

Statement on Policy & Practice for Adults with a Learning Disability

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Foreword by Dr Brian Gibbons AM, Minister for Health and Social Services



I warmly welcome the issue of our contemporary Statement on Policy and Practice for Adults with a Learning Disability. The time was right for us to bring our learning disability policy into the 21st Century and set it within the context of our other strategic approaches to modernize health and social services and improve the lives of our citizens.

For over 20 years, 3 main principles have underpinned our learning disability policy relating to the rights: to an ordinary pattern of life; to be treated as individuals; and to the provision of additional help and support so as to maximise potential. These 3 principles have almost become a mantra for many stakeholders. Our contemporary statement endorses these principles but says that they do need to be updated and re-affirmed. Paragraph 2.5 of our contemporary statement sets out our new statement of principles. I am sure that these will be adopted quickly by stakeholders and soon become as integral to the values and vision underpinning support for people with learning disabilities as the 3 principles that they update. I am delighted to affirm the Welsh Assembly Government's commitment to this contemporary statement of principles.

I commend to you all the preface in this statement provided by All Wales People First. This preface contains powerful messages and I endorse them.

I wish to acknowledge the significant contribution made to the development of our contemporary policy statement by our Learning Disability Implementation Advisory Group and to thank all those who responded to the consultation on the draft statement.



Dr Brian Gibbons AM

Minister for Health and Social Services

March 2007

Preface by all Wales People First

All Wales People First has been actively involved in preparing this Statement on Policy and Practice for Adults with a Learning Disability.

This has been a welcome opportunity for people with learning disabilities to get directly involved in policy making. We were able to give our very valuable viewpoint which reflects the desires, hopes, dreams, wants and needs of people with learning disabilities. Our involvement has come about through our membership of the Learning Disability Implementation Advisory Group that was set up by the Welsh Assembly Government following its response to the Fulfilling the Promises report. Many different groups, including parents, carers, and health, social services and education professionals, have been involved in producing this statement. It is a vision for everyone involved with learning disability.

The Statement on Policy and Practice will help to make it more possible for people with learning disabilities to become included in community living and have more opportunities to develop our own lifestyles. We want to build bridges between us and the world out there and we see this as a two way process. We want people to understand us better and value us. We can make a valuable contribution to the community and we can help people in the community to recognise us as valued citizens. Making these links, would make the community safer for all.

The Statement on Policy and Practice covers many areas but there are some topics that are vital to us:

Advocacy - speaking up for ourselves or having an advocate to help us make our opinions clear.

Self advocacy means many things to us, such as getting respect, saying no, speaking up for our rights, making a difference, gaining confidence, getting equal rights. Without self advocacy we could not speak out or get the support from other people - including support from other people with learning disabilities. Self advocacy gives us the confidence to overcome things that we never thought were possible.

Person Centred Planning - planning our life the way we want to with the right support and services to help us.

Person Centred Planning opens up the opportunity to do things differently. It is an important tool that can open up people's worlds. It means that we might choose to live on our own or plan our futures differently. Person Centred Planning allows us to make our own choices about not only what is possible but what might be possible.

Transition - planning for change into adulthood.

This is when people's lives really begin. In the past, lots of people slipped through the net and went from school to a day centre. Person centred planning at the transition stage of a person's life has already been a very positive experience for some people in helping them to have different options, involving them in their own plans for life changes. People from the different services should work together and listen to people with learning disabilities first and foremost and continue to work together to achieve our wishes and needs. Other people, including parents or carers should be involved giving positive support to the planning stage.

Day Opportunities - what people do during the day.

We want to have more meaningful opportunities in education, employment and supported activities. We want to move away from the standard sessions in day centres that everyone just goes to. We want to do more inspiring things. We welcome the modernisation programme for day services, where people are offered a range of activities and services that give people pleasure as well as allowing their skills to grow. We recognise that this is more difficult for people with complex needs, but we want people to recognise that they have the same desires.

Employment - real wages for a real job.

Employment often means very basic work for people with learning disabilities either in shops or factories. We believe that people with learning disabilities can start in a small way and work up in their jobs, developing greater skills. We don't want to be rocket scientists but we would ask everyone to have open minds to the possibilities of people with learning disabilities in the employment world. Already many people with learning disabilities work as volunteers in a wide range of jobs where they take lots of responsibility, for example in People First work.

In this way, they gain skills that can easily be shifted to other jobs. We need more opportunities to achieve bigger goals. It is important that we can choose from a range of work opportunities that we feel happy with where our likes and dislikes are taken into account. These opportunities should match our skills and potential.

We know there is a lot of concern from people with learning disabilities about paid employment because of loss of benefits. This is a real barrier to employment and we hope for change.

Education - the right to a full education.

People have a right to a full education. In colleges, there are specific and separate courses for people with learning disabilities but we also want the opportunity to participate in a broader range of courses including vocational courses.

We recognise that we may need extra support to achieve this and the education service needs to be aware of this and build it into services. This would lead to people having greater scope, better opportunities in their life and their future, and greater inclusion in community based learning.

Accommodation and Independent Living - Having a place and a life of your own.

Many of us see this as our main goal in life. Having a home that you can call your own can put you at the heart of a community. If we are going to make a success of living in our own homes we need to be able to choose from a range of good housing in suitable locations. And we need the right support that fits people's needs.

These key points show that by building on skills and by working with a wide range of people, we can achieve better inclusion in society. We can build bridges to work with the different services and businesses, and really live as valued citizens, as part of our local neighbourhood and as part of the wider community.

In each section of this Statement on Policy and Practice there are clear objectives. As our role on the Learning Disability Implementation Advisory Group continues, we will be able to monitor progress and look at developments and see whether the lives of people with learning disabilities in Wales have improved as a result of the statement.

This Statement on Policy and Practice is a challenging vision of how we would like our lives to be. All Wales People First is proud of this achievement and encourages all organisations working in the field of learning disability to work together to achieve its vision. There are people in our lives who have believed in us. This belief transforms our view of ourselves. It has given us the confidence to stand up for our rights and demand a better life. We would ask everyone to have the courage to believe in us and rise to the challenge.

All Wales People First

Statement on Policy and Practice for Adults with a Learning Disability

This Statement on Policy and Practice for Adults with a Learning Disability is issued under Section 7(1) of the Local Authority Social Services Act 1970.

1. Purpose

1.1 The Welsh Assembly Government recognises the continuing need to seek to improve the lives of people with a learning disability. The Welsh Assembly Government's approach is based on the foundation established by the 1983 All Wales Mental Handicap Strategy and the Revised Guidance that was published in July 1994, and reaffirmed by the Welsh Assembly Government Cabinet in June 2002.

1.2 The Welsh Assembly Government recognised that, while many of the principles, aims and objectives of the 1983 and 1994 Strategy documents remained pertinent, there was a need to provide a clear statement of intent for the 21st century. The Learning Disability Advisory Group was commissioned to provide advice to the Welsh Assembly Government on a framework of services.

1.3 The work undertaken by the Learning Disability Advisory Group is summarised in the report Fulfilling the Promises. This document was subject to wide consultation and the Welsh Assembly Government's response to the report and the consultation was set out in the June 2002 Cabinet Paper (01-02) 72. As a key part of its response, the Welsh Assembly Government issued the Section 7 Guidance on Service Principles and Service Responses for Adults and Older People with a Learning Disability.

1.4 Although the progress achieved in Wales during the last 20 years has been considerable, the Welsh Assembly Government acknowledges that further development is required if people with a learning disability are to live as independently as possible and be valued members of our society.

