joint Committee on Human Rights report (2008), A Life Like Any Other?
- highlights the need to integrate the rights of family carers to a balanced caring role/life (as stressed in the Carers Strategy) within the implementation of the policy objectives

Thus it is written from a Human Rights perspective, and takes a strong Human rights approach for both people with learning disabilities and family carers.

**Negative/adverse impact**

Could the policy have a *significant negative impact* on equality in relation to disability, ethnicity, gender, sexual orientation, age, or religion or belief for people with learning disabilities or family carers?

<table>
<thead>
<tr>
<th>Will your policy presents any problems or barriers to any community or group?</th>
<th>Disability</th>
<th>Ethnicity</th>
<th>Gender</th>
<th>Sexual Orientation</th>
<th>Age</th>
<th>Religion or Belief</th>
<th>Human Rights</th>
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</table>

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<thead>
<tr>
<th>Will any group of people be excluded as a result of your policy?</th>
<th>Disability</th>
<th>Ethnicity</th>
<th>Gender</th>
<th>Sexual Orientation</th>
<th>Age</th>
<th>Religion or Belief</th>
<th>Human Rights</th>
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<table>
<thead>
<tr>
<th>Does the policy have the potential to worsen existing discrimination and inequality?</th>
<th>Disability</th>
<th>Ethnicity</th>
<th>Gender</th>
<th>Sexual Orientation</th>
<th>Age</th>
<th>Religion or Belief</th>
<th>Human Rights</th>
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<td>N</td>
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</tbody>
</table>
Will your policy have a negative effect on community relations?

N  N  N  N  N  N  N  N

Positive impact

Could the policy have a significant positive impact on reducing inequalities that already exist for people with learning disabilities and family carers?

How will it meet our duty to:
1. Promote equality of opportunity?
2. Eliminate discrimination and harassment?
3. Promote social inclusion and good community relations?
4. Promote positive attitudes towards people?
5. Encourage the participation of people?
6. Consider more favourable treatment of people?
7. Promote and protect human rights?

The following table shows an initial assessment for both people with learning disabilities and family carers against each of the equalities areas.

<table>
<thead>
<tr>
<th>People with Learning Disabilities/ Family Carers</th>
<th>Disability</th>
<th>Ethnicity</th>
<th>Gender</th>
<th>Sexual Orientation</th>
<th>Age</th>
<th>Religion or Belief</th>
<th>Human Rights</th>
</tr>
</thead>
<tbody>
<tr>
<td>Promote equality of opportunity?</td>
<td>Y/ Y</td>
<td>Y/ Y</td>
<td>Y/ Y</td>
<td>Y/ Y</td>
<td>Y/ N</td>
<td>Y/ Y</td>
<td>Y/ N</td>
</tr>
<tr>
<td>Eliminate discrimination or harassment?</td>
<td>Y/ Y</td>
<td>Y/ Y</td>
<td>Y/ Y</td>
<td>Y/ Y</td>
<td>Y/ N</td>
<td>Y/ Y</td>
<td>Y/ N</td>
</tr>
<tr>
<td>Promote social inclusion and good community relations?</td>
<td>Y/ Y</td>
<td>Y/ Y</td>
<td>Y/ Y</td>
<td>Y/ Y</td>
<td>Y/ N</td>
<td>Y/ Y</td>
<td>Y/ N</td>
</tr>
<tr>
<td>Promote positive attitudes towards people?</td>
<td>Y/ Y</td>
<td>Y/ Y</td>
<td>Y/ Y</td>
<td>Y/ Y</td>
<td>Y/ N</td>
<td>Y/ Y</td>
<td>Y/ N</td>
</tr>
<tr>
<td>Encourage participation?</td>
<td>Y/ Y</td>
<td>Y/ Y</td>
<td>Y/ Y</td>
<td>Y/ Y</td>
<td>Y/ N</td>
<td>Y/ Y</td>
<td>Y/ N</td>
</tr>
</tbody>
</table>
Consider more favourable treatment? | Y/N | Y/N | N/Y | N/N | N/Y | N/N | N/N
--- | --- | --- | --- | --- | --- | --- | ---
Promote and protect human rights? | Y/Y | Y/Y | Y/Y | Y/N | Y/Y | Y/N | Y/Y

**Evidence**

The evidence for the answers above includes:

**Relevant Sources:**

A. Published work (including Government policies) that demonstrate (based on evidence) that people with learning disabilities face inequalities, in terms of outcomes, or because they are excluded from, or discriminated against within, mainstream or generic disability services or policies:

- Commission for Healthcare Audit and Inspection (2007) *A life like no other*: a national audit of inpatient services for people with learning difficulties
- Department for Education and Skills (2007) *Progression Through Partnership*
- Department for Work and Pensions (2008) *No One is Written Off*
- Disability Rights Commission (2006) *Equal treatment: closing the gap*. A formal investigation into the physical health inequalities experienced by people with learning disabilities and/or mental health needs
- Department of Health (2007a) *Promoting Equality*
- Department of Health and Home Office (2000) *No secrets*
- Little P (2005) *Through Inclusion to Excellence*

B. Published work (including Government policies) that demonstrate (based on evidence) that people with learning disabilities from Black and Minority Ethnic communities face inequalities, in terms of outcomes, or because they are excluded from, or discriminated against within, mainstream or generic disability services or policies, or from learning disability services or policy:

- Department of Health (2005a) *Valuing People: The Story So Far*


• Hatton, C. (2007) *Improving services for people with learning disabilities from minority ethnic communities*
• Hatton, C. (forthcoming) *Valuing People Now: Consultation Report*
• Mencap (2006a) *Reaching Out’*

C. Published work (including Government policies) that demonstrate (based on evidence) that *women or men with learning disabilities* face inequalities, in terms of outcomes, or because they are excluded from, or discriminated against within, mainstream or generic disability services or policies, or from learning disability services or policy:

• McCarthy, M. (1999a) *Gender Matters*
• Pearson V et al (1998), *Cancer and people with learning disabilities*

D. Published work (including Government policies) that demonstrate (based on evidence) that *people with learning disabilities* face inequalities, in terms of outcomes, or because they are excluded from, or discriminated against within, mainstream or generic disability services or policies, or from learning disability services or policy, on the basis of *sexual orientation*:

• Abbot, D. and Howarth, J. (2005) Secret Loves, Hidden Lives? Exploring issues for men and women with learning difficulties who are gay, lesbian or bisexual,
• Outsiders (2008a) Sex and Learning Disabilities Leaflet.

E. Published work (including Government policies) that demonstrate (based on evidence) that *people with learning disabilities* face inequalities, in terms of outcomes, or because they are excluded from, or discriminated against within, mainstream or generic disability services or policies, or from learning disability services or policy, on the basis of *age*:

• Foundation for People with Learning Disabilities (2003) *Today and Tomorrow Briefing*

F. Published work (including Government policies) that highlight *equalities issues* more generally, including within the wider disability movement:

• Ho, A. (2004) ‘To be Labelled, or not to be Labelled: that is the Question
• Keith, L. (1996) ‘Encounters with Strangers: The Public’s Responses to Disabled Women and How this Affects our Sense of Self’
• McDonagh, P. (2000) ‘Diminished men and dangerous women: representations of gender and learning disability in the early- and mid-nineteenth century Britain,
G. Other relevant published work relating to the issues or needs of people with learning disabilities:

- Mencap (2002) *Housing Time Bomb*
- Ware, J. (2004) ‘Ascertaining the Views of People with Profound and Multiple Learning Disabilities’

H. Published work (including Government policies) that demonstrate (based on evidence) how to **promote equality for people with learning disabilities**:

- Department of Health (2007c) ‘Services for people with learning disability and challenging behaviour or mental health needs,’
- Department of Health (2007d) Commissioning specialist adult learning disability health services - Good practice (DH 2007)
- Prime Ministers Strategy Unit (2005) *Improving Life Chances*
- Ware, J. (1996) *Creating a Responsive Environment for People with Profound and Multiple Learning Disabilities*

I. Publications relating to Carers

- HM Government 2008, Carers at the heart of 21st Century Families and Communities
- Wanless, D.(2006) *Securing Good Care for Older People*
Initial Analysis and Rationale for Assessment

People with Learning Disabilities

Disability

There is a large amount of academic literature, a growing body of government policy and guidance, and much anecdotal evidence that point to the fact that people with learning disabilities are excluded from, or at risk of exclusion from, a wide range of services or opportunities. Much of the academic literature focuses on the very specific needs of this group of disabled people in terms of access to healthcare and education, and communication needs. There is also a growing recognition that people with learning disabilities, as opposed to those with only physical impairments, may face even greater discrimination because of how they are perceived as adults and how intellectual impairment is perceived (Riddell, Ward and Thomson, 1993; Corbett and Barton, 1992; Phillips, 2004). This includes exclusion from the wider disability movement and the academic community writing about disability (Aspis, 1997).

The Cabinet Office Social Exclusion Task Force have identified people with moderate and severe learning disabilities as one of the most excluded groups still in our society; for this reason they are one of the four target groups for the cross-Government Public Service Agreement (PSA) 16, which has indicators for both paid employment and secure accommodation. This means that for the first time ever, from 2009, all local authorities across England will have to report annually against these two indicators for people with learning disabilities ‘known to them’. Valuing People Now sets out the Government commitments and actions to take forward work to support these indicators. A lack of baseline data in all areas where inequalities are faced by people with learning disabilities is an issue in itself which Valuing People Now seeks to address.

Valuing People Now is explicit in its aim to reduce inequalities faced by people with learning disabilities across a range of areas, including:

- **Access to health:** Healthcare For All - the report of an Independent Inquiry into access to healthcare for people with learning disabilities reported significant and ongoing health inequalities, (Sir Jonathon Michael 2008)
- **Paid Employment:** only one in ten of those known to social services has any form of paid employment, and of those only very few work more than 16 hours; the Joint Report on ‘Improving Employment Opportunities for People with Learning Disabilities’, 2006, sets out over 40 recommendations to reduce inequalities
- **Access to post-16 education and training:** Progression Through Partnership identifies many barriers to post-16 education for people with learning disabilities (Department for Education and Skills 2007)
- **Access to mainstream housing with support:** only 15% of adults with learning disabilities have a secure, long-term tenancy or a home of their own compared with over 70% of the general adult population who own their own home and nearly 30% who rent (Valuing People Now: From Progress to Transformation, DH, 2007); and more than 30% of people with learning disabilities live in residential care homes, a significant proportion of which are miles away from their place of origin and their families
- **Hate Crime:** people with learning disabilities report that they are often the victims of hate crime and bullying (anecdotal evidence and Hate Crime Petition presented to Government by the National Forum of People with Learning Difficulties.
• Human Rights: the 2008 report of the Parliamentary Joint Committee on Human Rights - *A Life Like Any Other?* – highlighted continued and extensive failure of services and society to accord people with learning disabilities their basic rights
• Access to advocacy, support and accessible information: the Parliamentary Joint Committee on Human Rights (2008) report makes recommendations that people with learning disabilities have access to these things to ensure their human rights are not breached

Furthermore, Valuing People Now recognises the fact that people with learning disabilities are not a homogenous group, but rather individuals with very individual needs, aspirations and lives. It highlights the specific issues for those defined as having ‘complex needs’, i.e. those who also have a range of multiple and additional needs, including those defined as having profound and multiple learning disabilities and those whose behaviour challenges. Valuing People Now also highlights the fact that people with learning disabilities also defined as being on the Autistic spectrum have not benefitted fully from the Valuing People policy. Although Valuing People Now does not explicitly differentiate any further, i.e. it does not highlight inequalities that may exist between those with learning disabilities who have difficulty with communication or social interaction and those do not, in promoting rights, advocacy, choice, control and independence it, arguably, provides a framework for recognising diversity and tackling a range of inequalities.

Therefore in terms of ‘Disability’ equality, Valuing People Now is expected to promote equality across all the questions above.

**Ethnicity**

Valuing People Now also has an explicit aim to improve engagement with people with learning disabilities from black and minority ethnic communities (BME), and their families, to ensure they benefit from the Valuing People policy, and from mainstream and specialist learning disability services. This in recognition of the fact that this group have not, to date, benefitted in the same way as their white, British counterparts. This is evidenced through a number of sources, including:

• Anecdotal evidence from people from BME communities and their families (from informal intelligence gathering via the Valuing People Support Team, the Learning Disability Task Force and other stakeholder groups)
• The formation of the National Advisory Group on Learning Disability and Ethnicity (set up as part of the Foundation for People with Learning Disabilities, and funded by Valuing People) in response to the recognition that people from BME communities experience discrimination and have specific needs
• Department of Health (2005a) *Valuing People: The Story So Far* states that people with learning disabilities from BME communities have not benefitted from Valuing People, 2001, as much as the general population (based on a consultation with over 3000 people)
• Fyson, R. and Fox, L. (2008) *The Role and Effectiveness of Partnership Boards*, shows that people from BME communities (self-advocates and family carers) are still underrepresented on partnership boards.
• Hatton, C. (2005) *Improving services for people with learning disabilities*
• Hatton, C. (2007) *Improving services for people with learning disabilities from minority ethnic communities*
• Hatton, C. (forthcoming) *Valuing People Now: Consultation Report* shows that there was minimal representation from people with learning disabilities and their families from BME communities in the consultation itself
• Mencap (2006) *Reaching Out* states that people with learning disabilities from some minority ethnic groups face a ‘double discrimination’

Valuing People Now, therefore commits to a strand of work to address inequalities in the area of ethnicity, although the delivery plan acknowledges that further scoping and research is necessary. For this reason, *Valuing People Now is expected to promote equality in the area of ethnicity against all of the questions above.*

**Other Areas**

Valuing People Now includes some specific aims and actions that are expected to promote equality in the areas of:

• **Gender** – in reducing inequalities in access to and take of healthcare screening, for
  i) women:  
  McCarthy, M. (1999a) *Gender Matters*
  
  ii) men: 
  Peate, I. and Maloret, P. (2007) Testicular self-examination: the person with learning disabilities - people with learning disabilities are at just as much risk as the general population are of contracting cancer. Mainstream men’s healthcare needs are often neglected and this is also true for men who have learning disabilities

• **Age** – in addressing the specific issues for older people with learning disabilities (i.e. over 65) in terms of end of life care, and access to post-16 (adult) education. (There is no hard evidence in these areas, but anecdotal and soft data, coupled with current policy objectives, point to the fact that older people with learning disabilities could potentially be excluded from mainstream services on the basis of their disability and from disability policy on the basis of age: see full analysis).

