



ESSENTIAL KNOWLEDGE

MEADOW COURT

LEARNING DISABILITIES

HISTORY AND CONTEXT



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14 Words that inform and signify-HISTORY & CONTEXT

Definition of learning Disability

A learning disability affects the way a person understands information and how they communicate. This means they can have difficulty: understanding new or complex information, learning new skills and coping independently

HEALTH

INFORMATION

STUDY

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ORIGINS

REMINISCE

&

CERTAINTY

OBSERVATION

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THEORY

EXPLANATION

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TRANCHE



History & Context of Learning Disability Services

History & Context

1. Definitions and terminology

1.1 Understand what is meant by learning disability

A learning disability affects the way a person learns new things in any area of life, not just at school. Find out how a learning disability can affect someone, and where you can find support.

A learning disability affects the way a person understands information and how they communicate. Around 1.5m people in the UK have one. This means they can have difficulty:

- understanding new or complex information
- learning new skills
- coping independently

It is thought that up to 350,000 people have severe learning disabilities. This figure is increasing.

Mild, moderate or severe learning disability

A learning disability can be mild, moderate or severe. Some people with a mild learning disability can talk easily and look after themselves, but take a bit longer than usual to learn new skills. Others may not be able to communicate at all and have more than one disability (see Profound and multiple learning disability, below).

A learning disability is not the same as a learning difficulty or mental illness. Consultant paediatrician Dr Martin Ward Platt says: "It can be very confusing," he says, pointing out that the term "learning difficulties" is used by some people to cover the whole range of learning disabilities.

"It is easy to give the impression, by using a term like 'learning difficulties', that a child has less of a disability than they really do," says Dr Ward Platt.

Some children with learning disabilities grow up to be quite independent, while others need help with everyday tasks, such as washing or getting dressed, for their whole lives. It depends on their abilities.

Children and young people with a learning disability may also have special educational needs.

1.2 Understand that the concept of "learning disability" has changed over time

HISTORICAL OVERVIEW OF LEARNING DISABILITY SERVICES

Introduction

In order to understand the current provision of learning disability services, it is important to have a knowledge of the historical perspectives and the origins of services for people with learning disabilities

People with learning disabilities tend to stand out from the rest of their immediate society because of an inability to cope satisfactorily in that society. They are perceived by society to be different, mainly because they require support to enable them to function and survive. Awareness of problems that people with learning disabilities may have and the steps taken to overcome these problems reflect the standards of behaviour which society demands from its members and the tolerance of society to when people deviate from those standards of behaviour.

Industrial Revolution

In the UK prior to the industrial revolution the problem of learning disabilities did not exist to such an extent. Most villages were able to cope with the 'idiot' in their midst, sometimes at the expense of ridicule and exploitation, sometimes with an almost reverent regard for their simplicity. With the industrial revolution came large towns, large numbers of workers crowded together who were dependent on the local factory, mill or pit for their livelihood. Also came an increase in education and a need for the more abstract skills of reading and writing to be mastered if any sort of social status was to be achieved. People were now being measured and valued by their ability to cope with the new technological and commercial processes in society. People with learning disabilities began to stand out as being educationally and practically of low competence, but at this stage were not regarded as a specific threat to society or specifically undesirable. Educatability of people with learning disabilities. Despite the fact that many people with disabilities were incarcerated in workhouses along with all the unemployed and unemployable poor, there was a theory, in academic circles, that these people, classed as "idiots" and "imbeciles" could be educated.

Eugenics Movement

A complete change in the direction of service development occurred at the turn of the century. The leaders of opinion in the medical and scientific world became pessimistic about the educatability of people with a learning disability and formed the view that such people would be a drain on society. These eugenic ideas were crystallised by Tredgold in his Textbook of Mental Deficiency in 1908. He advocated segregation in "farm and industrial colonies" to prevent "propagation" and to protect society from the criminal tendencies of such people and from the "burden due to their non productiveness. These views helped to formulate the Mental Deficiency Act (1913) which gave powers to the Boards of Control of the asylums to prevent the discharge of anyone they thought unfit to leave. Also, the provisions under which 'a defective' could be admitted were wide ranging (including habitual drunkenness or lack of a means of support).