1.5 This Policy and Practice Statement describes the key principles, aims, responses and outcomes that the Welsh Assembly Government believes are desirable. These build on previous Strategy Guidance and are consistent with the Welsh Assembly Government's 2004 Section 7 Guidance on Service Principles and Service Responses for Adults and Older People with a Learning Disability.

1.6 The initial draft of the Policy and Practice Statement was prepared by the Learning Disability Implementation Advisory Group. The Welsh Assembly Government issued this draft Statement for public consultation over a 16 week period between March and June 2006. Over 40 consultation responses were received from individuals, local authorities, Local Health Boards, NHS Trusts, a range of voluntary and other organisations, the Disability Rights Commission, the Welsh Language Board and ESTYN. The consultation responses were discussed with the Learning Disability Implementation Advisory Group who then worked with the Welsh Assembly Government to develop the final version of this Statement.

1.7 The National Assembly for Wales is under statutory duties to aim to ensure that its business is conducted, and its functions exercised, with due regard to the principle that there should be equality of opportunity for all people. As the majority of the National Assembly's functions have been delegated to the First Minister and are carried out by the Welsh Assembly Government, in practical terms it is the Welsh Assembly Government which has principal responsibility for fulfilling these equality duties. The Welsh Assembly Government has had due regard to these equality of opportunity considerations in developing this guidance.

1.8 The equality of opportunity agenda is underpinned by a large body of other legislation that applies to authorities and other employers or providers of services. This legislation includes:

- The Equal Pay Act 1970
- The Sex Discrimination Act 1975
- The Race Relations Act 1976
- The Disability Discrimination Act 1995
- The Human Rights Act 1998
- The Race Relations (Amendment) Act 2000
- The Employment Equality (Sexual Orientation) Regulations 2003
- The Employment Equality (Religion and Belief) Regulations 2003
- The Gender Recognition Act 2004
- The Disability Discrimination Act 2005
- The Equality Act 2006
- The Disability Equality Duty 2006

2. Vision

'Disabled people, whatever the origin, nature and seriousness of their handicaps and disabilities, have the same fundamental rights as their fellow citizens of the same age, which implies first and foremost the right to enjoy a decent life, as normal and full as possible.'

United Nations (1975) The Declaration on the Rights of Disabled Persons

2.1 Wales: A Better Country describes the way forward for Wales.

The document states:

Our vision is therefore for a sustainable future for Wales where action for social, economic and environmental improvement work together to create positive change:

- promoting a diverse, competitive, high added-value economy with high quality skills and education, that minimises demands on the environment
- action on social justice that tackles poverty and poor health and provides people and their communities with the means to help themselves and break out of the poverty trap
- action in our built and natural environment that enhances pride in the community, supports bio-diversity, promotes local employment and helps to minimise waste generation, energy and transport demands
- strengthening Wales' cultural identity and helping to create a bilingual country
- ensuring all our children and future generations enjoy better prospects in life and are not landed with a legacy of problems bequeathed by us
- supporting people to live healthy and independent lives
- promoting openness, partnership and participation.

2.2 The Welsh Assembly Government seeks to promote an inclusive society that provides a decent quality of life for all. The current policy statement explicitly recognises as part of this inclusion agenda that its stated aspirations for the people of Wales as a whole apply equally and fully to people with learning disabilities. In January 2002, the Welsh Assembly Government adopted an approach based on the social model of disability and it is committed to pursue the policy of inclusion systematically across all cabinet portfolios.

2.3 The social model of disability recognises that whilst individuals may have an impairment, they may also be disabled by the way in which society organises itself. For example:

- A person may have a visual impairment which may affect the ease with which he or she achieves particular work, recreational or daily living activities. But the degree of disablement which the person experiences can be lessened both by the attitudes and understanding of other people and by the extent to which environmental adaptation (e.g. text in Braille, clear and constant arrangement of furniture and walkways, personalised support such as a guide dog, or specific arrangements with colleagues at work) helps the person live their life.
- In a similar way, although people with learning disabilities have a range of needs directly arising from their condition, they are also disabled by economic, environmental or social barriers.

2.4 Helping people to lead full and inclusive lives requires attention to both maximising their potential for independent or supported action and removing economic, environmental and social obstacles.

2.5 The Welsh Assembly Government endorses the continuing relevance of the principles contained in the 1983 All Wales Mental Handicap Strategy, which were confirmed in the 1994 Revised Guidance. However, following advice from the LDIAG, the Welsh Assembly Government accepts that these principles require to be updated and reaffirmed. The Welsh Assembly Government's vision for the future is based on the following statement of principles:

“All people with a learning disability are full citizens, equal in status and value to other citizens of the same age. They have the same rights to:

- live healthy, productive and independent lives with appropriate and responsive treatment and support to develop their maximum potential
- be individuals and decide everyday issues and life-defining matters for themselves joining in all decision-making which affects their lives, with appropriate and responsive advice and support where necessary
- live their lives within their community, maintaining the social and family ties and connections which are important to them
- have the support of the communities of which they are a part and access to general and specialist services that are responsive to their individual needs, circumstances and preferences. “

3. Who are People with a Learning Disability?

3.1 The Welsh Assembly Government believes that terms and definitions need to be applied thoughtfully in order to strike a balance between addressing the needs of a significant proportion of the population and trying to achieve a genuine understanding of individual uniqueness and difference:

- The term 'learning disabilities' was adopted by the UK Government in 1991. It replaced previous terms used in the UK that now seem very pejorative such as 'mental handicap' or 'mental deficiency', and is an alternative to terms such as 'mental retardation' used in other countries.
- The term 'intellectual disabilities' is increasingly used in international dialogue as the term 'learning disabilities' is used in some other countries to refer to other conditions such as dyslexia where there is no necessary link with an intellectual disability.

3.2 What do people with learning disabilities have in common? From birth or early childhood they will have had an impairment of intellectual function that significantly affects their development and leads to difficulties in understanding and using information, learning new skills and managing to live independently. They are, therefore, more likely to require support and services to lead an ordinary life.

3.3 The degree of these difficulties varies considerably from mild to profound and each individual is different and therefore the range of support required varies from minimal to extensive. In practice, the number of people identified as having a learning disability by services suggests that the majority of people in Wales in receipt of services have severe or profound learning disabilities.

3.4 In general, the greater the degree of learning disability then the more likely it is that a person will have greater needs. While some people with mild learning disabilities may have few significant problems, those with severe or profound learning disabilities may have a variety of interconnecting needs that impact greatly on all aspects of their lives. Common difficulties concern:

- Understanding and using information
- Making choices and decisions
- Learning and using symbolic forms of communication

- Being independent at home and getting around in the community
- Dealing with social situations.

3.5 Arising from such difficulties, people with learning disabilities often need help with ordinary activities of daily life, including:

- Where and how to live
- Work and leisure
- Relationships
- Staying fit and healthy.

3.6 In addition, some people will have more complex needs that arise from additional problems, including:

- Physical impairments
- Sensory impairments
- Psychological difficulties
- Mental illness
- Neurological conditions (e.g. epilepsy, cerebral palsy)
- Behavioural difficulties.

These all vary in severity and degree of social impact.

3.7 The four key factors described in the Welsh Assembly Government's guidance on the Unified Assessment Process are autonomy, health and safety, managing daily routines, and involvement (see Section 5, Paragraph 5.4 onwards). For most individuals, the need for support to maintain these factors results from the severity of their learning disability.