Furthermore, it could be argued that by advocating individual rights, person centred planning, advocacy and choice, the specific needs of people of all ages, from both genders will be met and promoted. Hence *Valuing People Now is expected to promote equality in the areas of gender and age against all the questions above except for promoting more favourable treatment.*

Valuing People Now includes some actions that are expected to have a positive effect in the areas of:

• **Sexual orientation or identity**: by challenging the commonly held assumption that people with learning disabilities cannot, or should not, be supported to have meaningful and sexual relationships, including same sex relationships (Abbot, D. and Howarth, J. (2005), Outsiders (2008a); and by encouraging front line support staff to think about ways to enable opportunities for greater social interaction and for maintaining sexual relationships as well as parenthood (Craft, A. (ed) 1993).
• **Religion or belief**: by encouraging frontline staff to support people to actively participate in community activities, including faith groups. (There is no known quantitative data around participation in faith or religious groups, but the literature that does exist points to a denial of people with learning disabilities’ spirituality in policy development and implementation (Swinton, 2001, 2002 and 2004): this is something that needs further research)

Furthermore, it could be argued that by advocating individual rights, person centred planning, choice and inclusion the chances of a person’s sexuality/sexual orientation and/or religion/belief being acknowledged and accepted are greater. Hence **Valuing People Now is expected to promote equality in the areas of sexual orientation and religion against most of the questions above.**

Finally with respect to **Human Rights**, Valuing People Now is explicit in its aim to promote the human rights of all people with learning disabilities, and is written from a human rights perspective, as advised by the Parliamentary Joint Committee on Human Rights (2008) **A Life Like Any Other**?

In some respects, much of the above (i.e. against the areas other than disability) is about ensuring that Valuing People Now addresses the potential inequalities for some people with learning disabilities within the wider population of people with learning disabilities.

**Family Carers**

Valuing People Now also has, as a strong theme throughout, the specific needs and issues of family carers, building on the Carers Strategy (HM Government 2008) which states that:

‘Our vision is that by 2018, carers will be universally recognised and valued as being fundamental to strong families and stable communities. Support will be tailored to meet individuals’ needs, enabling carers to maintain a balance between their caring responsibilities and a life outside caring, whilst enabling the person they support to be a full and equal citizen’.

With reference to carers issues, messages from the 2001 Census (Office for National Statistics), and from Carers UK (2008) research suggest that:
- There are around 6 million unpaid carers in the UK. This is expected to increase to 13 million over the next ten years.
- 42% of carers are men, 58% women.
- 70% of care continues to be provided by women.
- There are 175,000 carers under 18 years.
- Only around 14% of carers have had a carers’ assessment
- Carers providing high levels of care (i.e. 50 hours or more) are more than twice as likely to suffer from poor health compared to people without caring responsibilities. Nearly 21% of carers offering over 50 hours care say they are in poor health compared to nearly 11% of the non-carer population
- Carers in the younger age groups (i.e. 16 and upwards) are significantly more likely to suffer ill-health than carers of the same age.

We do not have figures for the proportion of carers supporting someone with a learning disability (or indeed for other disabilities).
Additionally anecdotal and soft evidence (i.e. from stakeholder groups, such as the National Forum of People with Learning Difficulties) show that there are increasing numbers of people with a learning disability who are themselves carers of people with disabilities. Hence, this is an identified strand of work within the wider Valuing People Now Carers Programme.

It is expected that Valuing People Now will promote equalities for carers of people with learning disabilities within the mainstream carer movement, as well as in the following equalities strands:

- **Disability** – by addressing the issues and barriers faced by carers who are themselves disabled
- **Age** – by targeting older family carers for carers assessments and for housing assessments (as part of the Joint Strategic Needs Assessment process)
- **Gender** – by addressing carers issues in general, since the majority of carers are women
- **Ethnicity** – by explicitly seeking to engage family carers from BME communities as part of the Carers Programme of work
- **Human Rights** – by embedding the Valuing People Now work for Carers within the mainstream aims of the Carers Strategy (HM Government 2008). This aims that by 2018:
  - Carers will be respected as expert care partners and will have access to the integrated and personalised services they need to support them in their caring roles.
  - Carers will be supported so that they are not forced into financial hardship by their caring role.
  - Carers will be able to have a life of their own alongside their caring role.
  - Carers will be supported to stay mentally and physically well and be treated with dignity.
  - Children and young people will be protected from inappropriate caring and have the support they need to learn, develop and thrive, to enjoy positive childhoods and to achieve against the Every Child Matters outcomes (Department for Children and Family Services, 2006)

**Additional research or data required to fill gaps in understanding the potential or known effects of the policy**

Very little is known about the specific issues for/ impact on people with learning disabilities in terms of:
- Age
- Gender
- Sexual Orientation
- Religion or Beliefs

The sources in relation to the above tend to focus on the general population or the wider population of disabled people. Some academic writing in these areas (especially around gender) have come from the disabled people’s movement and particularly from women. Whilst it may be acceptable, at this stage, to assume that some issues for people with learning disabilities do not differ considerably in nature from those of the wider population (e.g. issues of presumed incompetence for disabled people who are parents), issues may differ in degree, and this may not be true in all areas. Further research/work is needed to
test out these assumptions. Further work/research will be needed as part of the scoping for the delivery plan, and the delivery plan itself. This may need to be commissioned.

Whilst there is an extensive database of research on carers, much of it does not necessarily differentiate between carers of people with learning or other disabilities. Additionally there is little evidence with regard to the specific issues for family carers who are themselves people with a learning disability.

**Initial Screening Assessment:**

Based on the initial screening assessment we have concluded that a positive impact is explicitly intended and very likely. A full equalities impact assessment is necessary to consider these issues in more detail.
Stage 2: Full Equality Impact Assessment

Title and description of the policy

Valuing People Now – A Three Year Strategy for Learning Disability (Making it Happen for Everyone (DH 2009) sets out the Government’s commitment to ensuring that the Valuing People policy (DH, 2001) is implemented more fully, and impacts on those groups which, to date, have benefitted least from its policy objectives. These are:

- people with more complex needs
- people from black and minority ethnic groups and newly arrived communities
- people with autistic spectrum conditions
- offenders in custody and in the community

Valuing People: A New Strategy for Learning Disability for the 21st Century (DH, 2001) was the first Government policy aimed specifically at people with learning disabilities, and highlighted the inequalities they face in key areas of life. It provided a vision for the lives of people with a learning disability and their families based on the four principles of Rights, Independence, Choice and Inclusion. It set out the Government’s commitment to improve the lives of people with learning disabilities and to tackle those inequalities.

In 2005, the DH published the then National Director’s report on the progress of Valuing People: ‘The Story So Far’. In developing the report the Director consulted with some 3,000 people for their views on what had changed and what still needed to happen to make rights, independence, choice and inclusion a reality for people with learning disabilities. Over a third of the respondents were people with learning disabilities.

As a response to this report, and the request of the then Minister for Care Services to ‘refresh’ Valuing People, DH published Valuing People Now: From Progress to Transformation, as a consultation document, in December 2007. The consultation closed in March 2008, and responses from over 10,000 people (estimate), were analysed by the University of Lancaster (this response is to be published alongside the revised strategy).

The Valuing People Now consultation indicated quite high levels of support for the big priorities and for many of the detailed proposals set out in the consultation document. But there were important messages about what was not so well supported, what was left out, and what needed to be strengthened. This strategy has been written in the light of the responses to the consultation document and subsequent meetings with key stakeholders to:

- give greater emphasis to the vital part played by family carers in the lives of people with learning disabilities;
- pay greater attention to ways of helping people with complex needs benefit from all of the proposals.
- be realistic about what is achievable;
- improve knowledge and understanding about the wishes and needs of people with learning disabilities and their families from different cultures and ethnic communities and, thus, offer more appropriate support;
- ensure that all agencies are rigorous in making change happen and monitoring progress effectively;
- give more attention to issues around relationships and transport and make sure that these are both properly integrated into all the proposals;
recognise that many people with a learning disability need support for the whole of their lives.

Valuing People Now is explicit in its aim and commitment to redress the balance for all people with learning disabilities, who as a generic group are still one of the most excluded groups in society in terms of access to mainstream services, such as healthcare, post-16 education, employment, housing etc, as evidenced by the sources above.

Moreover, Valuing People Now is also clear in its commitment to strengthen the delivery of the Valuing People Now objectives for all groups, especially those with complex needs and from Black and Minority Ethnic (BME) groups, and to involve family carers more fully. Valuing People Now also acknowledges that there are growing numbers of people with learning disabilities who are also family carers. They may be partners, friends, adult children or indeed parents but they are also directly affected by local policy and practice in supporting carers. It sets out more detailed plans for delivery (in both the strategy and the delivery plan), including strengthened central leadership, more robust mechanisms for reporting progress and self assessment, and greater emphasis on supporting local leadership and delivery.

Furthermore, it highlights the importance of better commissioning to drive up outcomes for people with learning disabilities and their families. In order to provide further support to local commissioners, we have developed a commissioning guide for the health and well being of people with learning disabilities which builds on the aspirations of the World Class Commissioning programme.

However, Valuing People Now does not sit outside of the 21st century policy or legislative context. Rather it seeks to respond to, build upon and to ensure fuller compliance with a range of policies, strategies and legislation that promote the equality of people with learning disabilities, including:

**Legislation**
- Race Relations Amendment Act, 2000
- Learning and Skills Act, 2000
- SEN and Disability Act, 2001 (amending part 4 of the 1995 DDA)
- Children Act, 2004
- Disability Discrimination Act, 2005
- Disability Equality Duty, 2006
- Mental Capacity Act, 2005 (came into force April 2007)
- Mental Health Act, 2007

**Policies**
- Department for Education and Skills (2007) *Progression through Partnership*
- Department of Health (2005a) *Valuing People: The Story So Far*
In particular, it sits firmly within the current social policy context of:

- The Transformation of Social Care and the personalisation agenda set out in Putting People First (DH 2007e)
- The Carers’ Strategy, Carers at the Heart of 21st Century Families and Communities (HM Government 2008)
- Aiming High for Disabled Children (HM Treasury/ Department for Education and Skills 2007)
- The Independent Living Strategy – a cross government strategy for all disabled people (ODI 2007)

Additionally this strategy:

- addresses what people have told us about the support people with learning disabilities and their families need
- reflects the changing priorities across Government which impact directly on people with learning disabilities
- sets out the Government’s response to the ten main recommendations in Healthcare for All, the report of the independent inquiry into access to healthcare for people with learning disabilities, chaired by Sir Jonathan Michael (2008)
- provides a further response to the Joint Committee on Human Rights report A Life Like Any Other? (2006)

It is written from a Human Rights perspective, and takes a strong Human Rights approach.

The Evidence Base

Published work

Disability:

- Department for Education and Skills (2007) Progression Through Partnership:
• Healthcare for All, the report of the independent inquiry into access to healthcare for people with learning disabilities, chaired by Sir Jonathan Michael (July 2008)
• Little, P. (LSC, 2005) ,Through Inclusion to Excellence’
• Mencap (2005) Treat me Right
• Mencap (2007) Death by Indifference
• Tyrer et al. (2007) The impact of physical, intellectual and social impairments on survival in adults with intellectual disability: a population-based register study

Ethnicity:
• Mencap (2006a) Reaching Out – Working with Black and Minority Ethnic Communities

Gender:
• HM Government 2008 The National Carers’ Strategy
• Pearson et al (1998), Cancer and people with learning disabilities
• McCarthy, M. (1999a) Gender Matters
• McCarthy, M. (2002a) Going through the menopause: perceptions and experiences of women with intellectual disabilities

Age:
• Emerson, E. and Hatton, C. (2008): People with Learning Disabilities in England estimate that the total number of adults with a learning disability (aged 20 or over) will increase by 8% to 868,000 in 2011 and by 14% to 908,000 by 2021. Significantly all the growth projection shows much higher increases in the number of adults aged over 60.
• Mencap (2002) Housing Time Bomb, estimates that over 29,000 adults live with a parent over the age of 70,
• Wanless, D (2006) Securing Good Care for Older People
Sexual Orientation/identity:
- Outsiders (2008a) Sex and Learning Disabilities Leaflet
- Outsiders (2008b) Sex and Your Child with a Disability Leaflet
- Outsiders (2008c) Disability and Body Image Leaflet

Religion or Beliefs:
- Just Care Diocese of Oxford (2005) Spirituality and Learning Disability,

Human Rights:
- Parliamentary Joint Committee on Human Rights (2008) A Life Like Any Other?

Family Carers:
- Becker, S. (2007) Global Perspectives on Children's Unpaid Caregiving in the Family: Research and Policy on 'Young Carers' in the UK, Australia, the USA and Sub-Saharan Africa
- Carers UK (2008a) Profile of Carers Research
- Carers UK (2008b) In the Know, Carers UK
- Department for Communities and Local Government (2006) Strong and prosperous communities - the local government white paper
- Department of Health (2006a) Our health, our care, our say: a new direction for community services, White Paper
Ongoing Intelligence Gathering and Engagement with Stakeholders

Since the publication of Valuing People in 2001, a number of key mechanisms have been established to ensure that people with learning disabilities and family carers (as the two main stakeholder groups) have a voice at Government level to influence the implementation of learning disability policy and to report against its progress or highlight barriers. These include:

- The National Forum of People with Learning Difficulties, made up of representatives from nine regional forums, where self-advocates from partnership boards, local self-advocacy groups and the community in general can meet to discuss issues that affect people with learning disabilities.
- The National Valuing Families Forum, made up of representatives from regional Family Carer Networks, made up of family carers who sit on local Partnership Boards.
- The Learning Disability Task Force (now replaced by the new National Learning Disability Programme Board) made up of representatives from both national Forums above (and thus providing a means of bringing issues and views up through to Government), the independent sector, commissioners (CSCI and HCC), Government departments and DH policy.
- The National Advisory Group on Learning Disability and Ethnicity, founded as part of the Foundation for People for Learning Disabilities, and funded by Valuing People monies: this group provides advice to the development of work around ethnicity.
• The Valuing People Support Team, made up of regional advisors across all nine regions who support local implementation and carry out informal intelligence gathering
• The National Learning Disabilities Programme Board, with cross-government representation, as well as representation from both the National Forums; this newly founded group is responsible for overseeing the delivery of Valuing People Now.

These mechanisms have provided DH with a source of intelligence gathering in relation to the progress of Valuing People 2001, as well as a means to test out thinking and new policy initiatives. In some cases, issues raised by stakeholders have influenced specific work strands, such as the work around Hate Crime (now part of Valuing People Now) that arose from a petition by the National Forum of People with Learning Difficulties.