In effect, many people who exhibited the prescribed behaviour (whether "defective" or not) were "certified". After the First World War more people became 'subject' to being dealt with under the Mental Deficiency Acts.:

As a result, the basic pattern of services in the inter-war years was large, isolated colonies which housed people with a wide variety of abilities.

Attitudes did not become enlightened – in fact, the eugenics movement found an outlet in Germany where people like Binding and Hoche (1920) had already advocated the disposal of

those who were "unfit" and a burden on society. These theories developed into a euthanasia policy in National Socialist Germany which was to prove to be the prototype for the holocaust (Wolfensberger 1987).

The 1959 Mental Health Act dealt mainly with the technicalities of admission and discharge. It created the "open door" policy of informal admission and it removed the certification procedure. However, the Act, whilst providing new definitions, still perpetuated the apparent need for institutionalisation as an alternative to keeping the individual at home. Thus in the 1960's, the majority of people with learning disabilities were accommodated in hospitals. abilities

Successive studies in the sixties continued to criticise institution based service provision and perhaps the most significant is that of Morris (1969). The author reported on a study of 35 subnormality hospitals aimed at discovering "what is actually happening". The findings were alarmingly similar to surveys carried out over a decade earlier:

- patients living in barrack-like buildings 60 or more to a dormitory
- patients had no personal clothing or belongings
- sanitary annexes were often rudimentary
- very little use of tests or assessment methods
- little agreement between staff on the objectives of treatment
- staff shortages – nurses and specialist staff
- very little co-ordination of input from medical, nursing and specialist staff
- most institutions were totally isolated in their location and visiting was not encouraged.

It should be noted that these conditions applied to 90% of the people with learning disabilities in residential care. Despite two decades of research findings advocating alternatives to hospital provision very little progress had been made.

In the early seventies the debate focused on the role of the specialists and care staff. A multi-disciplinary team approach was advocated by Gunzburg (1973), however, the medical clinicians maintained their status as the natural leaders of the team. In 1974 Barbara Castle took the office of Secretary of State at the DHSS and in 1975 she announced a number of initiatives.

The influence of normalisation is clear in the Jay Committee Report (1979) which set out broad principles of the rights of people with learning disabilities and a series of service principles, such as: "Mentally handicapped people should use the normal services where possible". Together with "An Ordinary Life" (Kings Fund 1980) the Jay Committee recommendations represented a major challenge to the medically dominated service. However, the Jay Committee report may have informed the debate but it was not implemented. Mrs. Thatcher came to power and much wider changes were envisaged by the government.

The 1981 White Paper – Care in the community, re-emphasised the government's commitment to community care and mandated a hospital closure programme (in relatively vague terms). The eighties saw a large expansion of private residential provision which exceeded the growth in local authority residential provision. The hospital residential service experienced a gradual but

small reduction and seemed unaffected by the pressure for change arising from the normalisation principle and "An Ordinary Life" which advocated a model of residential care based on ordinary housing.

Furthermore in 1992 the Department of Health issued a Local Authority circular on Social Care for Adults with Learning Disabilities which states that "few, if any, people need to live in hospitals". The needs and rights of individuals was brought into focus in the nineties by the growth of advocacy, in particular, citizen advocacy where a person without learning disabilities makes a commitment to advocate for the interests of someone with learning disabilities. In the mid nineties a position had been reached where many hospitals had been closed. This process has highlighted the difference between health and social care. The preferred pattern of service provision was that people with learning disabilities access the "normal" health services and receive "specialist" health services only when it meets their particular, individual need. The Government commissioned an independent evaluation of the different types of residential care for people with a learning disability. The first phase is the report "Residential Provision for People with Learning Disabilities" (Emerson et al, 1996). Perhaps the most important aim of the report was to: "establish the defining characteristics and aims of differing approaches to residential provision". It was noted by Parrish (1996) that during the wide ranging consultation process to achieve this aim, a high degree of consensus was reached on a number of issues:

- The overall aim of residential services should be to maximise the individual's quality of life.
- A high quality of life is one in which people receive individually tailored support which helps them to become full participants in community life.
- It is important to monitor how well the aims are progressing.
- Outside agents have an important role to play in evaluating the success and/or failure of the different residential services.

Parrish (1996) sounded a warning in the conclusions he drew from the Report of Emerson et al:

1. There is a significant variation in the quality and cost of all types of service. This variation is so great that for a significant minority of people living in small community-based houses, the quality of life is largely indistinguishable from the quality of life of people in hospital
2. When compared to the general population the quality of life of this client group in all settings is impoverished
3. Some aspects of service quality and the quality of life of people with a learning disability have received little attention, e.g. the effectiveness of services in protecting clients from physical and sexual abuse
4. The issue of ageing parents caring for their child at home is an area which requires specific attention for the future

By comparing the service provided at the beginning of the century to that of the present day it can be seen that great progress and improvement has been achieved, albeit belatedly.

Today, half of the population of adults with learning disabilities in England live with their families, most of the remainder (33%) live in residential care. Only 15% of adults with learning disabilities have a secure long-term tenancy or their own home. This is in comparison with 70%

of the general adult population who own their own home and nearly 30% who rent. Having a home guarantees a place in the community and is part of how people are accepted as equal citizens. People with learning disabilities are one of the most socially excluded groups in our society and this is primarily a result of an historical segregation of services that unintentionally deny people their own home, choice and control and a decent income; factors which ultimately deny citizenship and social inclusion.

There are many ways that people with learning disabilities can have their own homes, live with people they choose and get the support they need. This paper explores alternative opportunities to residential care; specifically supported living models that not only house and support people, but give people a real place in their community.

This paper does not say that residential care in itself is bad or wrong. Most of us will know someone who has had a good experience of living in residential care. That is usually because they are supported by good organisations and fantastic staff, and their experience is good despite the restrictive structure of residential care, not because of it.

Good quality residential care should remain a valid choice, but it should not be the only or predominant choice just because there is little or nothing else available. In the near future, Residential Care will be replaced by Supported Living as the option for support and care.

1.3 Understand how the use of different terminology has affected the way that individuals with learning disabilities are regarded by society

HISTORICAL STIGMA'S, DEROGATORY AND DEHUMANIZING TERMS

Mentally handicapped, Subnormal, Feeble-minded, Imbecile defective, retarded, simple, backward

Above meaning: People with learning disabilities, these terms are very offensive and stigmatising.

Mongol, 'Mong'

Above meaning: Person with Down's Syndrome, Term has become very offensive.

Spastic

Above meaning: Person with cerebral palsy. Term has become very offensive.

Modern Terminology and concepts

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Mild, moderate or severe learning disability

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"It is easy to give the impression, by using a term like 'learning difficulties', that a child has less of a disability than they really do," says Dr Ward Platt.

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Sources of support for learning disabilities

Some learning disabilities are diagnosed at birth, such as Down's syndrome. Others might not be discovered until the child is old enough to talk or walk.

Once your child is diagnosed with a learning disability, your GP can refer you for any specialist support you may need. You'll begin to get to know the team of professionals who will be involved in your child's care.

Support from professionals – including GPs, paediatricians, speech and language therapists, physiotherapists and educational and clinical psychologists – is available to help individuals live as full and independent a life as possible.

What causes learning disabilities?

A learning disability happens when a person's brain development is affected, either before they are born, during their birth or in early childhood.