3.8 For some others, particularly those with a mild learning disability, it is not the degree of learning disability that determines their status as a user of services, but the presence of some other significant factor such as autism, mental illness, offending behaviour or an individual's vulnerability. Some children assessed as having special educational needs by virtue of learning difficulties do not go on to be users of adult learning disability services.

4. How many People have a Learning Disability?

4.1 Learning disability has many genetic, environmental and social causes. It is not surprising, therefore, that the extent of its occurrence may vary between localities and over time.

4.2 The birth prevalence of learning disabilities is difficult to estimate as it is not until later in life when intelligence can be tested or the characteristic delays in social functioning and adaptive skills become clear. Only some of the conditions associated with even severe learning disabilities¹ are identifiable at birth. Typically, the age-specific prevalence of severe learning disabilities grows through the pre-school and school years as children with severe learning disabilities are identified. Estimates at the beginning of the 1990s suggested that there were about 5 people with severe learning disabilities per 1,000 total population aged 15-24 years. Allowing for mortality during childhood gives an estimated birth prevalence of at least 6 per 1,000.

4.3 Mortality among people with severe learning disabilities tends to be higher than among the population as a whole. Therefore, age specific rates tend to fall through the adult years. Estimates at the beginning of the 1990s suggested the following age specific rates for severe learning disabilities:

- 3.5-4.0 people per 1,000 aged 25-44 years
- 2.0-2.5 people per 1,000 aged 45-64 years
- 1.0-1.5 people per 1,000 aged 65 years and over.

4.4 The overall prevalence rate for people with severe learning disabilities was in the region of 360-380 per 100,000 total population. Applied to the population of Wales, such a rate would have suggested that there were about 10,830 people with severe learning disabilities living in Wales at that time. This is generally consistent with the fact that there were 10,168 people on local authority learning disability registers in Wales in 1990.

¹ References in this section and elsewhere in this document to 'severe learning disabilities' encompasses 'profound learning disabilities'.

4.5 Upward pressures on the incidence (i.e. new occurrence) of learning disabilities include:

- Increases in maternal age (associated with higher risk factors for some conditions associated with learning disability, such as Down's syndrome).
- Improved survival of 'at risk' infants, such as low birth weight infants, due to improved health care.
- Increases in more recently significant pre-natal threats such as HIV infection and substance abuse.
- An increase in the proportion of children growing up in poverty.

4.6 Downward pressures on the incidence of learning disabilities include:

- The impact of pre-natal screening for Down's syndrome (estimated to reduce a 'natural rate' of 1.5 per 1,000 births to about 0.9 -1.1 per 1,000).
- Improved health care and support resulting in fewer 'at risk' infants developing learning disabilities.

4.7 However, changes in the incidence (i.e. new occurrence) of learning disabilities take a long time to work through to affect the prevalence (i.e. number) of people with learning disabilities. By far the most significant factor affecting the prevalence has been increased life expectancy. This has outweighed any downward trend due to pre-natal screening and prevention. It is now thought that most adults with learning disabilities in developed nations who live past their third decade are likely to survive into old age and experience the normal ageing process. There are now 3.6 times more people aged 16 years and over on learning disability registers in Wales than there are children aged under 16 years.

4.8 Estimates suggest that there have been increases in the prevalence of people with severe learning disabilities since the beginning of the 1990s of between 15% and 25% in every ten-year age band between 35 years and 64 years, together with a doubling of the prevalence of people aged between 65 and 74 years and the beginnings of a significant very old population.

4.9 These estimates are consistent with the 26% reported increase in the number of people aged 16 years and over on local authority learning disability registers in Wales between 1990 and 2005 (see Table 1). Estimates from the Department of Health suggest that the trend towards an increasing number of people with learning disabilities will be sustained over the first two decades of the 21st century.

4.10 In addition to increasing the number of people with learning disabilities in the population, the reduction in differential mortality, which is particularly acute among people with the most severe and multiple disabilities, means that there is an increasing number of adults with complex needs requiring support. This, together with the general increase in numbers of people to be served, is recognised to have implications for increasing the levels of service provision and resource expenditure over the next 20 years.

4.11 There are no studies on the rate of occurrence of learning disabilities among BME communities in Wales. Data collected from 12 Welsh local authorities suggest that 1.1% of their adult learning disability clients are from BME communities. This proportion suggests an under representation. A number of studies in England have reported a higher prevalence of learning disabilities among younger age groups in South Asian communities. This has been variously attributed to higher levels of material and social deprivation, poor access to maternal health care, misclassification and higher rates of environmental or genetic risk factors. The conclusion of higher prevalence rates has, however, been disputed as potentially arising from chance variation given the small population sizes that have been studied. A larger scale study in Leicestershire found no greater prevalence of learning disabilities among adults from South Asian communities than White communities. Indeed, the prevalence in older age groups was lower, a finding which was attributed to the selection process inherent in first generation immigration. As communities mature, therefore, one might expect an increase in prevalence.

4.12 Changes between 1990 and 2005 in the numbers of people aged 16 years and over on learning disability registers and where they are recorded as living are shown in Table 1. Overall, the numbers of people 16-64 years and 65 years and over have increased by 23% and 53% respectively since 1990. In 2005, there were 439 people aged 16 years and over per 100,000 people in the Welsh population aged 16 years and over (511 aged 16-64 years per 100,000 people aged 16-64 years and 179 aged 65 years and over per 100,000 people aged 65 years and over).

4.13 Numbers in lodgings, supported living and residential care (NHS, local authority, private or voluntary, other) combined were about 3,100 at the beginning and 3,400 at the end of the period and somewhat lower in the mid 1990s. The 2005 level of provision is equivalent to a rate of 116 per 100,000 total population.

Table 1 Numbers of people with learning disabilities aged 16 years and over on local authority registers in Wales by place of residence for the years 1990, 1994, 1998, 2000, 2003 and 2005.

Year	Own Home	Family/ Foster Home	Lodgings/ Supported Living	NHS	LA	Private/ Voluntary	Other	Total 16-64 years	Total 65+ years	Total 16+ years
1990	586	4,545	181	1,478	584	765	85	7,717	607	8,324
1994	1,071	5,116	202	844	596	1,343	105	8,526	751	9,277
1998	1,168	5,239	276	469	428	1,572	57	8,251	860	9,209
2000	1,428	5,155	430	354	405	1,655	67	8,685	809	9,494
2003	1,980	5,049	724	218	322	1,752	80	9,284	841	10,125
2005	1,904	5,120	1,372	168	256	1,529	101	9,524	926	10,450

Notes:

1990: Distribution of Own Home, Family/Foster Home and Lodgings/Supported Living is estimated for Gwynedd from distribution in 1991 but based on known total of 'Community Placements' for 1990

1994: Data on Private/Voluntary accommodation in Clwyd are for 1993

1998: Data for Cardiff are for 1999 as 1998 dataset incomplete

5. Context and Scope

5.1 The Welsh Assembly Government believes that it is important that everyone is able to play a full part in a modern society. Perhaps more than any other group, people with a learning disability are vulnerable to social exclusion and discrimination. Therefore, barriers should be removed that prevent them assuming their equal place in society and getting the treatment and support appropriate to their needs. Moreover, although the presence of a learning disability may result in a shared experience of disadvantage, the degree of disadvantage is likely to depend on the level of disability. Research has consistently shown that people with the fewest independent skills have:

- greater health problems
- less active social lives
- lower community integration
- fewer friends
- lower involvement in ordinary household life, and,
- less constructive occupation throughout the day.