Specific issues around ‘complex needs’ and ‘ethnicity’ (identified in The Story So Far) led the Learning Disability Task Force to identify Champions (from within the Task Force) in those two areas in 2006. This was also in recognition of the fact that the Task Force, and government learning disability policy, were not always representative or inclusive of these two groups. The two complex needs Champions were an academic in the field and a mother of a son with complex needs. The Ethnicity champions were an Asian mother of a son with complex needs (also a member of the National Advisory Group on Learning Disability and Ethnicity) and a black self-advocate from the National Forum. Subsequent work with the Champions around the specific needs of people with complex needs and from BME communities, and their families, have informed the Valuing People Now strategy.

Large-Scale Consultations

Additionally the Department of Health has undertaken a number of key consultations with different stakeholder groups to review the progress of the policy. All of these have informed the development of both the Valuing People Now strategy and the Delivery plan.

The Story So Far

In 2005, the DH published the then National Director’s report on the progress of Valuing People: ‘The Story So Far’. In developing the report the Director consulted with some 3,000 people for their views on what had changed and what still needed to happen to make rights, independence, choice and inclusion a reality for people with learning disabilities. Over a third of the respondents were people with learning disabilities.

The findings from this consultation were that whilst there was good progress in many places this had left out people with the most complex support needs and there was not enough work being done with people from ethnic communities.

Valuing People Now Consultation

In December 2007, the DH published Valuing People Now: From Progress to Transformation as a consultation document. An easy read version was also published. The University of Lancaster was commissioned to carry out an independent evaluation of the responses.
A total of 2,009 usable responses were received. The responses included:

- Full version questionnaires (856)
- Easy read questionnaires (849)
- Service user consultation exercise sheets (63)
- Other responses in different formats (241)

There were a good range of responses from people with learning disabilities (730 responses), family members (407 responses), professionals (375 responses) and ‘others’ (375 responses), which included groups and organisations. There was also good representation from men and women, although very few responses were from people from black and minority ethnic communities.

There was strong agreement across all stakeholder groups that the big priorities put forward in the Valuing People Now consultation document were appropriate (overall over 90% agreement). There were several suggestions for additional big priorities, most commonly:

- Transport
- Partnership with families
- Meeting the needs of people with complex needs
- Enabling relationships, friendships and a fulfilling social life

Three of the report’s conclusions are as follows:

1. There are some groups who are under-represented in responses to the consultation, particularly people from black and minority ethnic communities, and the representation of the pool of respondents in terms of other important characteristics such as age, sexuality and religion is unknown. The Department of Health may want to consider doing additional, focused consultations with under-represented groups.

2. In general, people with learning disabilities were the most positive with families being the most concerned that the policy was not inclusive enough of people with more complex needs. This may partly be due to the likelihood that respondents with learning disabilities would have high levels of skills (where Valuing People Now was felt to be more relevant) and family members would be caring for people with more complex needs (where there were more worries about the suitability of Valuing People Now).

3. There were consistent worries about whether Valuing People Now will work equally well for people with complex needs, and some worries about its applicability to other groups such as older people and people from black and minority ethnic communities.

Smaller Scale Stakeholder Consultation and Targeted Engagement

In light of the consultation report’s findings (above), specific actions to engage with stakeholder groups were taken. These are:

- Stakeholder workshop (chaired by the then Minister for Care Services and the Director General for Social Care), (July 2008): to discuss how to include people with
complex needs, those from BME groups and family carers in the revised Valuing People Now strategy. The notes and list of attendees of this meeting are in Annex A.

- Carers Workshop (July 2008): to discuss the issues for family carers and people with complex needs in the redrafting of Valuing People Now. This meeting led to the redrafting of the families section of Valuing People Now.

- Learning Disability Task Force meeting, July 2008: to discuss the delivery of Valuing People Now and how people with complex needs and from BME groups could be included in the planned delivery programmes. This involved those from other government departments, the independent sector and representatives from both the National Forum of People with Learning Difficulties and the Valuing Families Forum. Outcomes are attached in note form (see Annex B).

- Ongoing engagement and liaison with the National Forum and Valuing Families Forum representatives during the redrafting of Valuing people Now, the Delivery Plan and this Equality Impact Assessment.

- Liaison with, and feedback from, the Chair of the Carers Standing Commission on the Equality Impact Assessment.

- Liaison with and feedback from, the National Valuing Families Forum on the equalities impact assessment (notes in Annex C)

Consultation Feedback

In the redrafting of Valuing People Now, and in carrying out this equalities impact assessment, the Valuing People Now consultation responses of specific groups has been referred to, and other groups have been actively involved in giving feedback during the redrafting process:

- Feedback from the Profound and Multiple Learning Disabilities Network on Valuing People Now (consultation document)

- Feedback from the National Advisory Group on Learning Disabilities and Ethnicity (consultation document) (see Annex D, which contains a race equality impact assessment of Valuing People Now). Their recommendations were as follows: A national action plan concerning people with learning disabilities from black and minority ethnic communities is required to:
  - ensure that Valuing People objectives are met for people with learning disabilities across all ethnic groups;
  - raise the profile of this issue and ensure it is taken seriously by all agencies supporting people with learning disabilities and their families;
  - identify emerging new areas, for example new refugee communities;
  - ensure that there is a clear programme for improvement for agencies, both mainstream and specialist, to work towards;
  - raise the profile of people with learning disabilities and their families from black and minority ethnic communities in decision-making processes;
o remove discriminatory barriers for all people with learning disabilities and their families from black and minority ethnic communities who require support;
o ensure that agencies will be accountable in the short and medium-term for their performance;
o draw together existing initiatives like the National Advisory Group for People with Learning Disabilities and Ethnicity and ensure they are securely funded and working efficiently together
o ensure Regional Ethnicity Leads work together with the National Advisory Group for People with Learning Disabilities and Ethnicity to develop and disseminate good practice to inform policy.
o work with all available resources to ensure maximum value for money.

- Ongoing feedback on the Valuing People Now strategy from Mencap, during the redrafting

**Examples of Good Practice**

**Inequalities in Health Screening (Disability)**

Through the DH Pacesetters programme, Walsall Integrated Learning Disability Service has taken forward a project to increase the number of eligible women with a learning disability who undergo breast screening. The dual aim was to reduce the number of cancers and to educate women with a learning disability as to why screening is important.

Through a range of innovative measures including awareness training for screening staff, easy read invitation letters, pre-familiarisation visits and collaborative clinics, the uptake for breast screening of eligible women was increased from 19% in 2002 to almost 100% in 2007. The service is now looking to embed this good practice and spread it to other learning disability trusts across the NHS. Although the numbers involved were small (60), the impact for this group was significant. In the long-term, we believe it will enable earlier diagnosis of breast cancer amongst women with learning disabilities.  

[Taken from the DH Single Equalities Scheme]

**Age Concern Projects – Older People with Learning Disabilities (Age)**

Age Concern Coventry has focused on raising awareness of learning disability issues of older people, adding dimensions to existing services. This has been implemented through Person Centred Planning training for staff and volunteers, enabling greater staff engagement and programming events that would otherwise not take place. Person Centred planning focuses on supporting people with disabilities by putting the person at the centre of a planning process and giving them control over it. In addition, AC Coventry has been successful in integrating a number of older adults with learning disabilities into mainstream craft classes.

Age Concern Leicester has been investigating the lack of representation of Black and Minority Ethnic (BME) communities on the learning disability register. The project continues to carry out research into the number of BME groups on the learning disability register.
register as well as the type of provision available. The project has also looked at service users’ and carers’ views of the future need to provide a more appropriate awareness of the extent of learning disabilities among over 50s and improve their expert knowledge of local available services, allowing more effective advice and support for users and carers.

**Age Concern Nottingham & Nottinghamshire** has been working towards addressing issues around the unique needs of people vulnerable to ‘double exclusion’, because of their age and their disability. In consultation with local people with learning disabilities, ACNN have been reviewing their practices, services, publications and other media to ensure that they are accessible and meet the particular needs and opportunities of older people with mild learning disabilities and their carers.

**Age Concern Norwich** has been working successfully to extend its existing programme of consultation with older people to provide a voice for older people with learning disabilities and to ensure that older people with learning disabilities are fully represented as a distinct group.

**Age Concern Norfolk** has been carrying out a piece of work which identifies the support needs of older people with learning disabilities engaged in mutual caring roles, normally with their older family carer/parent of many years’ standing. This piece of research was prompted by a project conducted on behalf of Sheffield Mencap through which the extent to which people with learning disabilities occupy a mutual caring role was explored for the first time.

**Family Carer Networks**

Dorset & Somerset Family Carer Networks enable family carers to network amongst themselves and utilise their families’ Person Centred Plans to drive the daily implementation of Valuing People Now principles as well as collectively drive the strategic development of Learning Disability in the county.

**What the evidence shows – key facts**

**Disability**

Much discrimination against people with learning disabilities is rooted in wrong assumptions about disability in general, misconceptions about intellectual impairment, and attitudinal barriers towards disabled people because they are ‘different’:

- Disabled people in general are viewed as ‘incompetent’; this affects how they are perceived as adults (CERI, 1988)
- People with learning disabilities, especially those with severe learning disabilities, are not automatically granted the full rights of citizenship, because of the notion of ‘incompetence’. Riddell, Ward and Thomson (1993)
- People with learning disabilities are viewed as ‘eternal children’ because they are not viewed as being competent to make decisions or act responsibly, Corbett and Barton, 1992
- Phillips (2004: 161) maintains that ‘people are not only judged by their cognitive impairment, the label also incorporates assessments of ‘challenging’ or ‘difficult behaviour’.”
• People with learning disabilities challenge Western conceptions of autonomy and individualism, and because of their ‘difference’ are considered a threat to the basic social order (Davis, 1998:103)

**Inequalities in Healthcare**

• Tyrer et al, 2007, found that for people with moderate to profound learning disabilities all cause and disease specific mortality rates were over three times higher than for the general population, but these varied considerably with age and there was also a clear gender effect, with increased rates for females.
• People with learning disabilities are 58 times more likely to die before the age of 50 than the general population (Hollins et al 1998)
• Women with learning disabilities are much less likely to undergo cervical smear tests than the general population (24% v 82% Pearson et al 1998)
• Uptake for cervical screening amongst women with learning disabilities is far lower than average. Just 3% of women aged 18 and over with learning disabilities living within a family, and 17% of those in formal care have had screening, compared to 85% for women aged 20-64 nationally¹.
• Incorrect assumptions about sexual inactivity, or negative attitudes about learning disability, result in women with learning disabilities not having routine cervical smear tests or breast screening (Stein, 2000).
• Mental Health problems are also more common amongst people with learning disabilities (RCN 2007). Prevalence rates for schizophrenia in people with learning disabilities are approximately three times greater than for the general population (3% v 1%; Doody et al 1998) with higher prevalence rates for south Asian adults with learning disabilities compared with white adults with learning disabilities (Chaplin et al 1996)

**Inequalities in access to Mainstream Housing and Independent Living**

• Only 15% of people with learning disabilities have a home of their own;
• More than 30% of people with learning disabilities live in residential care homes, a significant proportion of which are miles away from their place of origin and their families;
• Many people with learning disabilities are living with older family carers who have their own needs; Housing Time Bomb (Mencap 2002) estimates that over 29,000 adults live with a parent over the age of 70,
• Embedded attitudes towards learning disability (e.g. Smith 1994) lead to narrowed expectations and aspirations for these adults, in terms of supported housing of independent living.

**Inequalities in access to Employment, Education and Training**

• Only one in ten of those known to social services has any form of paid employment, and of those only very few work more than 16 hours; this is in spite of the fact that ‘work is perhaps the most important indicator of adult status’ in that it provides economic independence and status in the community for those

¹ The NHS – health for all? People with learning disabilities and health care, MENCAP, 1998
with disabilities, as well as opportunities for regular social interaction outside of home, (McGinty and Fish, 1992:14)

- The ‘Joint Report’ (ODI, 2006) highlights that attitudes of both employers and staff supporting people with learning disabilities prevent many of them from entering into paid employment.
- Within post-16 education, misconceptions about how and why people with learning disabilities learn often lead to provision that is unsuitable, irrelevant and poor in quality (Ofsted 2007; Dee, Devicchi, Florian and Cochrane, 2006).
- ‘Transition to adulthood is said to involve’:
  - Transition from school to training, employment or unemployment
  - Moving out of the parents’/carers’ home
  - Transition to adult sexuality, coupledom, marriage and possibly parenthood
  - Financial independence from parents (or other carers)
  - (Barnardo’s, 1996:9)

yet young people and adults with learning disabilities are often denied all of the above

**Inequalities of ‘Citizenship’, including Parenting, sexual relationships and personal safety**

- People with learning disabilities report that they are often the target of hate crime, that they are dependent on very limited and expensive public transport to get around, and that being lonely is one of the things they fear the most;
- The 2008 report of the Parliamentary Joint Committee on Human Rights - *A Life Like Any Other?* – highlighted continued and extensive failure of services and society to accord people with learning disabilities their basic rights;
- People with learning disabilities may find it hard to get the support they need to be parents. Many face continual scrutiny or the removal of their children because of assumptions that their children are, or will be, in danger (Keith, 1996). Fear of negative attitudes towards them and/or their support needs can act as a deterrent to approaching services and/or disclosing support needs (Morris and Wates, 2006).
- Professional assumptions and misconceptions about sexuality, the right to engage in sexual activity and the need for protection also undermine people with learning disabilities and their adult status ((Stein, 2000; Sheakespeare, 2000; Outsiders 2008a).
- Anecdotal evidence and other sources point to the fact that people with learning disabilities are often denied a meaningful sex education, opportunities to form relationships and opportunities to sustain sexual relationships including same sex relationships (Abbot, D. and Howarth, J. 2005, Outsiders 2008a))

**Ethnicity**

- Dee, Byers, Hayhoe and Maudslay (2002) raise the issue of recognising the differences in cultural expectations and traditions when developing a curriculum for people with learning disabilities (citing Morris, 1999 and Maudslay, 2000).
- A recent review of Partnership Boards (the Role and Effectiveness of Learning Disability Partnership Boards, The University of Nottingham 2008) indicated that
very few (only 17%) of Partnership Boards involved families from BME communities.