Several factors can affect brain development, including:

- the mother becoming ill in pregnancy
- problems during the birth that stop enough oxygen getting to the brain
- the unborn baby developing certain genes
- the parents passing certain genes to the unborn baby that make having a learning disability more likely (known as inherited learning disability)
- illness, such as meningitis, or injury in early childhood

Sometimes there is no known cause for a learning disability.

Some conditions are associated with having a learning disability, such as cerebral palsy. This is because people with these conditions are more likely to have one.

Everyone with Down's syndrome, for example, has some kind of learning disability, and so do many people with cerebral palsy. People with autism may also have learning disabilities, and around 30% of people with epilepsy have a learning disability.

Profound and multiple learning disability (PMLD)

A diagnosis of a profound and multiple learning disability (PMLD) is used when a child has more than one disability, with the most significant being a learning disability.

Many children diagnosed with PMLD will also have a sensory or physical disability, complex health needs, or mental health difficulties. People with PMLD need a carer or carers to help them with most areas of everyday life, such as eating, washing and going to the toilet.

If you are looking after a child or adult with PMLD, you can find help and support in Care and support.

Autism is a lifelong developmental disability that affects how a person communicates with, and relates to, other people. It also affects how they make sense of the world around them.

It is a spectrum condition, which means that, while all people with autism share certain difficulties, their condition will affect them in different ways. Some people with autism are able to live relatively independent lives but others may have accompanying learning disabilities and need a lifetime of specialist support. People with autism may also experience over- or under-sensitivity to sounds, touch, tastes, smells, light or colours.

Asperger syndrome is a form of autism. People with Asperger syndrome are often of average or above average intelligence. They have fewer problems with speech but may still have difficulties with understanding and processing language.

1.4 Understand the difference between the “medical” and “social” models of care

The medical model of disability looks at the person with a disability as ‘the problem’. A disabled person could be seen as ‘a person who has to adapt to fit into the world’, and would be best placed in an institution or isolated at home, where their basic needs are met.

The model revolves around identifying the disability, finding out what it is, understanding it, learning how to deal with it, learning how to improve it, and attempting to cure it, or expand or improve the functionality of the disability. This lies with the medical profession who would be deemed as having central core of this responsibility.

This is viewed by those who stereotype disability, and look at ‘the problem’, and not the social needs of the person.

The social model of disability looks at the person with a disability as a human being, a person with human rights who has a right to full participation in all walks of life.

This model is supported by disabled people today, and they believe the ‘cure’ to the problem of disability lies in the restructuring of society, for example according to the Disability Discrimination Act 1995, service providers, or employers are required to make ‘reasonable adjustments’ to their policies or practices, or physical aspects of their premises, are actually removing the barriers that disable. According to the Social Model of Disability, this means they are effectively removing the person’s disability.

1.5 Understand the difference between “person centred” and “institutional” care.

Person Centred Planning is a way of assisting people to work out what they want; the support they require and helping them get it.

- Person Centred Planning has the person at the centre, is carried out in alliance with friends and family and is focussed on getting real lives for people.
- Person centred planning plays a particularly important role in delivering objectives in the “Valuing People Now” document.

What is Person Centred Planning?

Person Centred planning is a way of enabling people to think about what they want now and in the future. It is about supporting people to plan their lives, work towards their goals and get the right support. Person Centred Planning is a collection of tools and approaches that can be used to plan with a person– not for them. Planning should build upon the person’s circle of support and involve all the people who are important in that person’s life. Person centred planning is built upon the values of inclusion and looks at what support a person needs to be included and involved in their community.

Person centred approaches offer an alternative to traditional types of planning which are based upon the medical model of disability and which are set up to assess need, allocate services and make decisions for people.

Being person centred or using person centred approaches means ensuring that everything we do is based upon what is important to a person from their own perspective.

Person Centred planning discovers and acts on what is important to a person.