5.2 Particular attention, therefore, needs to be given to how to meet principles of equity and inclusion for people with the most severe learning disabilities.

5.3 Considerable progress has been made in changing the nature of service support available to people with learning disabilities and their families but more needs to be done. In this regard, the specific needs of children will be addressed by means of the National Service Framework for Children, Young People and Maternity Services in Wales.

5.4 This statement sets out policy and practice in relation to adults. The Welsh Assembly Government has established clear expectations in terms of equality for all people in Wales. In this respect, the effective local implementation of the guidance on Health and Social Care for Adults: Creating a Unified and Fair System for Assessing and Managing Care should lead to greater equity and fairer access to care services across Wales. It is likely that Health Social Care and Well Being Strategy guidance will in the future encourage authorities to take full account of equality issues and utilise information in relation to their local populations to develop strategies which will improve the health, social care and well being of all their local residents.

5.5 It is important that the provision of service treatment and support is led by people's needs. Eligibility for adult social care services should be based on an holistic individual assessment. There are four key factors which must be addressed:

- **Autonomy:** the control a person has over their immediate situation and the extent to which they are able to make and act on informed choices.
- **Health and Safety:** including mental and physical health, maintenance of current health and preventing deterioration, risks to health, safety from harm (from self or others), the safety of others from harm caused by the person (harm can be intentional or unintentional).
- **Managing daily routines:** the ability of a person to look after either their own personal care, domestic needs and other daily routines or dependent family members or others close to them.
- **Involvement:** in work, education and learning, family life and social networks and community activities, including recognition of social roles and responsibilities such as parenting and caring.

5.6 Under the Creating a Unified and Fair System for Assessing and Managing Care guidance, the fact that an adult may have a learning disability is not sufficient in itself to determine whether an individual should receive services. Rather it is the impact on an individual's independence that will determine whether needs exist that require services to be provided and the nature of such services.

5.7 Each local authority by means of its social services functions is required to provide a lead in the planning of services for adults and older people with a learning disability. In addition, the Health Social Care and Well-being Strategies require a joint strategic local health board and local authority approach to be taken to address the health and well-being of the population of their local area. It is also necessary to ensure that there are clear links between the Health Social Care and Well-being Strategies and other local community strategies.

5.8 It is important that the development of local services and support for adults with a learning disability also takes account of the Health and Social Care Review (the Wanless Report), the Carers' Strategy, Supporting People, Promoting Partnership in Care; Making the Connections and other relevant Welsh Assembly Government guidance. Addressing the needs of people with learning disabilities will also need to be taken into account in the development of broader community agendas that apply to all citizens in Wales.

5.9 Such an approach is reinforced in the Welsh Assembly Government's Designed for Life: Creating World Class Health and Social Care for Wales in the 21st Century. Designed for Life promotes:

- the provision of services and support for people at home, or as close to home as is safely possible
- a focus on helping everyone achieve the highest level of independence and personal potential
- services that are accessible, fast, safe and effective, simple to understand, easy to use and responsive to changing needs
- care environments that are safe, offer proper protection to children and vulnerable adults, and respect people's dignity, and
- skilled staff who provide services that work every time, but are still personal to the individual.

5.10 Designed for Life focuses on three basic principles to ensure that the NHS is fit for purpose:

- user-centred services
- getting the most from resources, and
- targeting continuous performance improvement.

5.11 During 2005, the Welsh Assembly Government published their Healthcare Standards for Wales. Their aim is to further develop safe, high quality care for all patients in Wales; to improve the patient experience and to place patients at the centre of the planning and delivery of services. There are 32 Standards covering the patient experience; clinical outcomes; healthcare governance and public health.

5.12 In its strategy for social services over the next decade set out in Fulfilled Lives, Supportive Communities, the Welsh Assembly Government has set out its vision of social services which:

“are strong, accessible, and accountable, in tune with citizens' and communities' needs and promote social inclusion, citizens rights and good outcomes.”

5.13 This vision of social services will be delivered in a joined up, flexible and efficient way, in partnership with the service user and to consistently high standards across Wales. This fully complements and reinforces the Welsh Assembly Government's vision and principles for people with a learning disability set out earlier in section 2.

5.14 Fulfilled Lives, Supportive Communities also sets out the principles for services to be shaped by service users and their needs. Local authorities and their partners will need to:

- “simplify access and assessment, develop self referral and self assessment
- ensure appropriate access out of normal hours
- develop services that give people a real say about when and how they are delivered
- deliver person centred care services with dignity and respect for the individual and no tolerance of abuse
- provide better information to service users and carers
- make joint working more effective with all partners and give a real commitment to address the barriers to better collaboration
- greatly increase the extent of joint commissioning with health and other services
- influence and develop services that deliver improved nutrition and food security for users and their carers
- develop clearer outcome-based approaches to care planning
- recognise that we all accept risk as part of our daily lives and enable more informed and shared decisions about managing risks
- have clear, simple systems of complaint and redress.”

5.15 These principles apply to all citizens but have a particular resonance for people with a learning disability as they reflect many of the aims and ambitions that have been pursued over many years.

6. Putting People First: Person-centred Planning, Accessible Information and Advocacy

6.1 That local services should be shaped by the users of services and their needs lies at the heart of the Welsh Assembly Government's strategic approach. Individual planning approaches are fundamental to achieving this aim and to establishing a collaborative approach between adults with a learning disability, their family and all professionals involved in providing support. This expectation was restated in the 1994 Guidance:

“Everyone who wants one, should have an ‘Individual Plan’ co-ordinating care throughout their life and properly reflecting their needs and preferences. All those involved must work closely together to provide continuity of planning, ensuring there are no sudden changes as individuals move from the care of one agency to another.”

6.2 It is recognised that transition planning should begin in childhood and continue throughout the many transitions which people make through life. Inadequate planning and provision during childhood can have adverse consequences not only for the individual but also for the level of service support required throughout adulthood. The Welsh Assembly Government's National Service Framework for Children, Young People and Maternity Services in Wales, says that planning for an individual's transition from children's to adult services should start in the year before their 14th birthday and that a key transition worker should be appointed for each child at age 14. Such key transition workers co-ordinate the planning and delivery of services before, during and after the process of transition.

6.3 Allowing sufficient time for effective transition planning for other life events such as an individual moving from the family home into independent living is equally important. Moreover, the transition from mid-life to old age and the bringing together of the mechanisms for reviewing and commissioning service and support for older people with learning disabilities are becoming increasingly relevant as people with learning disabilities live longer.

6.4 The Welsh Assembly Government's guidance Health and Social Care for Adults: Creating a Unified and Fair System for Assessing and Managing Care establishes processes for determining eligibility criteria. This is further assisted by the specific SSIW guidance, Person Centred Assessments within the Statutory Assessment Processes, produced for people with a learning disability which has been formally integrated as annexe 11 to the Creating a Unified and Fair System for Assessing and Managing Care guidance.

6.5 Clear, up to date and accessible information for individuals with a learning disability and their families/carers is important if they are to be involved fully in decision making. The provision of information empowers individuals to make informed decisions, to exercise choice and exercise their rights. Local authorities, NHS LHBs/Trusts and other service provider organisations must ensure that users and carers have timely access to comprehensive, clear, appropriate and helpful information, in a range of formats and languages. Core information materials should be produced in both English and Welsh but may also need to be produced in other languages to reflect the demographic make-up of the locality.