- In the second national survey of Partnership Boards undertaken by the University of Lancaster (Hatton, 2007), of the 54% that responded only 22% said that a race impact assessment had been undertaken – either for the board itself or as part of a wider Equalities Impact Assessment; and 48% said that no checks were being done to make sure services treated everyone equally whatever community they belonged to.
- Ethnicity appears to be a factor in morbidity and mortality, with rates being higher amongst those from minority ethnic communities
- Among adults with Intellectual Disabilities, South Asians have similar prevalences of disabilities to whites and significantly lower skill levels. South Asians show similar levels of psychological morbidity, but make significantly lower use than whites of psychiatric services, residential care and respite care. South Asians use community services as extensively as whites, but feel that they have a substantially greater unmet need, especially with regard to social services. (McGrother et al 2002)

Gender

- Gender issues within the learning disability field have been largely neglected until relatively recently and are still addressed only in quite specific ways: most work on gender is in fact about women; and most relates to sexuality and reproductive health (McCarthy, M. 1999a).
- Society generally, and service providers specifically, tend to see people with learning disabilities now as either children or adults. Not as girls and boys, women and men who may have different and conflicting needs and desires. (op cit)
- The small body of literature which focuses on men with learning disabilities is almost exclusively about their sexual behaviour (Thompson 1994, Thompson and Brown, 1998, Cambridge, 1995)
- Research and practice in sexuality and learning disability has directly and indirectly highlighted the pathological sexual behaviour of men with learning disabilities, particularly their abuse and exploitation of women with learning disabilities, and relatively high HIV risk sexual behaviour with men without learning disabilities. It is consequently argued that there has been a relative neglect of their wider sexuality and sexual needs (Cambridge and Mellan, 2000)
- Although sexuality and sexual abuse predominate as themes for women with learning disabilities too (see for example McCarthy in press, Millard 1994, Chenoweth 1992) there is far greater coverage of diverse topics such as body image (McCarthy 1998), deinstitutionalisation (Johnson 1998), health matters (BILD Bulletins 112/4, 112/5, 112/6).
- There is evidence from the feminist literature within the wider disability movement (Morris, 1996) that (some) disabled women want support to do things other than enter paid employment (although paid employment is a key aim for most, and the two are not exclusive)
- Victorian values and ideals about masculinity and sexuality played their part in the separation between those with intellectual impairments and society in general, and between ideas about men and women (McDonagh, 2000; Walmsley, 2000).
- For disabled women in general, and for women with learning disabilities, gender roles, self identity and sexual identity may remain ambiguous because of how their lives and identities are constructed by the professionals who come into contact with them (Phillips, 2004)
• Gender issues within learning disability services do not just relate to service users, but also to service providers. There are clear gender inequalities within the workplace, with most direct care work being done by women in low paid and low status jobs, whilst men are over-represented in the more highly paid managerial positions, with influence and authority (McCarthy, op cit)

Age

• Emerson and Hatton, 2004, estimate that the total number of adults with a learning disability (aged 20 or over) will increase by 8% to 868,000 in 2011 and by 14% to 908,000 by 2021. Significantly, all the growth projection shows much higher increases in the number of adults aged over 60.

• Mortality and morbidity among older adults with intellectual disability: health services considerations, Janicki, Matthew P.; Dalton, Arthur J.; Henderson, C. Michael; Davidson, Philip W. 1999: The main finding was that although individuals in the current generation of older adults with intellectual disability still generally die at an earlier age than do adults in the general population (average age at death: 66.1 years), many adults with intellectual disability live as long as their age peers in the general population. The results suggest that the longevity of adults with intellectual disability, whose aetiology is not attributable to organic causes, is progressively increasing. The results also confirm an increased longevity for adults with Down syndrome (average age at death: 55.8 years). Findings also showed that the causes of death for the study cohort were similar to those of the general older population, with cardiovascular, respiratory and neoplastic diseases among the most prominent causes of death.

Sexual Orientation/identity

• There is little thought given to supporting people with learning disabilities to develop their sexual identity (Outsiders, 2008a); this is linked to the fact that people with learning disabilities are often viewed as being ‘asexual’, childlike and needing protection (Corbett and Barton, 1992; Shakespeare, 2000)

• Concerns about what is felt to be ‘inappropriate’ sexual behaviour or sexual vulnerability lead, in some cases, to a complete denial of a person’s sexuality or sexual identity in practice (Outsiders, 2008a)

• The issue of sexual identity and sexual orientation need to be further researched and addressed more explicitly in policy (from all the references cited, and lack thereof)

• The feminist literature on disability, and the literature on the lives of people with learning disabilities suggests that for women (and men) with learning disabilities, the issue of sexual identity needs to be explored within their gender identity (from all the references cited)

Religion or Belief

• There is little evidence of the specific needs of people with learning disabilities who hold different beliefs, religious or otherwise in the body of literature

• Little thought is given to the spiritual needs of people with learning disabilities when developing policy or services (Swinton, J. 2001, 2002, 2004) even though spiritual
expression is viewed as a human right (Religious Expression, A Fundamental Human Right: A Report of an action research project on meeting the religious needs of people with learning disabilities (written by Chris Hatton, Susanna Turner, Robina Shah, Nabela Rahim and Julie Stansfield)

- It is important for people with learning disabilities to be supported and given the opportunity to think about their spiritual needs, to pray and to have opportunities to express their spirituality (from above reference)

Family Carers

Many analysts, and most relevant voluntary sector groups, already consider carers to be a disadvantaged group in their own right, facing social exclusion and discrimination (especially in relation to work and education) as well as a deterioration in their health and financial situation, both of which tend to worsen with length of caring and with the intensity of caring. The case for including carers in UK equalities legislation has been outlined in several recent documents; the Equalities and Human Rights Commission has identified carers as an important ‘cross-cutting theme’ in its work; and carers in part of the UK already have protection (as persons with dependants) under the Northern Ireland Act 1998 Section 75. Depending on its outcomes, the Coleman case, currently ongoing, may also have significant implications for carers.

[Carers Strategy Equalities Impact Assessment, DH, 2008]

The following information is taken from the Carers Strategy Equalities Impact Assessment (DH, 2008), as it is relevant for the Valuing People Now Strategy:

Overall, among people of working age, caring is most prevalent among people in the Bangladeshi, Pakistani, Indian and White British population groups. However due to the specific geographical concentrations of people from BME groups, and to the different age structure of some ethnic minority populations, both the absolute numbers of BME carers, and their numbers relative to the local White British population, fluctuate enormously from one locality to another. This produces different kinds of challenges for delivering culturally sensitive services and for meeting different needs in different localities. Table 1 shows the numbers of carers in each ethnic group: note that socio-economic and age differences may explain some of the % variation.

Table 1 Carers by ethnicity: England

<table>
<thead>
<tr>
<th>Ethnic group</th>
<th>Number of people (all ages) who are carers</th>
<th>% of specified population group who are carers</th>
</tr>
</thead>
<tbody>
<tr>
<td>White British</td>
<td>4,704,279</td>
<td>10.3</td>
</tr>
<tr>
<td>Indian</td>
<td>106,035</td>
<td>10.2</td>
</tr>
</tbody>
</table>

3 A European (ECJ) judgment, on whether discrimination by association with a disabled person is illegal, is awaited in relation to the case brought by Sharon Coleman; this is expected to clarify the law on this point.
4 Analysis of the 2001 Census (Yeandle et al 2007, Carers, Employment and Services Report Series, London: Carers UK), shows, for example, that in the London Borough of Southwark, 40% of carers belong to a range of different BME groups, whereas in West Sussex, the figure is just 5% (with only 2% of West Sussex carers belonging to non-White BME groups, compared with 31% in Southwark).
<table>
<thead>
<tr>
<th>Ethnic group</th>
<th>Number of people (all ages) who are carers</th>
<th>% of specified population group who are carers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Other White</td>
<td>92,411</td>
<td>6.9</td>
</tr>
<tr>
<td>Pakistani</td>
<td>67,476</td>
<td>9.4</td>
</tr>
<tr>
<td>White Irish</td>
<td>65,010</td>
<td>10.1</td>
</tr>
<tr>
<td>Black Caribbean</td>
<td>44,675</td>
<td>7.9</td>
</tr>
<tr>
<td>Black African</td>
<td>26,822</td>
<td>5.6</td>
</tr>
<tr>
<td>Bangladeshi</td>
<td>24,815</td>
<td>8.8</td>
</tr>
<tr>
<td>Any other Asian background</td>
<td>20,970</td>
<td>8.7</td>
</tr>
<tr>
<td>Chinese</td>
<td>12,905</td>
<td>5.7</td>
</tr>
<tr>
<td>White and Black Caribbean</td>
<td>10,355</td>
<td>4.4</td>
</tr>
<tr>
<td>White and Asian</td>
<td>10,048</td>
<td>5.3</td>
</tr>
<tr>
<td>Any other mixed background</td>
<td>8,782</td>
<td>5.6</td>
</tr>
<tr>
<td>Any other black background</td>
<td>6,053</td>
<td>6.3</td>
</tr>
<tr>
<td>White and Black African</td>
<td>4,161</td>
<td>5.3</td>
</tr>
<tr>
<td>Any other background</td>
<td>13,008</td>
<td>5.9</td>
</tr>
</tbody>
</table>

Source: 2001 Census Commissioned Tables, Crown Copyright 2003

Additionally:

- There are a growing number of people with learning disabilities who are themselves family carers (from anecdotal evidence).
- The 2004 Carers UK report ‘In Poor Health: the impact of caring upon health’ shows, through analysis of the census, nearly 21% of carers providing over 50 hours of care say they are in poor health compared to nearly 11% of the non-carer population with nearly 700,000 carers reporting that they were not in good health in the census.
- Among people of working age, there is a higher incidence of caring among women than men in all ethnic groups. On average, women provide slightly longer weekly hours of unpaid care than men. After age 75, however, the incidence of caring is higher among men than women. (Carers Strategy Impact Assessment, DH 2008)

Further Analysis

Positive Effect on Equalities

How is the policy likely to affect the promotion of equality and elimination of discrimination in the areas of age, disability, gender (including transgender), race, religion or belief, sexual orientation (and identity), and human rights?

Disability

Valuing People Now is underpinned by the vision that people with learning disabilities are equal citizens. It makes particular reference to the Disability Discrimination Act (2005), and the duty on all public services to ensure they are compliant with the Disability Equality
Duty. In this respect the whole strategy promotes the equality of people with learning disabilities, as a sub-group of the wider group of people defined as having a ‘disability’.

Additionally, the approach taken in this strategy i.e. with its strong emphasis on rights for the most excluded and in advocating person centred approaches for all planning and commissioning, will benefit the wider population of disabled people. If services and professional supporting people with learning disabilities implement the changes advocated in this strategy the potential wider impact for many vulnerable and excluded groups (including older people) will be positive.

**People with Complex Needs**

Valuing People Now also places much greater emphasis on people with complex needs, recognising that within the learning disability spectrum there are people for whom access to mainstream services and other opportunities is an even greater challenge. It challenges the assumption that people with complex needs are passive recipients of services and promotes the view that they can be active, intentioned citizens with a role to play in society. It promotes their human rights and gives examples of best practice in areas such as communication, ongoing support and planning and support to enter employment. It also recognises that innovative and creative approaches to planning and support are necessary to enable them to lead fulfilling lives as part of the community.

Valuing People Now commits to the following in order to promote the equality of people with complex needs within the wider strategy for people with learning disabilities:

- The appointment of a Complex Needs Lead (‘champion’) within the new national team of programme leads (within the Office of the National Director)
- A strand of work to ensure that people with complex needs, and their families, are engaged in, and benefit from, the implementation of Valuing People Now. This will include the following (taken from the Delivery Plan for 09/10):
  - The Department of Health, through the Office of the National Director, will commission work to support improvements in basic and best practice communication with people with the most complex needs. **Commission in February 2009 and disseminate information in September 2009.**
  - The Department of Health, through the Office of the National Director, will scope work, using information currently available, to identify and support people with the most complex needs. This will then be used to generate models for local application. **Commission work Feb 09; disseminate information Summer 09.**

**Promoting equality of access to Healthcare, Housing, Post-16 Education, Employment Support, Transport, Leisure Services**

Specifically, Valuing People Now contains a number of commitments to *promote* the equality of people with learning disabilities, where inequalities currently exist (as evidenced above). Headlines are:

- The appointment of National Programme Leads in: Health, Housing, Advocacy, Transition and Employment to lead national, cross Government work strands to
implement Valuing People Now and promote equalities for people with learning disabilities

- Work within DH and across Government to ensure that the reform set out in *Putting People First* includes and benefits all people with learning disabilities and their families.

- Work strands in response to the 10 main recommendations set out in the Independent Inquiry Report around Healthcare (Healthcare for All, DH, 2008) including (taken from the Delivery Plan):

  - The Department of Health will commission a scoping study for a confidential Inquiry into the premature deaths of people with learning disabilities. 2009/10.

  - The Department of Health will commission the development of a Public Health Observatory to collect, collate and analyse data regarding people with learning disabilities. 2009/10

  - The Department of Health will continue to support Annual Health Checks for people with learning disabilities known to local authorities through GPs and will monitor this via the Vital Signs indicators. 2009-2012

- Work on ensuring the NHS fully respects the human rights of people with learning disabilities and their rights including the first NHS Constitution setting out the rights and responsibilities of all individuals in relation to the NHS.

- A joint programme of work between DH and CLG, beginning in early 2009, to consider how mainstream housing policies can best be made inclusive of people with learning disabilities

- The publication of a cross Government Employment strategy to increase the number of people with learning disabilities, including those with moderate to severe learning disabilities, into paid work (and linked to the PSA 16 indicator for this group around employment) (Spring 2009)

- Joint work between DH and DCSF to ensure that *Aiming High for Disabled Children* and the Transition Support Programme will support local areas to improve their transitions arrangements and consolidate person centred approaches, working closely with Adult Social Services.

- Continued leadership of the *Getting A Life Project*, aimed at young people in Transition, with a focus on joined-up assessment and planning locally, ensuring that the learning is captured and disseminated to inform policy and practice.

- Continued support of the cross-Government post-16 education strategy (Progression through Partnership, DfES 2007)

- Joint work between DH and DfT to audit national actions around Transport to ensure the inclusion of people with learning disabilities

- Liaison between DH and the Department of Culture, Media and Sport to explore how local leisure services can be made more accessible for people with learning disabilities.

**Promoting social inclusion, citizenship and community cohesion**

Additionally, Valuing People Now contains commitments to promote the social inclusion and citizenship of people with learning disabilities, including work around relationships, parenting and participation in advocacy groups and partnership boards:
• Work with CSCI (and subsequently the Care Quality Commission) to address the role of registered care services in supporting people to develop and sustain relationships, including sexual relationships, increasing access to mainstream leisure and recreational services, and supporting people to keep in contact with their friends and families.

• The production of toolkits for health and social care professionals about promoting safe relationships within the laws of safeguarding and human rights.