Person Centred planning helps us do this by discovering and acting on what matters to a person. It gives us a structure to help us continually listen and learn about what is important to a person now and in the future and to act on this in alliance with friends and family. It requires a fundamental shift of thinking from a “power over” relationship to a “power with” relationship.

The Key Five Features of Person Centred Planning:

There are 5 key features that help distinguish person centred planning from other forms of planning:

1. The person is at the centre: person centred planning is rooted in the principles of rights, independence and choice. It requires careful listening to the person and results in informed choice about how a person wants to live and what supports best suit the individual.
2. Family members and friends are full partners: Person Centred planning puts people in context of their family and communities. The contributions that family and friends can make are recognised and valued and gives a forum for creatively negotiating conflicts about what is safe, possible or desirable to improve a person’s life.

3. Person centred planning reflects upon a person's capacities, what is important to a person (now and for the future) and specifies the support they require to make a valued contribution to their community. Services are delivered in the context of the life a person chooses and not about slotting people into "gaps".
4. Person centred planning builds a shared commitment to action that recognises a person's rights. It is an ongoing process of working together to make changes that the person and those close to them agree will improve a person's quality of life.
5. Person centred planning leads to a continual process of listening, learning and action and helps the person get what they want out of life. Learning from planning can not only inform individuals but can affect service delivery as a whole and inform and inspire others to achieve greater things

Institutionalisation refers to the process of embedding something (for example a concept, a social role, a particular value or mode of behaviour) within an organization, social system, or society as a whole. The term may also be used to refer to committing a particular individual or group to an institution, such as a mental or welfare institution. The term may also be used in a political sense to apply to the creation or organization of governmental institutions or particular bodies responsible for overseeing or implementing policy, for example in welfare or development.

In the United States and most other developed societies, severe restrictions have been placed on the circumstances under which a person may be committed or treated against their will as such actions have been ruled by the United States Supreme Court and other national legislative bodies as a violation of civil rights and/or human rights (see e.g. *O'Connor v. Donaldson*). Thus a person is rarely committed against their will and is never committed for an indefinite period of time.^[1]

1.6 Understand the concept of inclusion

Historically, people of all ages with learning disabilities have faced poor life chances, largely due to social exclusion. They've struggled with acceptance from mainstream society, facing stigmatisation, prejudice and even fear.

Social exclusion has been a major factor in many learning disabled people living a life of limited opportunity. Previously, many learning disabled people were removed from their communities and institutionalised. However, in developed countries there has been a move in recent years to take positive steps and change direction towards social inclusion for people with learning disabilities. This has involved steps such as care in the community and action toward greater integration amongst mainstream society.

The ethos behind this progression is to provide assistance and education for learning disabled people to gather the skills to live a less marginalised and more independent life within society, as well as learn about citizenship. For children, social inclusion also means finding ways for the child to integrate into mainstream state schools if the support is available.

Explaining Social Inclusion

The term 'social inclusion' has come to replace older terminology, such as 'community development work'. Social inclusion in practical terms means working within the community to tackle and avoid circumstances and problems that lead to social exclusion, such as poverty, unemployment or low income, housing problems and becoming housebound and isolated due to illness.

Quite often, social inclusion is self-perpetuating and becomes long-term due to a number of factors exacerbating each other. It can sometimes lead to additional problems such as mental illness. This can be especially true for people with learning disabilities who have no support or co-operation from within their community, and no means to help themselves.

2. Historical context

2.1 Know the types of services that have been offered to individuals with learning disabilities over time

What is the Learning Disability Service?

This is a service made up of social care and health workers. It provides a variety of support to help those people with a learning disability and their carers.

What is a Learning Disability?

A learning disability starts before adulthood, which has a lasting effect on development. Having a learning disability affects the ability to:

- understand new information
- learn new skills
- cope independently

Who can use a Learning Disability Service?

You can use the Learning Disability Service if they:

- have a learning disability
- live in the local area
- are over 18

What services is provided?