6.6 Minority ethnic communities often face substantial inequalities and discrimination in employment, education, health and social services. Service use tends to be lower amongst such communities. Training to improve competence in cultural awareness, working in partnership with community groups, bilingual staff and accessible information, recognition of community support networks and tailoring support services to needs within specific cultures will help to reduce inequalities.

6.7 Many people with a learning disability will require support to assist in making their views known and advocacy has an important role in such situations. But in proceeding in this way, authorities, service providers, advocates and families/carers must ensure that they are fully compliant with the requirements of the Mental Capacity Act 2005.

6.8 Statutory authorities and other non-statutory service provider organisations should ensure that access to an appropriate range of advocacy services is available to give a voice to individuals to ensure their views are fully taken into account. The empowerment of individuals so that they do play a full role in decisions surrounding and affecting their lives is a key element of the Welsh Assembly Government's strategic approach.

6.9 Authorities across Wales have made good progress in promoting or developing individual planning approaches and the provision of information and advocacy. Sustaining these improvements and continuing to build on these foundations remains important. The Welsh Assembly Government's Guidance on Service Principles and Service Responses for Adults and Older People with a Learning Disability continues to provide authorities with guidance on these issues.

7. Leading an Ordinary Life

7.1 Since the inception of the 1983 Strategy, the then Welsh Office and the Welsh Assembly Government have sought to ensure that comprehensive support for people with learning disabilities is developed locally. This includes:

- Provision of a range of housing options with varying levels of support to allow adults to live independently within their local communities in the way that they and their families choose.
- Provision of a range of opportunities for constructive occupation, work preparation and employment.
- Development of inclusive recreational and social opportunities and enhanced involvement of the general public in the concerns and lives of people with learning disabilities.
- Access without discrimination to generic services available to the rest of the population (including health and social services, housing, career guidance and other forms of citizen advice).

7.2 The 1994 Revised Guidance had a number of clear objectives:

- Provision of a range of accommodation so that people with learning disabilities have as much freedom as anyone else to choose where they live and with whom they live, and a level of support which enables them to continue to live in the community.
- Help to obtain a real job for most adults and support to help them keep it - all adults who are able to work should have the opportunity of paid employment alongside other members of the community.
- Help and support to become part of the community and to take part in leisure activities among other people.
- Access to the same healthcare as others living in the community, with additional support to meet special health needs.

7.3 The Welsh Assembly Government continues to endorse these aims and objectives. Individuals with learning disabilities are citizens and should contribute to the life of their local communities, have opportunities to benefit from their communities and be seen in a positive light.

Community Living

7.4 Community living extends to all ages, although accommodation requirements can typically change across an individual's lifespan. However, the Welsh Assembly Government believes that it is more than simply a matter of an authority seeking to address an individual's physical accommodation requirements (accepting that these are very important), an authority must also take into account the promotion of independence, citizenship, relationships and lifestyles.

7.5 In addressing these various elements, authorities will need to keep support and service arrangements under review as an individual's requirements may typically change over time including, for example, when an individual with a learning disability becomes a parent. The Welsh Assembly Government considers that an authority's goal should be for people with learning disabilities to have a genuine opportunity to live as others of the same age and play a full part in the society in which they live. Social Services, Health, Education, Housing, Transport services and provider organisations need to work effectively together, in both planning terms and day-to-day provision, to provide the opportunities and support required for individuals to follow the lifestyle choices which maximise their well-being and personal development.

7.6 Statutory agencies will also need to work with independent and voluntary sector partners including organisations representing people with learning disabilities or their families to imbue communities to value and support community members with disabilities. It is important to develop positive community attitudes towards all forms of disability. Ensuring that people with disabilities are portrayed positively and are supported to occupy valued roles, such as an employee or friend, helps to counter stereotyped negative impressions and the stigma which continues to be attached to people who are seen as different.

7.7 In doing so, it is of course important that services which are provided to help people with learning disabilities become more accepted members of the community and lead more fulfilled lives, do not themselves perpetuate negative perceptions of people with a disability. Everything should be done to make sure that people are represented as full citizens with rights and expectations which are typical for others of the same age. Overprotection can be as damaging to people's quality of life as under-protection. Care needs to be taken when referring

to people's genuine needs for guidance, support and particular treatment to avoid the impression that individuals are incapable of exercising choice and control, or of making a positive contribution to society.

7.8 The principles set out in the Welsh Assembly Government's vision for people with learning disabilities should apply to every strand of activity undertaken by statutory, independent and voluntary sector bodies alike. If the principles are to become part of the day to day culture, putting them into practice in all aspects of service delivery is important, no matter how small. Every opportunity should be taken to include and encourage ways in which the individual can contribute to the community. When self-esteem is raised - by helping people gain respect and be seen as valued members of society - disability is minimised.

7.9 Physical access to community amenities and services, and environmental arrangements which enable ease of movement and transport within the community, are vitally important to people with disabilities. Local authority planning departments and NHS organisations have a responsibility to ensure that the built environment is disability friendly. Local public transport policies should also consider the needs of people with disabilities.

7.10 Thereafter, successful community living requires a range of community services and supports to be available that are sensitive to the needs, preferences and desired lifestyles of people with learning disabilities. Accommodation, for example, should be developed in line with individuals' choices and preferences and offer individuals the same rights as are available to others including tenancies. Arrangements made should facilitate rather than hinder individuals to maintain the relationships with their families and the wider community networks and activities of community life which they value.

7.11 There are great variations in the difficulties which people with learning disabilities encounter in developing independence, exercising control and participating fully in the activities of everyday life. Authorities should plan for individuals to receive competent additional help where necessary in order to sustain a satisfactory lifestyle in the community. There has been considerable progress made in recent years by authorities in assessing the nature of people's individual difficulties and tailoring their approach and support to be most effective. Authorities should re-assess their service provider contracts and/or their own direct service provision to ensure that a competent workforce is available and capable of delivering best practice. Such additional and appropriate help for

individuals may need to be provided flexibly and be available at times when it is most needed rather than when it is easier for provider organisations to deliver it.

7.12 The Welsh Assembly Government's Direct Payments scheme, with associated local support schemes, provides individuals with the opportunity to better match their care and support arrangements to their particular circumstances. The purpose of Direct Payments is to give recipients greater control over their own life, through being directly able to contract services which increase opportunities for independence, social inclusion and enhanced self-esteem. The Welsh Assembly Government's Direct Payments Policy and Practice Guidance Wales 2004 contains all the relevant information. The Welsh Assembly Government will continue to monitor the implementation of the Individual Budgets' pilot schemes in England and will keep under review the opportunity for other forms of individual budgets in the light of evidence from these pilot schemes in England.

7.13 Disability and other discrimination legislation places various duties on authorities and providers of services. All such organisations should actively seek to eliminate unlawful discrimination and promote equality of opportunities for people with learning disabilities as this is of paramount importance to promoting inclusion into the wider community. It is vital that people with learning disabilities are shown in a positive light and that the principles set out in this document are actively promoted in day-to-day business.

7.14 Offering support to people to participate in leisure and community activities and to form personal relationships is as important as supporting other aspects of their lives. Participation in leisure activities alongside non-disabled people is particularly important if people with learning disabilities are to have opportunities to form long-lasting friendships widely among the general population. Authorities should promote non-discriminatory policies on access to facilities and amenities open to the public.