• Work with all relevant government departments to ensure that all relevant information for parents with a learning disability is available in accessible formats by 2011

• Dissemination of various sets of good practice guidance for people supporting parents with a learning disability

• An Advocacy work programme to focus on supporting advocacy to achieve a greater impact including a toolkit for self advocacy groups

• Work to support and strengthen local Learning Disability Partnership Boards, including an annual self assessment process whereby self advocates and family carers sign off these reports

Finally, Valuing People Now includes a strand of work to tackle the discrimination and harassment that people with learning disabilities often face, namely Hate Crime:

• Home Office and DH will work together to make sure that the HO Hate Crime Strategy, which includes Disability hate crime addresses the specific issues for people with learning disabilities.

• The Home Office will also work with DH on developing specific learning disability guidance for Crime and Disorder Partnerships, which include local authorities and the police

This work is part of the wider equalities agenda that the Home Office are leading on and it is expected that this work will also help to promote community cohesion as well to reduce harassment.

Coupled with this, is the work led by the Crown Prosecution Service to develop a new policy on prosecuting crimes where people with learning disabilities are victims or witnesses.

Regional and Local Actions

Underpinning all of the above national commitments are a number of recommendations and recommended actions that Valuing People Now sets out for regional and local implementation. This includes the recommendation that all Partnership Boards carry out their own Equalities Impact Assessment as part of their local monitoring of progress against the Valuing People Now objectives. The expectation is that these actions will lead to a reduction in inequalities in service delivery and a promotion of rights for people with learning disabilities.

Furthermore, Valuing People Now is explicit in its aim to challenge widely held assumptions and prejudices about people with learning disabilities. The strategy document does this in its narrative, and this is also embedded in most of the work strands as addressing inequalities involves changing attitudes. The Delivery Plan for Valuing People
Now has an aim and priority for 2009/10: to raise awareness of Valuing People Now across national and local government, private and voluntary sectors, and within wider society. This will be a key aim for the Stakeholder Engagement and Communication Strategy. Raising awareness will involve promoting the rights of people with learning disabilities and demonstrating, through evidence and good practice, that they can lead ordinary, fulfilled lives within society. In doing so, it is expected that this will not only reduce inequalities but promote their social inclusion and improve community cohesion. As Valuing People Now is implemented and as more people with learning disabilities begin to take their place in their local communities, in schools, colleges, workplaces, leisure centres, parent clubs etc, it is expected that attitudes towards them will change and levels of discrimination, harassment and hate crime against them will reduce.

**Ethnicity**

Valuing People Now recognises that people from black and minority ethnic groups (and newly arrived communities) did not benefit from Valuing People in the same way as some other groups. It refers to the ‘double discrimination’ that some people with learning disabilities from BME communities face. It states that all services must comply with the requirements of the Race Relations Amendment Act and that public authorities must monitor their work for any adverse impact on race equality, i.e. that all actions and initiatives described in *Valuing People Now* will need to be assessed for their impact on minority ethnic communities, whether they are settled or migrant.

Valuing People Now also points to guidance on working with people from minority ethnic groups in rural areas, where they can be less visible. Specifically it commits to:

- The appointment of an Ethnicity lead (Champion) within the new national programme team to take forward a programme of work around ethnicity including:
  - raising the profile of this issue to ensure it is taken seriously by all agencies supporting people with learning disabilities and their families so that locally they will design and commission services to ensure genuine inclusion; and
  - working together with the National Advisory Group for People with Learning Disabilities and Ethnicity to develop and disseminate good practice to inform policy, in line with recommendations made by the National Advisory Group on Ethnicity and Learning Disabilities (as cited earlier).

The Delivery Plan also states that as part of this work and linking to the family carers work strand, will be joint work on reaching families from BME communities from rural areas.

Other commitments around ethnicity are included in work around:

- **Personalisation:** within the context of transformation and personalisation agenda it is important that the issues specific to people with learning disabilities and their families are properly addressed. This is particularly the case for those with more complex needs and from BME communities.
- **Advocacy:** the *Valuing People Now* national advocacy programme will include a strand of work to support advocacy for people from black and minority ethnic communities and people with complex needs.

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5 People from minority ethnic backgrounds living in rural areas. Ghazala Mir, Centre for Research in Primary Care, University of Leeds, ... www.valuingpeople.gov.uk/echo/filedownload.jsp?action=dFile&key=459 -
Recommended actions state that Partnership Boards should develop their own Equalities Schemes to show how they are implementing and monitoring Equalities legislation.

**Gender**

Valuing People Now does not make any specific reference to gender, although some actions (e.g. those intended to reduce inequalities in healthcare screening) may have positive outcomes for women and men as separate groups. There is mention of access to maternity services, which will affect women for the most part. Additionally, the notion of person centred planning and approaches underpinning this strategy should result in a focus of the need of the individual, of which gender is a key part.

However, the lack of attention to the specific gender identity and issues for both men and women with learning disabilities is acknowledged. Further research and scoping is necessary. This is detailed in the Actions grid.

**Age**

Valuing People Now sets out a commitment to improve the lives of all people with a learning disability. However, it is a strategy for adults with a learning disability, since children fall within the remit of the statutory Special Educational Needs process in terms of access to educational support and social care. Additionally, there are a number of existing policies that target disabled children and cover the needs of this group.

The exception to this is the fact that Valuing People Now directly targets *young people* (from year 9 onwards) going through ‘Transition to adulthood’ since this is a time when many young disabled people, and especially those with a learning disability, fail in the gap between children’s and adults services (Morris, 1999) and fail to receive the necessary support to enable them to move into adulthood as independent and empowered citizens.

Furthermore, the strategy recognises the fact that tackling discrimination and exclusion for people with learning disabilities starts in school. The Including Everyone and Employment sections point to schools as key players in raising the aspirations for children with a learning disability and inspiring them to believe that can grow up to get paid jobs and live independently.

Valuing People Now also recognises that *older people* (i.e. over 65) with a learning disability can often be ‘forgotten’, both by learning disability policy and practice and by mainstream policy and practice for older people. In this respect, they fall between two posts, and historically services have not had to provide for many older people as survival rates have been quite low. This is expected to change (Emerson and Hatton, 2004).

Furthermore, it specifically addresses the needs of older people as follows:

- Valuing People Now (VPN) refers to access to end of life care, and the dementia strategy, in recognition of the fact that people with learning disabilities will live longer, and to ensure that older people with learning disabilities have equal access to these services.
VPN states that over 29,000 adults live with a parent over the age of 70,\(^6\) (Mencap estimate). This recognises that a growing number of people with learning disabilities live at home with elderly parents who act as their carers.

VPN recommends that Joint Strategic Needs Assessments identify the housing needs of people with learning disabilities to inform strategic planning including the number of people with learning disabilities living with family carers over 70. This is particularly important because stakeholders have told us that the impact of poor housing (particularly issues around physical access like soundproofing; safe neighbourhoods etc) becomes more acute with ageing carers: in many cases the provision of a stair lift, bathroom adaptations, access to a Care and Repair service may enable the family to remain in their own neighbourhood.

VPN highlights the ‘importance of planning for people who are past the retirement age and may want things other than work’ (p.57) within the section on work, education and Transition. This recognises that access to post-16 (adult) education and recreational or leisure activities may be as important as paid work for adults of all ages, including older people. It also acknowledges that ‘access to post-16 education has been a problem because of priority being given to young people and achieving level two qualifications’. Valuing People Now references Progression through Partnership, the cross-Government post-16 education strategy, and commits DH (via the Office of the National Director) to continuing to work with DCSF, DIUS and DWP to fully implement the strategy, including ‘ensuring that meaningful and relevant learning opportunities are accessible, and that imminent changes to the funding of all post-16 education benefit all people with learning disabilities’ (p. 59). Progression through Partnership is aimed at adults of all ages, not just young people, although it does not make explicit reference to older people’s learning.

**Sexual Orientation (and identity)**

Valuing People Now promotes the notion that people with learning disabilities are sexual beings with a need to have meaningful and sexual relationships. The section on relationships seeks to challenge the assumption that people with cognitive impairments cannot or should not have either. One of the specific issues for staff supporting people with a learning disability, especially within a residential setting, is finding the right balance needed between their ‘duty of care’, including the implementation of protection and safeguarding protocols, and the promotion of independence and autonomy for the individual. Often the presumption of sexual inactivity and the fear of risk lead staff to take more drastic action than is necessary.

Valuing People Now commits to actions to promote the equality of people with learning disabilities in terms of developing and maintaining sexual relationships:

- The National Directors will work with CSCI (and subsequently the Care Quality Commission) to address the role of registered care services in supporting people to develop and sustain relationships, including sexual relationships, increasing access to mainstream leisure and recreational services, and supporting people to keep in contact with their friends and families.

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\(^6\) Housing time bomb
The National Directors and Valuing People regional team will produce toolkits for health and social care professionals about promoting safe relationships within the laws of safeguarding and human rights.

In this respect, it could be argued that *Valuing People Now* will promote the equalities of people with learning disabilities in terms of supporting them to develop and express their sexual identity. Sexual orientation is not addressed explicitly, however.

**Religion or Beliefs:**

*Valuing People Now* states that ‘greater personalisation’ means more consideration being given to responding to people’s *cultural and religious beliefs*. It also recommends that wherever possible, people with learning disabilities should be supported to work, pay taxes, vote, do jury duty, have children, and participate in community activities or *faith groups*. In this respect, it can be viewed as promoting the rights of individual people with learning disabilities to practice their own religion.

Other than the above, there is no mention of religion or belief. This needs further consideration.

**Human Rights**

*Valuing People Now* is written from a Human Rights perspective and this is made explicit in the Introduction:

This strategy promotes a human rights based approach. It confirms that adults with learning disabilities have the same human rights as everyone else. It sets out the further steps that are needed for people with learning disabilities to achieve freedom, respect, equality, dignity and autonomy in their everyday lives. This includes action to:

- promote human rights in healthcare through promoting good practice
- support independent advocacy to achieve a greater impact for people with learning disabilities, including people from black and minority ethnic communities, those with complex needs and family carers
- address the specific issues for people with learning disabilities on safeguarding in the *No Secrets* consultation
- reduce hate crime for people with learning disabilities
- address issues around social exclusion, poverty and isolation
- work with professional and regulatory bodies, national workforce organisations, education providers and others to ensure appropriate training for NHS, social care and mainstream public services staff on equality and human rights

Underpinning this approach is the expectation that services delivering support to people with learning disabilities will act to ensure they are fully compliant with the law, especially the Human Rights Act 1998 and the Disability Discrimination Act 2005. The Disability Equality Duty within that Act requires public bodies to check the impact of their policies on the lives of disabled people – especially where the outcomes for people with learning disabilities are worse than the population as a whole (e.g. health, employment, housing).
Valuing People Now is expected to have a significant impact on the human rights of all people with learning disabilities.

Family Carers (linked to ethnicity, gender and age)

Valuing People Now seeks to build on The National Carers’ Strategy, which states that:

“Our vision is that 2018, carers will be universally recognised and valued as being fundamental to strong families and stable communities. Support will be tailored to meet individuals’ needs, enabling carers to maintain a balance between their caring responsibilities and a life outside caring, whilst enabling the person they support to be a full and equal citizen.

Valuing People Now has a strong emphasis on promoting the rights of family carers, in general, and in recognising them as partners in the support of their family members with learning disabilities. Specific commitments to promote the equality of family carers include advocating for carers assessments whenever there is planned change in the support given to an individual, or for carers of people with complex needs.

Valuing People Now also states that people with learning disabilities who are themselves ‘family carers’ need to benefit from wider carers programmes of support and in particular the Carers Strategy.

In the Delivery Plan, the National Valuing Families Forum has agreed the following priorities for 2009/10:

- Building and sustaining the capacity of mainstream carers organisations to meet the needs of family carers
- Support to people with learning disabilities who are carers
- Supporting families from black and minority ethnic communities
- Supporting older family carers.

These will inform the national Families Programme as part of Valuing People Now.

Adverse effect or potential adverse effect

If the policy is likely to have a negative effect, what are the reasons for this?

Disability

Valuing People Now uses the Valuing People 2001 definition of ‘learning disability’ as distinct from the wider definition of people with learning difficulties and/or disabilities used by other government departments from time to time, and especially in the context of education policy. It actively seeks to address the inequalities for this group of disabled people because evidence shows they are amongst the most disenfranchised in society and in services.
In this respect, it could be argued that it will have a differentiated outcome in respect of disabled people, and could, potentially, have an adverse effect on some people who are not included in the learning disability definition (e.g. people on the autistic spectrum with communication difficulties who do not have a 'learning disability') if professionals or services prioritise this agenda over the wider disability agenda, or do not fully understand the need to use the Valuing People principles across all services planning, delivery and commissioning as recommended in the strategy itself. To mitigate this risk, DH/OND will ensure that the implementation of Valuing People, via support from the regional Valuing People Leads, will promote person centred planning approaches for all groups with communication difficulties, including older people.

Valuing People Now places great emphasis on employment as a means of promoting social inclusion and independence for all people with learning disabilities, and states that it should remain as aspiration for those with the most complex needs.

Dee et al. (2001:9) state that ‘the emphasis given to employment as the main marker of adulthood...is open to considerable debate’ as far as those with profound and complex learning difficulties are concerned. But that this is not to suggest that this should not be a goal for their transition to adulthood, but that, perhaps, society needs to re-adjust the way it assigns adult status and value to individuals.

Arguably, the strong focus on employment and the assertion that this is possible for all could have a negative impact on people with the most complex needs if it is used as the main marker for both ‘adulthood’ and status. This is especially the case if it is aimed for at the expense of recognising and addressing other immediate needs in areas like healthcare, communication and advocacy (this was a concern of many carers in the consultation feedback, and is supported by stakeholders such as Mencap).

To mitigate this risk we have redrafted the Including Everyone chapter of Valuing People Now to reflect the concerns that those with complex needs will need ongoing support to enter paid employment and to emphasise that other needs, particularly around communication, should not be ignored. We will continue to engage with stakeholder groups as the Delivery Plan is implemented, and work with Mencap and the PMLD Network to ensure that the programme around complex needs is broadly focused upon the range of needs of this group.

**Ethnicity**

Valuing People Now sets out to reduce inequalities for people with learning disabilities from BME communities. However, there is little data around numbers of people across England from different ethnic communities and there has been little research or targeted engagement with people from different communities to explore the possible effects of Valuing People Now. This is a risk that needs addressing as part of the delivery plan.

The NAGLDE expressed concerns with regard to the consultation document:

- Health - we felt there was some evidence of poor equality monitoring in this section as no reference was made to higher level of poor health in minority communities making risk even higher for people with learning disabilities from these communities. The DRC’s formal investigation (‘Equal Treatment Closing the Gap) into primary healthcare for people with learning disabilities from minority
communities states “People with Learning Disabilities and/or mental health problems from BME communities face complex barriers. These range from the practical – e.g. lack of health information available in community languages – to the attitudinal.” We also cannot find acknowledgement of the work “Health Action Plans and Black and Minority Groups” R. Flynn. DH, 2003.

- Housing - we were disappointed not to find specific mention within the Valuing People Now section on ethnicity and housing of the cultural variation in understanding and valuing individual housing need. BME communities may not have the same value base concerning individual achievement over communal well being. This was comprehensively outlined in the original Valuing People documentation. (“Learning Difficulties and Ethnicity” DH 2001 pages 29-35). The base line for planning housing for people from minority communities may be different and without paying full attention to their options will be limited.

- Advocacy - issues around advocacy again raise the difference between attitudes to individualism versus collectivism. By not acknowledging this, VPN is in danger of non-delivery to many from BME communities. The recommendation that the Valuing People national advocacy fund will pay particular attention to people at greatest risk of losing choice and control in their lives, such as those from minority communities” will need careful examination. From whom do people from BME communities lose control? Before this agenda can be carried forward, all involved will need to respect BME values.

The lack of specific reference to areas where people from BME communities face even greater barriers to understanding or where their values differ to that of the general population of people with learning disabilities is a risk. A lack of cultural sensitivity needs to be addressed as the Ethnicity work strand is scoped and developed with key stakeholder groups.

Feedback from another source suggests that whilst the recognition of cultural and religious preferences is vital, families are also changing in these communities. The concept of family as opposed to individual decision-making is very strong, but the next generation may in turn wish to have independence, a home of their own. So whilst the values of those from different communities should of course be valued there is a need to recognise a diversity of views and aspirations.

Further engagement with stakeholders from a variety of communities (of all ages) needs to take place in the scoping of any work around ethnicity.

**Gender**

Valuing People Now does not make explicit reference to gender. This is a risk that the Delivery Plan needs to mitigate, since the feminist disability literature shows that experience of disability is gendered (Thomas, 1999).

Feminist literature from within the wider disability movement suggests that paid work and financial independence have ignored or marginalised other explanations for disablism, as well other aspects of disabled women’s lives, where oppressive forces and cultural ideologies prevent them from fulfilling their desired social roles (Morris, 1996). These other aspects are summarised below:
Reproduction: advances in technology with regard to prenatal screening and the 'prevention of impairment through termination of pregnancy, have served to undermine disabled people (Bailey, 1996; Morris, 1991).

Parenting: people with disabilities who are also parents often have their parenting skills questioned (Morris and Keith, 1996). Research and policy on young carers tends to assume that children of disabled parents are responsible for them. This greatly undermines the social status of disabled women as mothers (op cit).

Caring for: Morris (1996) maintains that women want personal assistance that ‘enables them to look after children, to run a home, to look after parents or others who need help themselves’ (p. 10). Asch and Fine (1997) argue that disabled women suffer a ‘double oppression’ because they are exempted from both ‘the “male” productive role and the “female” nurturing one’ (p. 242).

Body image, self identity and sexuality: physically disabled people are marginalised because of the way that society idealises the body; the image of the ideal body is a social construct stemming from ‘our patriarchal culture’s desire for control of the body'; disabled women suffer more than disabled men from the idealised body because in patriarchal culture women are judged more by their bodies than men (Wendell, 1996) and because women define themselves through their attachments and relationships with others (Keith, 1996).

Lack of data and understating of gender issues and gender identity amongst people with learning disabilities also means a potential adverse effect. Further research and work is needed in this area.

Age

There is little evidence to suggest that Valuing People Now will have an adverse affect on older people with a learning disability (age 65 and above), for whom healthcare and access to adequate social care funding and support will become more of a priority, as it will for all of us (Wanless, 2006)

However the emphasis on Transition, employment and post-16 education (often focused on, and funded as a statutory right for, people between 16 and 25, with a focus on preparation for employment), could potentially, have an adverse effect on other adults, especially those beyond the age of retirement, in terms of access to leisure services, adult education programmes and other daytime activities.

The issue of access to adult education other than for ‘work preparation’ is one that the cross-Government post-16 education strategy (Progression through Partnership) seeks to address. Similarly it aims to increase opportunities in further and higher education for people with a learning disability beyond the age of 25 who want to return to education as part of their pathway into employment. The EQIA for Progression through Partnership states that:

With respect to the other groups under the ‘equalities agenda’ there is no evidence to suggest that this policy will have any adverse effect whatsoever; in fact the converse is likely. The underpinning notion of this ‘strategy’ is that young people and adults with ‘learning difficulties and/or disabilities’ will be given the support they need to follow individual learning pathways that meet their personal needs and aspirations. Thus we expect that issues of culture, ethnicity, age and gender (and possibly sexual orientation) will be given greater prominence than at present in the ‘person-centred planning’ that this strategy seeks to promote.
The same could be said for Valuing People Now, but whilst it references the aforementioned issues, the delivery needs to ensure that people aged 25 and above are not forgotten in any planned activities around promoting equalities across post-16 education, employment and leisure.

**Sexual Orientation**

Valuing People Now does not say anything explicit about sexual orientation. This is potentially a risk as it could be read as implying a heterosexual bias in any work around relationships. According to Joyce Howarth, author of ‘Secret Lives, Hidden Loves’, who advised DH on the development of the strategy and EQIA, the following can encourage secrecy about sexual identity and orientation:

- Not mentioning lesbians, gay men and bisexuals in sex education
- Making assumptions about a person’s sexual orientation - not asking if the person fancies men or women or both.
- Not including gay venues/films/plays in general social activities – regardless of what people’s sexual orientation is thought to be.
- Only allowing people to dress in clothing of the opposite gender at specific, restricted times.
- Making jokes about lesbians, gay men, bisexuals or transgendered people. Sense of humour needs to be balanced against sense of hidden hurt.
- Assuming lesbians, gay men, bisexuals or transgendered staff will do all the work with lesbians, gay men, bisexuals or transgendered service users
- Lesbians, gay men, bisexuals or transgendered staff being discouraged from talking about their relationships.

Valuing People Now commits to producing guidance for staff about how to support people to have safe relationships within the safeguarding guidelines. This guidance needs to explicitly mention lesbians, gay men, bisexuals or transgendered people to promote equality in this area.

Lack of baseline data about lesbians, gay men, bisexuals or transgendered people is an issue. DH (OND) needs to explore how best to capture this data, since for some people with learning disabilities, sexual identity (and orientation) may not be something that they have been supported to develop or understand. This also needs to be addressed in guidance for staff.

**Religion or Belief**

Valuing People Now makes minimal reference to the religion, belief or spiritual needs of people with learning disabilities by mentioning participation in faith groups. Further research is needed in this area as the denial or oversight of spiritual needs could be viewed as a breach of human rights (refs cited above)). Enabling people with learning disabilities to think about their spiritual needs and to have the space to pray or contemplate spiritual matters needs addressing in guidance to staff supporting people as part of the delivery plan. Religion or belief needs to be included in planned data collection.
Human Rights

There is no evidence to suggest that Valuing People Now will have a negative effect on the human rights of people with learning disabilities, other than if the communication or support needs of people with complex needs are ignored due to an over emphasis on paid work (as mentioned above) or any other objective. Valuing People Now makes it clear that this must not happen and person centred approaches are advocated so that in implementing the delivery plan, and particularly the Employment Strategy, the specific and individual needs of people with complex needs will be addressed.

Family Carers

Valuing People Now places a strong emphasis on the role of family carers and their rights as individuals. Yet concepts of family care may vary across communities. The National Carers Strategy (page 24) notes that ‘cultural concepts of care are not universally shared throughout communities in Britain. Many people from other countries do not have experience of a welfare state and therefore, among a whole range of concepts, would not understand the concept of carer. The National Black Carers and Care Workers Network have highlighted that they have been unable to find a word in Gujarati, Urdu, Punjabi or Bengali which translates into ‘carer’. ‘Additionally, many of our BME communities do not have direct translations for ‘learning disability, personalisation, person centred planning etc.’

Hence good interpretation and translation services are vital to ensure that everybody is fully understood. Valuing People Now is being translated into the six main ‘other languages’. Additionally work strands around engaging family carers from other communities needs to recognise and be sensitive to the fact that the western philosophy or care, independence and welfare state are not necessarily shared by those communities.

The National Valuing Families Forum highlight the potential adverse affect for family carers and the lack of evidence for long-term family carers:

More research/evidence needs to be added around the partnership between long term family caring (50+ years), the impact on a carer and the impact Valuing People Now principles will have on the lives of many institutionalised carers.

This revelation from government is inspiring and inspirational but WILL have an enormous upheaval in families’ lives as they adjust their thinking and ways of life.

It is essential IMPACT ASSESSMENTS/ carers assessments are frequently given to families of those still living at home. It seems essential that we advocate person centred planning with them as a family, and also as individuals in their own right, as it will enable them to identify the changes coming, e.g.:

1. **Someone having a more flexible day -**
   - Preparing not to have the house to themselves 9am -3pm (traditional day centre times).
   - Having a stranger (care provider) in the house along side them
   - These support workers using the mobility car to get to activities.
2. **Learning to understand the choices that their child will begin to take**
   - Preparing for their child to be making decisions (sometimes mistakes in order to learn)
   - Preparing themselves for them to have relationships, get a job.
   - Being able to have a place of their own – not go straight into residential setting

3. **Someone moving on into supported living**
   - preparing not only practically (financial implications) but emotionally as well as (being alone, not having a friendship network, little known in their community, never worked etc...)

These reactions are not of over protective parents who cant let go, they are instilled, indoctrinated attitudes forced on older parents by past society attitudes - and as you see transitional families coming through with high aspirations will be the ones to show these older carers what is possible. It is never too late (but **age** of carer and adult could determine people’s attitude to supported living etc)

Linking Valuing People to the Personalisation agenda is essential - and ensuring that people with a learning disability and their carers are not a disadvantaged group in it’s role out. Those able to choose to handle their finances and broker care/support for themselves are at a distinct advantage over those with a Learning disability and/or have elderly family carers.

The above issues need further exploration as we develop and take forward the delivery plan and the families programme of work.

**Equality impact assessment - summary**

A positive impact is explicitly intended and very likely in many areas, and the policy has the clear potential to have a positive impact in other areas by reducing and removing barriers and inequalities that currently exist. In some areas, parts of the policy have the potential for minimal adverse effect, but actions listed below can help prevent this.

**Next steps**

See Annex A for an outline action plan, based on the challenges and opportunities identified.

**For the record**

Your name and today’s date: **Sally Hall-Demir, 16 December 2008**

Name of Director and date endorsed by Director: **David Behan, 17 December 2008**
<table>
<thead>
<tr>
<th>Annex A: Action plan grid</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Actions</strong></td>
</tr>
<tr>
<td>Engagement and consultation with key stakeholder groups</td>
</tr>
<tr>
<td>Commissioning of new research work and scoping</td>
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<tr>
<td>Data collection, collation, analysis and dissemination</td>
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</tbody>
</table>
and minority ethnic communities. The scoping study will then be used to identify gaps and action.

<table>
<thead>
<tr>
<th>Making links and embedding work in other work streams</th>
<th>Make links with the <em>Ageing Strategy</em>, the <em>Carers Strategy</em> and the work commissioned by the Learning Disability Coalition to inform future policy and spending proposals</th>
<th>2009, as part of the delivery plan</th>
<th>National Director</th>
</tr>
</thead>
<tbody>
<tr>
<td>Strengthening performance measuring</td>
<td>DH (OND) will publish a Performance Framework position statement, setting out how the various frameworks relate to services for people with learning disabilities. Plans to measure progress for family carers and people with learning disabilities in specific equalities groups need further research.</td>
<td>By end March 2009</td>
<td>National Director</td>
</tr>
<tr>
<td>Communications and awareness raising</td>
<td>Develop the website <a href="http://www.valuingpeople.gov.uk">www.valuingpeople.gov.uk</a> to provide a comprehensive information base.</td>
<td>April 2009, as part of the delivery plan</td>
<td>National Director</td>
</tr>
<tr>
<td>Monitoring, evaluating and reviewing – including publishing the results</td>
<td>Develop a database to monitor and support progress in the implementation of Valuing People Now drawing on information from the Care Quality Commission, the NHS Information Centre for health and social care and the work of the Valuing People regional leads.</td>
<td>July 2009-2011, as part of the delivery plan</td>
<td>National Director</td>
</tr>
</tbody>
</table>
List of attendees

Alison Giraud-Saunders (Co-director of the Foundation for People with Learning Disabilities)
Barbara McIntosh (Co-Director of the Foundation for People with Learning Disabilities)
Charlotte Spencer (Cabinet Office)
Vicki Raphael (Valuing Families Forum)
Vivien Cooper (Valuing Families Forum)
Dame Jo Williams (Chief Executive of Mencap)
James Churchill (Chief Executive of ARC)
Simon Whitehead (Interim National Director)
Michael Ratcliffe and Supporter (National Forum for people with learning disabilities)
Richard Blake and Supporter (National Forum for people with learning disabilities)
Jim Mansell (Tizard Centre)
Sheila Hollins (St George’s Hospital)
Jane Alltimes (Mencap)
Joe O’Keeffe (Mencap)
Carol Boys (Downs Syndrome Association)
Sheila Heslam (Downs Syndrome Association)
Jean Willson (National Family Carers Network)
Robina Mallett (National Family Carers Network)
Anne Richardson (DH – was attending for Sir Jonathan Michael)

Apologies

Sir Jonathan Michael
Nicola Bailey (ADASS)
Lesley Strathie (Chief Executive of Job Centre Plus)
Simon Duffy (In Control)
Nick Bason (Employer’s Forum)
Karen Flood
Stuart Rigg (Advance Housing)

1. Introduction

David Behan welcomed everyone to the meeting and set out the purpose – to feed into the consultation response on three key issues:

- Family carers
- What people do during the day
- Black and minority ethnic issues

2. Discussion

The following points were made in the discussion;
1) General remarks at start of session

- Importance of housing – really important to the way people live independently. Also issues around impact of housing market slowdown
- Importance of getting the language right. Important to emphasise that “Independent Living” does not mean living without support. Need for the Department of Health (DH) to think carefully about language and how to present issues in final strategy
- Black and minority ethnic communities – suggestion that the team check back to see how many responses might actually represent mixed communities
- Really important not to polarise issues between families and people with learning disabilities – and not giving a sense of judging right and wrong positions/views. The crucial thing to remember is that everyone wants positive outcomes.