7.15 People with learning disabilities also need to be able to access a variety of forms of lifelong learning opportunities ranging from informal teaching/support in everyday skills to organised college courses on subjects of their own choice. Experience over the last twenty years has demonstrated that the segregation imposed by the old institutional forms of care was not the only barrier to people with learning disabilities forming friendships and participating in community activities as equals. The expansion of individuals' social networks and their social

and leisure activities in the community remains a challenging objective and requires a proactive approach, not only within each individual's care plan but also at a wider strategic level across the full range of an authority's responsibilities.

7.16 Authorities should recognise that aspects of some individuals' disability or associated conditions may result in it being more difficult for them to develop typically full and varied lifestyles using ordinarily available facilities. Individuals with complex and challenging needs present particular challenges for authorities, but they too should have the option to live in ordinary housing and have access to local community facilities. Special arrangements may be required in some situations to manage the possible risks that individuals may pose to themselves and others. The competence of staff support is a crucial aspect in the quality of provision.

7.17 There will also be situations, particularly at times of crisis, where unplanned short or longer term interventions will be required, and it is essential that authorities have the flexibility to respond appropriately in a timely way in these situations. A successful outcome of such interventions will see the individual returning to and/or being sustained in community living.

7.18 The Welsh Assembly Government's Guidance on Service Principles and Service Responses for Adults and Older People with a Learning Disability continues to provide authorities with more detailed guidance on these issues.

Employment and Day Services

7.19 The Welsh Assembly Government believes that it is important that authorities seek to maximise an individual's potential to be gainfully or constructively employed. Prior to retirement age, people with a learning disability should have equal access to government or other training schemes and other educational or lifelong learning opportunities where such schemes could help their personal development or career prospects and, in particular, help them secure employment.

7.20 Such schemes must become more skilled at working with people who have a learning disability so as to become more effective at supporting them to achieve recognised training and employment outcomes. Opportunities for employment, and for further education which might lead to employment, must be considered

as part of the person's individual or transition planning processes. These processes may need to involve, as appropriate, the individual college, Careers Wales: the Community Consortia for Education and Training, or the Employment Service/ Jobcentre Plus.

7.21 Service models such as supported employment² which obtain jobs for people and then train them on site have been shown to be more effective than more traditional employment training for people with more severe learning disabilities and for those with complex or challenging needs. Supported employment has been shown to extend the range of adults who are able to gain and retain a job and it therefore has a considerable role to play in meeting the objective in the 1994 Revised Guidance of helping most adults to obtain a real job. Supported employment requires well-trained job finders and job coaches, and extra training may be required to support individuals with complex and challenging needs more effectively.

7.22 While supported employment is one pathway, authorities should also consider other routes to employment and other meaningful day activities in order to provide a comprehensive programme of constructive occupation for all. Day services should provide people with meaningful and rewarding activities which reflect their interests and develop their confidence, independence and skills. It is important for authorities to critically re-assess on an ongoing basis their existing service models to ensure that they remain appropriately focused and provide the range of community based employment and other constructive activities.

7.23 On reaching retirement age, the Welsh Assembly Government believes that it is as important for people with learning disabilities, as for others of similar age, to undergo a planned transition to old age which preserves the positive relationships, extent of constructive activity and sense of self-worth which individuals have built up throughout adulthood. Day services should provide people with meaningful and rewarding activities which reflect their interests and develop their confidence, independence and skills. Access to educational or lifelong learning opportunities should continue to be available.

2 Supported employment is paid employment for persons with learning (or other) disabilities: (a) at or above the minimum wage, (b) in any workplace where persons without disabilities are employed, and (c) where the person is supported by any activity needed to sustain their employment. This definition emphasises the principle that work should be 'real', involving a 'real' job in a 'real' workplace not in a pre-vocational or sheltered work setting, for 'real' pay. In other words, supported employment enables the people being supported to experience 'real' working life in all its aspects directly. The support needed may be short, medium or long-term. Support may involve training, job support, aids and adaptations and any other mechanism to ensure successful performance of the job.

7.24 The Welsh Assembly Government's Guidance on Service Principles and Service Responses for Adults and Older People with a Learning Disability continues to provide authorities with guidance on these issues.

Health

7.25 The Welsh Assembly Government believes that people with a learning disability must have as equal a right of access to primary, secondary and specialist health care services and routine national health screening programmes as any other citizen. The Healthcare Standards for Wales should be embraced and applied equally when the patients involved are people with a learning disability.

7.26 There is strong evidence that people with learning disabilities have poorer general health and more specific health needs than the general population. Designed for Life describes people with a learning disability as "... people with more significant care needs". The Health Evidence Bulletin - Wales indicates that there is increased illness in a number of areas, such as problems with hearing and eyesight, mental health and behavioural difficulties, epilepsy, thyroid disorders, heart disorders and dental problems. Specific patterns of health need may also arise from some of the known causes of learning disability. An example of this would be the high rate of early onset Alzheimer's disease in individuals with Down's Syndrome.

7.27 As noted earlier in this document, people with learning disabilities are living longer, with the consequence that more will also come to develop health problems associated with increasing age, including those that are terminal in nature such as dementia or some forms of cancer. More people with learning disabilities, therefore, will experience a prolonged phase of dying in old age that may require special support and advice from palliative care services.

7.28 As highlighted by the Disability Rights Commission formal investigation into health inequalities (Equal Treatment: Closing the Gap 2006), despite increased health needs, people with learning disabilities do encounter problems in accessing health services, including dentistry services and routine health screening services, and do not always receive the health provision they require. There may be a lack of recognition of common and treatable medical conditions, particularly

if the individual has difficulty in communicating symptoms, and carers and health professionals lack experience or training in the identification of health needs.

Problems may arise from:

- Lack of accessible information for people with a learning disability and their carers about health promotion
- Lack of support and time to prepare individuals for routine health promotion interventions or investigations
- Difficulties in accessing services that may be available
- Inadequate identification of, or lack of attention paid to, health concerns when undertaking individual planning
- Inadequate training of health and social care staff related to the needs of people with learning disabilities and how to address difficulties that may arise in communication, judging capacity and consent
- Lack of knowledge of health issues in people with learning disabilities among health professionals, in both primary and secondary care, and how to identify and address them
- Difficulties for health care professionals due to insufficient time to conduct complex consultation in primary and secondary care
- Specific problems in primary or secondary care facilities due to communication difficulties and a lack of recognition of or 'masking' of other conditions.

7.29 The Welsh Assembly Government believes that people with learning disabilities should have access to evidence-based services for common and treatable medical conditions. This will require those services to ensure that they make appropriate adjustments to accommodate the needs of people with learning disabilities particularly if an individual has difficulty in communicating symptoms. As part of this process, the interaction between community nurses and GP practices should be reviewed. The promotion of a healthy lifestyle, especially better diet and exercise, should form part of these considerations. People with a learning disability who also have mental health needs should be able to access the available range of generic as well as specialist local mental health services to address their mental health needs.

7.30 All individuals should have a multi-disciplinary assessment in accordance with the Unified Assessment Process to identify and plan for their health as well as their social care needs.

7.31 During 2006, the Welsh Assembly Government introduced as part of the LHB directed local enhanced services, an annual healthcheck arrangement for all adults with a learning disability who are on the local authority maintained learning disability registers. Authorities should encourage all eligible people to access their right to an annual healthcheck. The Welsh Assembly Government is working with the National Public Health Service for Wales and the Welsh Centre for Learning Disabilities, Cardiff University to monitor the public health outcomes from the healthchecks for people with a learning disability.

8. Complex Health Needs

8.1 People with learning disabilities, particularly those with severe learning disabilities, may have complex and interrelated health care problems, which may include: physical disabilities, hearing and eyesight problems, communication difficulties, epilepsy, chest and heart problems, swallowing difficulties, other chronic medical conditions, mental health problems and psychological problems.