2) Family carers

- really, really great that DH is taking the time and engaging so positively with family carers’ concerns
- Language of partnership with families should run through the document
- When talking about housing, must say “housing with support”
- Reality of local authority cuts, Fairer Access to Care Services (FACS) criteria etc and circumstances people find themselves in colour reactions to Valuing People Now
- Not all people with learning disabilities can work a full week – need a mixed economy of things to do in the day
- In producing the final strategy, there should be a carer awareness impact assessment
- Parents of people with learning disabilities had other children too, and much of frustration stems from comparing life experiences of the other children and the child with learning disabilities
- Very difficult to see how translate Valuing People Now for people with complex needs and/or challenging behaviours. Huge burden for carers.
- The main issue was how to make things happen, how to get the right support
- Bad decisions cost more than good, and are still being made
- How to translate policy into practice and reality?
- How does Valuing People Now link to the recently launched carers’ strategy? What does that offer for families of people with learning disabilities?
- How can carers really believe the support needed will be there?
- Support provided needs to be quality assured
- Real issue about the attitudes of people who provide support – usually poorly paid and lowly valued. Their role is to be enabling but many don’t seem to be in that mindset
- Need for advocacy to address poor quality of support
- Family carers’ concerns about poor quality support and being let down (again)
- Need clarity how families can be assured that support will be decent quality, what measures are needed to make change happen, and especially to change attitudes
- Social workers, support staff etc should be trained by people with learning disabilities and carers
- Training for social work crucial for the whole personalisation agenda
- Need a shift from crisis management to proactive development
- Not easy to change attitudes as they are determined by a range of factors including circumstances in which people work, funding, lack of proper planning and focus
- Need a proper process to make things happen
• Support isn't been provided to a standard people want now. So how can it be improved?
• Issues about how drive change in reality, change the way the system works
• Leadership is vital
• Question as to what support there will be overall for delivery
• Role of the Valuing People support Team (VPST) to pick up some of the issues coming out from here very urgently
• Don't just focus on people with complex needs – there are a lot of people who need relatively low levels of support which drastically improve lives
• How ensure people have skills and incentives to deliver good quality care
• What's the model for changing services?
• Barriers to training of staff by people with learning disabilities because of the way in which training is structured and funded
• Typical way in which people with learning disabilities – example of a young man not receiving an invitation to his own annual review and therefore refusing to go, and then the offensive language in the written review report
• We know what we want to do, the anxiety is how we get it
• Family carers don't just need, we offer. Why aren’t we asked regularly to score what our loved one is getting and what needs to be done to make it better
• Family carers are – and should be seen as – stakeholders and you need our support to drive through the personalisation agenda. Need to give support to bodies – including those represented round the table – who support families and especially those who deal with ethnically mixed communities
• Please don’t disband the family carers’ support resource in the VPST – immensely valuable
• Government’s role is to say what we stand for, how things should be – making it happen is the challenge, and getting it into people’s practice
• Families are a resource to assist, not the enemy, not part of the problem but part of the solution. Social workers need to recognise that

3) what people do during the day

• It shouldn’t be about either a job or day care – people should have access to a mix of provision and options and there should be resilience in the system for people to move – ie if the job collapses, they can get alternatives and not lose everything
• People with complex needs can work – some really interesting examples from North America. Should consider having some national dissemination projects
• Need a cultural shift to enable people to move between options – work/benefits/day care. And need to build expectations in schools.
• Need to give people flexibility to experiment in the working world but ensure that if it doesn’t work out they have something to go back to
• Challenge to local authorities to recognise the importance of a building (doesn’t have to be an adult training centre) where people with learning disabilities can go to meet their friends
• Issue about discontinuation of support for people with learning disabilities once they are viewed as established in work – that can lead to collapse of job. Need ongoing support
• Losing day centres can be very distressing for people who use them. Need to be creative about establishing a base
• There aren’t enough services to get people into employment
• Lots of sponsorship for schemes by private sector in north America – need to get more of that in the UK. Role for social enterprise
• Need also to engage local authorities and social workers as stakeholders in supporting people into employment
• Social workers and local authority staff can feel stuck in corners – want positive outcomes too
• We should ask every stakeholder grouping what the enablers are and the accountabilities
• Experience as a learning disabled person trying to get a job can be very hard. And there are real risks of poverty traps – sometimes people are financially better off not working. And don’t forget that some people with learning disabilities are carers and so can’t work
• Problem of the DWP approach of a fixed end point for support into work. People with learning disabilities may need different approaches
• Need creativity around using personal carer/supporter to support people with learning disabilities into work
• Need robust flexibility about people who also have severe health needs on top of their learning disability
• Must emphasise that there are (increasing numbers of) people with learning disabilities who are no longer of working age and for whom provision of things to do during the day can’t focus on work!
• Agencies have a job in ensuring that family carers know how things are supposed to work
• Family carer networks need support to get information out to individual families
• Why is In Control so rigid? It claims to put people in control of their funding, but it can take ages to agree how to spend really tiny amounts of money. That’s not really control
• Issues about partnership boards – people with learning disabilities should be paid for participating (not to mention coming to DH meetings!)
• Family carers can sometimes be too exhausted to engage
• Plenty of employers are willing, but need support to find people with learning disabilities to employ
• The earning disregard remains a big problem, not least because it hasn’t risen in line with the minimum wage
• The watchwords are flexibility, creativity, adaptability and a continuum of provision

4) Black and minority ethnic issues

There was insufficient time to discuss in detail. Everyone was invited to e-mail the DH team with good practice, ideas etc

5) Comments from the Ministers for Care Services, Ivan Lewis (PS(CS))

• How do we make this document real in a real world?
• Agree professionals should recognise family carers as a resource and stakeholder but shouldn’t pretend it’s all cosy. There are some family carers who may not have the same interests and aspirations as their learning disabled family member – for the best of reasons – and they can be part of the problem
• What can government do to give this document real teeth? Part of that is about getting services judged by the people who use them. Need to find levers and forces for change to put into the system; one option might be a right to have a person-centred plan
• How do we use people with learning disabilities and carers to influence not just professionals but also other people with learning disabilities and families to show what is possible
• Social networks, leisure, personal lives, friends, quality of life – all are vital to enable so people with learning disabilities really get to live ordinary lives
Annex C: Notes of Task Force Meeting, July 2008

Equalities Issues

- There should be an ethnicity lead within the new team structure
- Personalisation: clear guidance and information that reaches people with learning disabilities and family carers is needed; this should include information about the support that is available
- Support for older family carers to think through issues
- Family carer needs must also be funded – currently lack of confidence as family carers left to pick up the pieces when services fail or ideas change.
- Need to find ways of linking family carers and people with learning disabilities into support from other family carers. This should include people with learning disabilities people with complex needs and BME backgrounds
- Including more BME groups could happen by involving their community and charity groups which will already have funding knowledge.
- User Lead Organisations – need to fully include people with learning disabilities and with complex needs, black and ethnic minorities BME and family carers, evaluation needs to include these groups.
- Better help, advice and support for parents and families
- Making sure that families and advocates understand their rights
- Give family carers more time and support
- Stories about peoples lives that have improved – that are delivered by parents
- Organise events for carers.
- Finding existing BME agencies to take on Learning Disability agendas, cultural awareness training
- Go into local ethnic community schools to raise awareness of what can be done to support people with learning disabilities.
- Spending more money on housing to meet more complex needs
Annex D: Feedback from the National Valuing Families Forum

It is essential to understand the current impact on Human rights of family carers:

- Huge presumptuous restrictions on their human rights
- Unlike any other group in society they are given a life long commitment caring role
- Limitations put on them on to choose their own caring/ Life balance
- Little opportunity to work/gain income/save/build a pension/ RETIRE!!
- Almost always living in poverty – therefore becoming dependant on their child’s income
- Little support/opportunity to put their own health needs first
- Little choice/use of respite in a preventative role rather than emergency breaks
- No preventative measures in place to reduce emergency family breakdown
- Little implementations/positive use of Carer registers in GPs
- Preparation for older carers to hand over the reins
- Little effort to raise aspiration of older carer used to the institutionalised care
- Hospital campus reprovision just being implemented
- Very limited ability to form and maintain relationships outside the caring role
- Little effort to raise aspirations to achieve in their own lives
Annex E: Summary of work on Ethnicity supported by The Foundation for People with Learning Disabilities

There has been awareness over many years that people with learning disabilities from BME communities and their families face double discrimination. It has also been recognised that they often experience insufficient and inappropriate services, despite great levels of need.

There is also awareness of increasing numbers of children and young people from black and minority ethnic communities being identified as having special educational needs and more profound disabilities.

Since the publication of Valuing People (and the accompanying report by Ghazala Mir and colleagues concerning people with learning disabilities from black and minority ethnic communities), the Valuing People Support Team and DH have started several initiatives designed to remove discriminatory barriers to services:

- Prioritising people from black and minority ethnic communities for Learning Disability Development Fund spending. (2005 –2007)
- A national ethnicity network managed by the Association for Real Change.
- Regional ethnicity networks managed through Valuing People Support Team regional leads.
- A national ethnicity-training network managed by the University of Leeds.
- Leadership training programmes building local leadership to improve services for people with learning disabilities and their families from black and minority ethnic communities.
- Monitoring of Partnership Board progress and reporting to ministers.

However, following the second survey of Partnership Boards by Chris Hatton at Lancaster University and the “Making Things Better” consultation meetings in London, Birmingham and York Commissioned by the National Advisory Group for People with Learning Disability and Ethnicity and funded by the Valuing People Support Team, it is clear that there has been little change. The Current review of Partnership Boards commissioned by the National Task Force (The Role and Effectiveness of Learning Disability Partnership Boards, The University of Nottingham 2008) indicated that very few (only 17%) of Partnership Boards involved families from the BME communities.

Although the national survey has indicated some small improvement particularly due to LDDF having ethnicity as a priority, the evidence suggests that there is still a lot to be done and a long way to go before we can deliver equal access to BME communities.

The second survey indicated that more Partnership Boards have information on adults from minority ethnic groups (88% of Partnership Boards who responded to the survey gave information on adults with learning disabilities using services for 2006, which is up from 74% in 2004/5). More Partnership Boards also have more detailed information including information about people’s experience of services. This is important as Valuing People in The Story So Far said that people from minority ethnic communities are more
likely to be properly included if Partnership Boards have basic information, like how many people should have and are accessing services and how well they are served.

Making ethnicity a priority for LDDF spending had a big impact on Partnership Boards. A lot more Partnership Boards are using some LDDF money to fund initiatives for people from minority ethnic communities (52% in 2005/6, compared to 22% in 2004/5, 10% in 2003/4). Many Partnership Boards also aimed for their general LDDF initiatives to have an impact on people from minority ethnic communities. Partnership Boards were able to report more examples of good practice across a broader range of activities in 2006/7 compared to 2004/5

Problems areas

Only 40% of Partnership Boards were able to give information on children from minority ethnic groups using services. It is difficult to plan services for the future without this information, especially given the predicted increase in this population.

Almost half of all Partnership Boards said that nothing had happened about equality impact assessments – either for the board itself or as part of a wider EIA. Valuing People The Story So Far said that people from minority ethnic communities are more likely to be properly included if there are action plans for improvement as required by the Race Relations Amendment Act (2000) and strong leadership to deliver those plans.

In some rural areas there are small numbers of people from minority ethnic groups and they can be less visible. This can mean that services do not meet people’s needs. There is guidance on working with people from minority ethnic groups in rural areas that can help and regional networks can also help as experience can be shared across areas.

The National Advisory Group for People with Learning Disabilities and Ethnicity has consulted with all the organisations and Regional Representatives about the content of Valuing People Now. [Each region is represented at the Advisory Group by the regional ethnicity lead, people with learning disabilities and family representatives] [Membership of the group is attached] The group commissioned a Race Equality Impact Assessment of Valuing People Now (attached), and they were disappointed that ethnicity was not perceived as a priority. Although there was agreement that ethnicity should be an underlying theme in all priorities, evidence suggests that there is a long way to go for this to be sufficient in making change happen for individuals and families from the BME communities. The Advisory Group makes a series of recommendations for Valuing People Now to be strengthened.

A vision for the future

Following discussion by the National Advisory Group on Learning Disabilities and Ethnicity key aspects of a vision for the future were identified. These included:

- Each person should be treated as an equal from birth.
- Diversity should be valued and welcomed.
- Different religions and cultures should be respected.
- People with learning disabilities from black and minority ethnic communities and their families should be widely consulted and in positions to influence government policy.
- People should be supported to part of their community and not hidden.
- There should be action to tackle the causes of fear.
• There should be more accountability in services.
• All communities should experience equality of access to services and supports.
• All communities should experience equality of outcomes resulting from services and supports.
• Equality of access and outcome should be across all areas of people’s lives, including school/college, housing, jobs, daytime activities, health, leisure, social relationships, the criminal justice system and transport.
• Opportunities and services should be person centred, meeting individual needs.
• The workforce should be more diverse.

Recommendations:

• The initiatives developed to date to redress the inequality experienced by individuals and their families from black and minority ethnic communities should be drawn together to provide some invaluable resources for a national action plan
• A national action plan concerning people with learning disabilities from black and minority ethnic communities is required to:
  • deliver the benefits of Valuing People to all people with learning disabilities, and ensure that Valuing People objectives are met for people with learning disabilities across all ethnic groups;
  • raise the profile of this issue and ensure it is taken seriously by all agencies supporting people with learning disabilities and their families;
  • to identify emerging new areas, for example new refugee communities;
  • ensure that there is a clear programme for improvement for agencies, both mainstream and specialist, to work towards;
  • raise the profile of people with learning disabilities and their families from black and minority ethnic communities in decision-making processes;
  • remove discriminatory barriers for all people with learning disabilities and their families from black and minority ethnic communities who require support;
  • ensure that agencies will be accountable in the short and medium-term for their performance;
  • draw together existing initiatives like the National Advisory Group for People with Learning Disabilities and Ethnicity and ensure they are securely funded and working efficiently together
  • ensure Regional Ethnicity Leads are securely funded and work together with the National Advisory Group for People with Learning Disabilities and Ethnicity to develop and disseminate good practice to inform policy.
  • work with all available resources to ensure maximum value for money.