8.2 The Welsh Assembly Government believes that people with learning disabilities should not be disadvantaged in gaining access to high quality assessment, treatment and support for their health problems. Indeed, they will often require more time, more specialist skills and more resources in order to receive a clear diagnosis and interventions that are appropriate and sensitive to their specific needs. It is important to recognise the debilitating impact ill health has on an individual's quality of life.

8.3 In line with the aims and objectives in Designed for Life and the Healthcare Standards for Wales, it is essential that primary and secondary health services, including dental services and health screening services, make the necessary adjustments to ensure that all people with learning disabilities are given the same access to the same high standards of health care as other citizens. Specialist services also need to be further developed in order to:

- Provide specific specialist health skills where needed, such as in the fields of challenging behaviour, mental health, epilepsy, mobility and speech and language therapy.
- Facilitate a person's progress through an episode of care.
- Support and educate families and carers.
- Recommend and provide specialist aids and adaptations and establish and monitor specific treatment programmes which promote a fuller and longer life.

8.4 In meeting the complex health care needs of people with learning disabilities, it is important to endeavour not to compromise an individual's ability to have an ordinary life in their local communities. People with complex health needs should also be encouraged and facilitated to access the healthcheck arrangements

introduced by the Welsh Assembly Government (paragraph 7.31 of this document refers).

8.5 The Welsh Assembly Government's Guidance on Service Principles and Service Responses for Adults and Older People with a Learning Disability continues to provide authorities with guidance on these issues.

9. Behaviours which Challenge

9.1 A number of different terms have been used to describe disturbances of behaviour with a range of severity; for example: 'behaviour disorders', 'behaviour problems' and 'challenging behaviour'.

9.2 The term 'challenging behaviour' was developed in order to emphasise the interaction between an individual's behaviour and their social and environmental context, biological state, behavioural repertoire and learning history. The nature of the challenge being emphasised is that of understanding the basis or cause of a person's behaviour so that action can be taken to help the person behave differently.

9.3 The use of the term 'challenging behaviour' is not a diagnostic label, as if the behaviour were solely a property of the person. Challenging behaviour is not intrinsic to the individual; it is a description of an interaction in time and place. Behaviour can vary considerably in different settings and at different times.

9.4 Behaviours which are defined as challenging are typically those which are perceived as problematic by others. These include aggression to others, destructiveness, self-injury and unacceptable behaviours. However, the extent to which behaviours are seen as problematic is not a constant. Behaviours seen as challenging by some people under some circumstances may not be seen in the same light by others under other circumstances. Training on how to respond well to challenging behaviour when it occurs can give staff, carers and others the confidence to deal with it. Authorities should consider whether a collaborative joint training approach encompassing health and social care staff and family members/carers would be beneficial to avoid inconsistencies of practice.

9.5 Studies have suggested that 12% - 17% of people with learning disabilities present challenging behaviour and, of those, 40% - 60% may show more severe problems. It is a major cause of social exclusion and stigma within communities. Challenging behaviour may be indicative of an underlying problem such as physical disability or illness, mental illness or psychological distress, and may be associated with particular causes of learning disability, such as Lesch-Nyhan syndrome, or associated problems, such as autistic spectrum disorder.

9.6 The Welsh Assembly Government believes that authorities should consider whether understanding, assessing and managing challenging behaviours is made a core function of community learning disability teams, where all professional disciplines have relevant diagnostic and treatment skills. The management of persistent and severe challenging behaviours requires additional specialist skills such as in the analysis of the functions which behaviours may fulfil, the design of intervention procedures or the assessment and treatment of underlying physical or mental health problems.

9.7 The Welsh Assembly Government believes that authorities should fully recognise that early intervention is essential and plan service delivery models accordingly. In addition to attempting to reduce the severity and frequency of the behaviour, authorities should assess the benefits of providing advice, training and support to regular carers and other service providers as this will help them to develop coping skills. A range of services and therapeutic skills is necessary, including functional analysis, applied behaviour analysis, positive behavioural support, cognitive-behavioural and other psychotherapeutic approaches, and psychiatric assessment and treatment. Approaches should address solutions not only at the individual level but also consider whether any changes may be required at the systemic level.

9.8 Interventions should involve professionals who have expertise in the analysis of challenging behaviour, design of intervention procedures and/or assessment of mental health needs. Specialist psychiatric services for people with a learning disability play a key role in the assessment of concurrent mental illness and the potential impact of neuropsychiatric conditions, such as epilepsy, on behaviour.

9.9 Interventions can be provided from specialist challenging behaviour support teams or from community learning disability team professionals, which in particular would include psychologists, psychiatrists, speech and language therapists, community nurses and behaviour specialists. The Welsh Assembly Government believe that the purpose of their work should be to reduce the challenging behaviour, design management strategies, help carers to develop coping skills and reactive procedures, and develop a plan to promote the quality of life and community participation of the people concerned. Their work could also involve providing advice, training and support to regular carers and service providers (see paragraph 9.7 above). Authorities should consider whether a collaborative intervention approach commencing at an early age would be

beneficial. This would require a co-ordinated approach involving, for example, specialist adult services, education services, childrens' social services and CAMHS teams.

9.10 The Welsh Assembly Government considers that local service provision should seek to ensure that people remain in their homes and local communities. Where this proves to be impossible to achieve, temporary alternative accommodation and residential support may be needed until they can return home or go to new long-term accommodation in the community. The Welsh Assembly Government encourages authorities to review the appropriateness of arrangements where individuals have been transferred to services outside of their local area. Such arrangements can create difficulties for families to maintain contact and for local care managers to monitor the standards of service provided and outcomes achieved.

9.11 There is some evidence which suggests that authorities can reach differing conclusions as to whether the provision of accommodation, residential support, respite services and day services for people with severe challenging behaviour should be considered to be 'social care' (and be commissioned and funded by local authority social services departments) or 'health care' (and be commissioned and funded by health authorities).

9.12 Such a division between health and social care can prove to be a barrier to addressing the needs of individuals satisfactorily. Local authorities and LHBs should review whether they need to develop new joint service models that cut through these boundaries - using the flexibilities that are available under the Health Act 1999 - in responding to the challenges with which all services are presented. Such considerations may need to encompass developing the role of non-NHS agencies in delivering crisis response, respite and supported living services. In considering such new joint service models, it will be essential for authorities to ensure that competences in working with challenging individuals are developed and sustained across agencies and tiers of services.

9.13 Where individuals have committed criminal offences or are charged with doing so, there should be policies and procedures in place for appropriate diversion from court. Authorities should focus on how best to meet the needs of these individuals effectively, enabling them to enjoy as full a life in their local communities as possible while protecting the safety of others. This will include ensuring appropriate provision for those people who are detained under the Mental Health Act.

10. Families and Other Carers

10.1 The Welsh Assembly Government recognises and welcomes the roles of families and other unpaid carers in supporting people with learning disabilities in various ways. It recognises that carers want to have the same opportunities in life as other people while at the same time wanting to maximise the wellbeing of the people for whom they care. The Welsh Assembly Government therefore, through its Carers' Strategy, seeks to encourage authorities to provide a widening range of flexible support for carers, co-ordinated between the relevant organisations.

10.2 The Welsh Assembly Government has brought a number of legislative measures into force to support carers in Wales. These include the Carers (Recognition and Services) Act, the Carers and Disabled Children Act and the Carers (Equal Opportunities) Act. The implementation of the legislation supports the principles, policies and work of the Carers' Strategy.