Christine Burke – August 2008
Useful links

Valuing People Support Team newsletter about ethnicity
This newsletter about ethnicity is now available on the Valuing People Support Team website at:
http://valuingpeople.gov.uk/dynamic/valuingpeople60.jsp

Link to the minutes of the National Advisory Group
http://www.learningdisabilities.org.uk/ethnicity/

Link to regional news (refer to the minutes of the National Advisory Group)
http://www.learningdisabilities.org.uk/ethnicity/

‘Beyond We Care Too’
Yvonne Pearson - Carers Development Manager for CSIP
http://afiyatrust.org.uk/index.php?option=com_content&task=view&id=61&Itemid=2

NAGLDE easy read information flyer http://www.learningdisabilities.org.uk/ethnicity/

2nd National Survey of Partnership Boards and the “Making Things Better” meetings in London
http://valuingpeople.gov.uk/dynamic/valuingpeople90.jsp

2nd National Survey of Partnership Boards by Chris Hatton
http://valuingpeople.gov.uk/dynamic/valuingpeople90.jsp

Representative on the National Advisory Group for People with Learning Disability and Ethnicity

People First
Equality and Human Rights Commission
People In Action (Leeds)
Turning Point
York People First
ARC
Lancaster University
Leeds University
Dudley Learning Disability Services
EHSAS
Afiya
scie
Foundation for People with Learning Disabilities
CSCI
Centre for Research in Primary Care
REU
Bucks CC
Brent PCT
SCIE
Values into Action
Valuing People Support Team
Mencap
Race Equality Impact Assessment of Valuing People Now

The purpose of this report is to examine how this policy may make it difficult for some communities to receive a fair and good service. It is prepared in response to a request made at the National Learning Disability and Ethnicity Network (NLDEN) conference held in April 2008.

This work was requested by the lead for the Valuing People Support Team (Sue Carmichael). This was then coordinated by the lead of NLDEN (Bridget Fisher) in conjunction with the National Advisory Group on Learning Disability and Ethnicity (NAGLDE). Significant contribution was made by Dr Ghazala Mir (lead of the National Ethnicity Training Network).

Members of NAGLDE wanted to note that this impact assessment seems to be quite late in the process. An impact assessment should look at groups that are already excluded to see if Valuing People Now could affect them in a positive way or leave them out even more. The consultation deadline has already passed and the fact that not many replies have included comments about ethnicity does not mean that there are not issues. In fact this could be a sign that minority ethnic communities are still so left out that they probably do not know about the policy or have the support to comment upon it. A lack of comment should not mean an assumption that all is fine - the number of comments does not necessarily show how the policy will affect minority groups who may have already been left out. Therefore the equality impact assessment should have been part of the whole review process.

In order to make this assessment as useful as possible the report has concentrated on the priorities of Valuing People Now. Each section has a brief outline of that priority, followed by analysis of the likely causes of disadvantage and finally targets that should remove barriers to people with learning disabilities from BME communities experiencing the same positive outcomes. In the DH paper on Initial Equality Impact Assessment there is reference to “the policy strategy is also likely to include commitments to publish more detailed delivery aims, such as statutory guidance for the field.” We hope that the targets contained within this document will be built into this guidance.

The request within the DH paper for more detailed evidence “as to the extent to which these differing sub-groups will be affected differently as this strategy is implemented” is possibly not so relevant to the BME group where ample evidence has been collected including that within the original VP document “Learning Difficulties and Ethnicity”, the 2 Partnership Board surveys, the Framework for Action on Ethnicity for Partnership Boards and several reports on ethnicity research from the University of Lancaster. It is on the basis of this knowledge that we base our recommendations.
The Five Key Areas

**Personalisation.**
People having real choice and control over their lives and services through individual budgets, direct payments and person-centred planning, underpinned by strong self-advocacy and family carer support.
Targets for BME – none.
Communication is vital and the personalisation message must be explained fully and checked for comprehensiveness to the service user and families (person centred planning). Personalisation is going to be the main driver for addressing cultural needs so it is absolutely vital that funding is designated for this work. All other targets directly link into this agenda.

Suggested Targets
Target 1
That every person with learning disabilities from minority a community has a named support who will link with them and their family directly (and who will be fully trained in cultural expectations of their client group). This worker to be the lynch pin for ensuring the Valuing People Now agenda is understood and accessed by people from minority communities.
Target 2
If this commitment to choice and control is to be realised for people from BME communities, Direct Payments should be widely promoted – with families adequately supported to understand budgeting arrangements and beneficial outcomes.

Close attention and meaningful interpretation of the phrase below should help meet these targets
Valuing People Now 5.2.2 – “Local authorities and others need “NEW SYSTEMS” that give people more control over their support and allow them to use resources more flexibly.”

What people do during the day (and evenings and weekends)
People to be socially included in their local communities, with a particular focus on paid work and as a result seeing big changes in traditional day services.

Helping people to get lives in the local communities will focus on paid work and changes to traditional day services.

What is a local community? Does this mean people with learning disabilities are more limited in the range and variety of people that they meet? BME service users may have a wider community than that perceived by social care workers and by their families. Has this change been fully explored and evaluated with BME service users and their families? Many families are concerned over the safety, well being and educational development of a person with learning disabilities. Day service modernisation may be happening without full reference to their concerns. Much support is needed in communities to explain changes and investment needed to make changes meaningful. “I used to go to the day centre now I go to the park”.

Service users and families from BME communities are known to have poorer economic situations than the majority population. Paid employment may not be the normal experience for many families. This combined with on going poor explanation of both the limits and potential of each individual’s learning disability may mean that the ambition of employment may not even be on the “radar” of some people from minority communities. In order to give them the same aspirations and thus opportunities, extra investment will be needed. There is the possibility that without this input the drive for life-enhancing opportunities will not be equally sought and therefore not equally gained by people from
minority communities. The work in Newham (VPN 6.2.9) should have a specific section on inter-agency working that involves BME 3rd sector organisations.

Suggested Targets

Target 3
That one of the “Getting a Life” sites is chosen to target an area with high BME population.

Target 4
That the Day Service modernisation is fully explained by staff who understand concerns of BME families. Thus making “prioritise change for people from BME communities who currently use traditional day services” (VPN 6.2.4) happen “with” people rather than “to” people. The named support worker suggested in Target 1 ensures life opportunities, including work, are fully appropriate and beneficial to the people they support from minority communities. (LDDF again to be used proportionally)

Valuing People Now 6.2.1 The policy objective is “to support people to live the lives they want as equal citizens in their community...”. This presupposes an understanding that all communities have a similar recognition of what life as an “equal citizen” may be.

Better Health

Work will ensure the mainstream NHS provides full and equal access to good quality healthcare for people with learning disabilities and that specialist healthcare services are modernised.

Targets for BME- none.

We felt there was some evidence of poor equality monitoring in this section as no reference was made to higher level of poor health in minority communities making risk even higher for people with learning disabilities from these communities. The DRC’s formal investigation (“Equal Treatment Closing the Gap”) into primary healthcare for people with learning disabilities from minority communities states “People with Learning Disabilities and/or mental health problems from BME communities face complex barriers. These range from the practical –e.g. lack of health information available in community languages – to the attitudinal” We also cannot find acknowledgement of the work “Health Action plans and Black and Minority groups” R. Flynn. DH 2003.

Target 5
“The health agenda will be a priority for the Valuing People delivery support programme for the next three years and for LDDF in delivering the PSA indicator on health equalities.” (VPN7.3.1) This work should take full account of the extra needs of BME communities and LDDF should be designated accordingly (Equal amounts do not deliver equality when a group is severely disadvantaged)

Target 6
The DH preferred framework for health checks (which the VPST is promoting at regional events VPN 7.2.3) to include all aspects of health prevalent in BME communities.

Access to Housing

Housing for people with learning disabilities will reflect what they want and need. There will be an emphasis on proper housing, that is home ownership and real tenancies.

Targets for BME –none.

We were disappointed not to find specific mention within VPN section on ethnicity and housing of the cultural variation in understanding and valuing individual housing need. BME communities may not have the same value base concerning individual achievement over communal well being. This was comprehensively outlined in the original Valuing People documentation. (“Learning Difficulties and Ethnicity” DH 2001 pages 29-35). The
base line for planning housing for people from minority communities may be different and without paying full attention to their options will be limited.

Target 7
All those actively involved in delivering the housing policy of VPN (including staff from housing associations, LAs, “Mixed Communities” programme etc receive training to be aware of these differences in attitude to independence. Unless this happens the pledge “support providers need to provide services and support that responds to people’s different cultural backgrounds” (VPN 8.2.11) will be difficult to achieve.

Target 8
If the chosen option is for the person with a learning disability to remain in the family home then plans need to be in place to support aging family carers in BME communities and to ensure adaptations etc make living at best levels. Choice in housing will need to be reviewed (another link to Target 1)

Making Sure That Change Happens

Advocacy
People with learning disabilities will be encouraged to speak up and have their voices heard. They will be given information to make good choices, to understand their legal rights and challenge when those rights are not respected.
Issues around advocacy again raise the difference between attitudes to individualism versus collectivism. By not acknowledging this VPN is in danger of non-delivery to many from BME communities. The recommendation that the Valuing People national advocacy fund will pay particular attention to people at greatest risk of losing choice and control in their lives, such as those from minority communities” will need careful examination. From whom do people from BME communities lose control? Before this agenda can be carried forward the all involved will need to respect BME values.

Target 9
The new advocacy development programme (VPN 9.3.1) has funding specifically to support work BME groups and that there is at least one action and learning site concentrated on an area of high BME population.

Partnership with Families
Family carers are recognised as essential long term partners in achieving positive change for people with learning disabilities. It is encouraging to see the promise that “£3 million per year funding for an information service/helpline for carers that will be in place in summer 2008 and will provide easy access to accurate, up to date and relevant information . People from minority ethnic communities are among those identified as being a focus for this service.
Members of NAGLDE emphasised for this report that family carers and service users must feel confident and comfortable in using services and not be scared that services will be removed from them if they complain . Family carers need reassurance that professionals have adequate knowledge ,skills and competencies in Assessment, Formulation, Intervention and Outcomes. That means that they are confident that the care mgmt process and the interventions used arise from a basic principle that all needs are not the same and that difference in service planning, service provision and service delivery is valued in a positive way. The local actions outlined in VPN 10.2.5 will go a long way to meet these concerns.

Target 10
Families from BME communities are enabled to fully participate in the new initiatives for carers and benefit from the recognition of their role. This would be most likely to happen if Target 1 was implemented.
Including Everyone
This section will be key to making sure the Learning Disability improvement agenda is beneficial for people from minority communities. However, as shown, we believe their needs must be considered in every part of VPN.

The evidence that 52% of Partnership Boards used LDDF to develop ethnicity work is encouraging but we think it was only 52% of those that responded to the survey giving a falsely positive picture. Although constant monitoring of progress should encourage service improvement, it is difficult to justify the resources spent, in time and money, on further surveys of Partnership Boards and ethnicity if failings revealed are not dynamically acted upon.

This report forms part of the assessment mentioned in VPN 11.2.4. BUT, even if there is no evidence of negative impact there may be poorer service delivery by indifference if BME communities are not fully supported to benefit from every section of VPN. “Local agencies will have information on the ethnicity of people with learning disabilities, their use of public services and the differences between that and usage for the population as a whole. This will enable targeting of initiatives to introduce culturally appropriate services that will achieve greater equality of opportunity and outcome” (VPN 11.2.5)

Target 11
To make this a reality a person within each agency must be designated the accountable lead and progress monitored against equality legislation
The further development of the leadership programme may have positive outcomes but only if those taking part are able to sustain their learning and finances are available to alter practice.

Target 12
A review of those who took part in Ethnicity Leadership programmes to see what has altered as a result of their attendance. A further leadership programme will reflect this.

People as Local Citizens
Many people with learning disabilities experience hate crime. People need to feel safe in their communities and guidance will be produced for advocacy groups and LAs on addressing these issues.

Hate crime against people with Learning disabilities who are from minority communities is often a double attack with racism also being used within the abuse. Any work done on tackling hate crime should consider the impact of racism or people from minority communities will not have the tools to combat hate crime.

BME families frequently are concerned about the safety of family members with disabilities and packs for self advocates may need to be promoted and explained to families.

Target 13
Home office grants to support voluntary sector initiatives should include work considering the double whammy of race and disability-driven abuse.

Relationships
There will be a focus on relationships when planning with people about their own lives, including personal and sexual relationships.

This work must be carried out sensitively and with respect for family values within minority communities. In promoting personal relationships “local commissioners and service providers should pay greater attention to being sensitive to different approaches from different cultural groups” (VPN 12.3.2) The basis for this work possibly springs from a westernised model of relationships. There is a danger that supporting people with learning disabilities from other cultures in the relationship work may be seen as too complex and therefore not attempted. In order for this section of VPN not to fail minority communities.
staff should be trained in cultural expectations within communities and be able to support people in appropriate relationships. Possibly Black 3rd Sector groups could have significant input here.

*Making the Transition to Adulthood a positive experience*

“Aiming High for Disabled Children” has a clear commitment to person centred planning from age 14. Young people with learning disabilities should be able to access the same opportunities as every one else as they move into adult life.

Young people from minority communities with learning disabilities face a bewildering range of demands, as work on the Moving on up project has shown(www.movingonup.info)
They may have been educated to expect different life goals than their family believe is possible. The range of VPN is all part of transition. Any work around person-centredness needs explanation to families (see again target 1)

**Target 13**

Any multi-agency transition strategy should include representatives from minority groups within its implementation group.

*Implementation*

The remainder of Valuing People Now considers the process of getting it right. Within every aspect of this,- staff recruitment, training and commissioning there should be inbuilt development to ensure ethnicity is part of any developments. This is covered by the race equality legislation. We have reflected within this report where we would like to see training and policy change. If our recommendations were implemented then these improvements should follow.. We would like to see the LDQ training for staff having a discrete element on ethnicity and cultural good practice. When in-service training for staff on the “whole life” agenda takes place good practice for minority communities should be built in as a matter of course.

Within this remit it is difficult to comment on National and Local leadership and support. More should be done to make the policies of Valuing People known to communities. Understandably families want to know how policies will affect their individual situation. They need someone who can explain this to them and help them access the better services VPN promises. Partnership Boards need further support to address improved outcomes for BME groups. The Valuing People regional advisers should include ethnicity in supporting best practice reviews of all Partnership Boards in 2008 (VPN 15.3.1 ). In the CSCI review of Partnership Board effectiveness, work with minority communities should be included. Local leadership on this issue should be improved by the leadership course and as equality assessment is more rigorously applied. NAGLDE has repeatedly suggested that clear national leadership is needed in Learning Disability and Ethnicity.

People working in learning disability should be encouraged to gather evidence (possibly overseen by regional VPST lead) on any impact new initiatives are having on the lives of people from minority communities. Successful developments need to be reported and shared. We have some of this work in place but it is ad hoc and poorly funded. Without formal mechanisms for evidence collection, it will be difficult to assess if VPN is impacting positively in people’s lives.

When the DH commissions the next major survey of the lives of people with learning disabilities (possibly 2009) attention should be paid to finding and reporting on the lived experience of people with learning disabilities from minority communities.

Bridget Fisher on behalf of the National Advisory Group for People with Learning Disabilities and Ethnicity. 26.
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