10.3 The Welsh Assembly Government's Carers' Strategy emphasises the importance to carers of:

- Good information - so that they:
 - are informed advocates for the person for whom they care
 - know what services and benefits are available and how to access them
 - can negotiate and be confident about service availability during life cycle transitions, and
 - are aware of their own rights and entitlements.
- Contribute to individual decision-making and have a say in all aspects of strategic planning - so that they:
 - become real partners in the provision of care for the person they are looking after
 - can represent the interests of the family, including those of the person they are looking after
 - can monitor and influence the quality of services provided, and
 - can be confident in the adequacy of service provision.

- Adequate care and support in relation to their own needs - so that they:
 - can combine employment with caring
 - are able to have a personal and social life of their own, and
 - can maintain their own health, well-being and peace of mind.

10.4 The Welsh Assembly Government believes that families and carers require full and timely information about all relevant matters. Authorities should ensure that such information reflects the full range of services to meet the needs of individuals, including those provided by other authorities and organisations, and incorporate details of their nature, purpose, objectives, philosophy of care, facilities, access, charges and the people for whom they are designed. Such information should be available in a range of formats and languages.

10.5 One of the most important concerns for carers is to contribute to the individual decision-making process alongside the person for whom they care. This role is emphasised in legislation, guidance and case law. The 1994 Revised Guidance states that:

“Individuals and their carers should be closely involved at all stages in the individual planning process and, where possible, priority given to their wishes and preferences.”

10.6 Information should, therefore, also be readily available to explain how individuals and carers can participate in the Unified Assessment or other individual planning process, what happens in the assessment and care management process, relevant timescales, the eligibility criteria applied to services and direct payments. Families and carers also need to know about the role that individuals and carers can play in all aspects of strategic planning. Similar information about carers' assessments is also crucial.

10.7 In its Learning Disability and Carers' strategies, the Welsh Assembly Government has identified that carers, alongside users of services and other stakeholders, should play an important role in all aspects of strategic planning, including the planning of services, policies and procedures, service development, monitoring and evaluation. The overall aim is to maximise the potential of people with learning disabilities and to ensure that the range of services becomes more extensive and can more flexibly meet their needs and wishes. Carers, as well as users and other stakeholders, need to have confidence in services.

10.8 Carers are entitled not only to be considered in the assessment of the needs of their family members for whom they care, but also to a separate assessment of their own needs in order to improve their own life, health and well-being. The Welsh Assembly Government recognises that authorities are now under a duty to inform carers of their right to an assessment. Where such assessments occur, it encourages authorities to adopt approaches to ensure that carers bring forward their own needs rather than those of their family member.

10.9 A range of support to families and carers has been made available by authorities under the learning disability and carers' strategies, including help in the home via the provision of domiciliary support workers or family aides, specialist sitting-in services and arrangements to give carers a break from their caring role. The Welsh Assembly Government acknowledges that families and carers do not want to view their caring role as a burden from which they need respite. Rather, the emphasis should be on enabling carers to achieve other personal ambitions such as having a career, pursuing educational or other interests or participating in social activities with friends, colleagues and neighbours.

10.10 Adopting such an approach has implications for authorities when considering the nature, timing, duration and regularity of support to carers. Support for carers to pursue educational or leisure activities and maintain their own friendship networks has to be available at the times when such activities typically occur and to be of sufficient duration to be worthwhile.

10.11 Similarly, when the family member with disability spends time away from the family in the evening or week-ends this should be viewed as a positive opportunity to enhance the person's quality of life, and not simply as a means to give respite for family carers.

11. Strategic Planning

11.1 While much has already been achieved under the All Wales Mental Handicap Strategy, there remains a perception of an inequality in the availability of services across local authorities for reasons other than variation in demand. The Welsh Assembly Government believes that authorities need to continue to systematically and critically review their learning disabilities service provision:

- to further develop the availability of services and other supports so that the aims and objectives of the Strategy are experienced by progressively more people with learning disabilities and their families in Wales, thereby reducing geographic disparities in provision, and,
- to continue to refine their monitoring and evaluation of the quality of services being provided and the outcomes being achieved to ensure that resources are being used to best effect and that the needs of individuals are being met.

12. Working Together

12.1 Experience in Wales over the last 20 years demonstrates that good and effective joint working between authorities and other organisations can be achieved. Local Authorities and health agencies working together with people with a learning disability, their families/carers, voluntary organisations and other agencies in the planning, commissioning, monitoring and evaluation of services results in decision-making that best meets local needs.

12.2 The 1983 All Wales Mental Handicap Strategy and 1994 Revised Guidance required local authorities to develop strategic planning in partnership with local stakeholders. There is some perception that following the re-organisations of the local authorities and health services over recent years the effectiveness of joint working arrangements across Wales has become inconsistent. The Welsh Assembly Government believes that it is essential that people with a learning disability, their carers and other stakeholders should be active and equal participants and contributors in all service planning, development, monitoring and evaluation processes. All stakeholders need to be committed to the process in order to maximise the benefits of joint working.

12.3 Through effective joint working, people with a learning disability, their carers and other stakeholders should be able to contribute to the shaping of (and have confidence in) the delivery and future development of services in their locality.

12.4 Such service planning should be responsive to local needs, taking into account the demographics of the local area and likely future requirements as well as ensuring that they meet individual needs identified via the Unified Assessment process. Planning for the delivery and future development of services for people with a learning disability must take account of and be included in local Health Social Care and Well-being Strategies and Implementation Plans. Other strategies such as Community Plans should also be considered for their relevance and the opportunities they can provide for people with a learning disability and their families.

12.5 In developing joint working arrangements, the Welsh Assembly Government believes that it is important for authorities to ensure that appropriate arrangements are in place to support the involvement and participation of people with learning disabilities and their families/carers effectively. This will encompass considerations such as the timing and location of meetings, ensuring timely access to information in accessible formats and managing the conduct of meetings to ensure participation is achieved.

13. Workforce Planning

13.1 In its Fulfilled Lives, Supportive Communities document setting out the strategic direction for social services, the Welsh Assembly Government fully recognises that services are only as good as the people who work in them. The document also goes on to say:

- that more personalised and responsive social services require people with the right personal qualities as well as formal training and skills
- as services are changed towards earlier intervention and new models of care it will be important that the workforce evolves to deliver the flexible and responsive services needed in the future.

13.2 Designed for Life also emphasises that workforce development is critical to improving standards.

13.3 The Welsh Assembly Government believes that it is important that health and social care staff working with adults with a learning disability have the appropriate values and skills, reflected in their training and qualifications, to meet the challenges set out in this document and in the Section 7 Guidance on Service Principles and Service Responses for Adults and Older People with a Learning Disability.

13.4 Effective joint working is an essential component to developing the workforce that is required to support adults with a learning disability. Whilst progress has been achieved, more needs to be done to increase the number of staff that have appropriate qualifications, particularly in the context of the ever-evolving community accommodation arrangements and employment or day activity support. Authorities will need to consider what arrangements should be in place for training and developing staff in those services that they directly provide and in those services provided by other contracted providers.

13.5 Welsh Assembly Government guidance has been provided to the NHS in Wales and local authorities in respect of workforce planning. It is important that authorities take proper account of current and future staffing requirements. In so doing, the workforce qualification and national occupational standards requirements and expectations established by NHS Wales, the Care Council for Wales and in those services regulated under the Care Standards Act will need to be addressed.