Advice and Support from Carer and Support Workers, Social Workers and Nurses. They will work with you to identify and get hold of the care and support you need.

Health Care Services are provided by nurses, psychologists, speech therapists, physiotherapists and specialist behavioural therapists.

Day Services provide a range of activities (delivered in a person centred way) to promote independence and life skills. These may include:

- community participation
- leisure activities
- help to build skills to get a job
- working with computers

Residential Services helps people live as independently as possible. They may help in peoples own home with support such as managing finances or cooking. We also provide supported accommodation where assistance is available 24 hour assistance.

Short Term Break (respite) Services provide additional support for parents and carers of people with learning disabilities.

How can you get these services?

By contacting the Local Authority Adult Assessment Team.

Is there a charge for using the Learning Disability Service?

There is no charge for the assessment or for any information and advice we may give. However, there may be charges for some of the services provided. A Social Worker will discuss about any charges or financial support available.

Complaints, suggestions and comments

Local Authorities are committed to providing quality services. They have robust complaints, suggestions or compliments systems to ensure the quality of the service recieved.

Safeguarding Adults

If anyone is being abused or suspect that somebody you know is being abused in any way, it can be reported on concerns or worries by contacting the Safeguarding Adults Team.

No names need to be given and any information will be treated confidentially. Authorities always respect the wishes and feelings of the person at risk of abuse.

Information in other formats and languages

If information is required in another language or format there is a member of staff from Adult Services that can advise.

Whether providing support in the home, in supported accommodation or in a residential setting, at Meadow Court we understand the importance of personalised support.

Everyone's support needs are different: some people only need occasional support around the home, while others with more complex or challenging needs may need a round-the-clock service. We work with people and their families to work out what type of support – and what support environment – will best suit their needs. In short, they tell us how they would like their support to be delivered.

It's vital that the people we support are living in the right environment for them. At Meadow Court we work closely with a range of housing associations, private landlords and estate agents so that individuals can access mainstream housing and live as independently as possible in the best setting for them.

We also help people to get fully involved in their communities and to have the same opportunities as everyone else. We work with them and their circle of support, as well as other carers and social services to do this.

Supported living

Supported living provides a helpful balance between round-the-clock support and independent living.

Supported living is an excellent option for people with a variety of learning disabilities and related conditions. Those with physical disabilities can live in a home environment that's purpose designed around their specific mobility challenges. People with learning disabilities are able to develop the skills they need for increasingly independent living in a safe and secure environment. Supported living is a great option for people who are 'stepping down' from residential care and who are making the transition to living independently in the community.

What is supported living?

Supported living services enable people to live independently in their own home. This could be a flat, house or bungalow. People also have the option to share accommodation with others.

People can decorate their accommodation in any way they wish, have friends to visit and have full control of how they live. Their support team will agree a package of care with them and their family, or circle of support, and this may be anything from two hours a week to go shopping, to seven days a week complete care. However, support workers can offer 24-hour support, sleep in cover and monitor from a distance using assistive technology if required.

Money and budget advice

Supporting an individual to take control of their money, developing the skills to manage their day-to-day finances so that they have the resources to live the life they want.

Advising and supporting individuals to manage their money, their personal/individual budgets and direct payments so that they can take more control of their life.

Supporting them to:

- have their own bank account
- understand and access the benefits they're entitled to
- pay bills or save up for the things they want
- ensure that their utility and mobile phone bills and contracts are set up in a way that they understand.

Support at home

There are a range of support options that enable individuals to live independently in their own home.

Outreach services

Outreach services are flexible support services designed to meet different needs at different times.

Transitional support

Supporting people through the process as they gain the confidence and skills they need to live more independently.

2.2 Understand how present services are affected by past ways of working

STEREOTYPING AND LABELLING (PREJUDICE AND DISCRIMINATION)

A stereotyping is something that signifies specific types of individuals, particular race or a group of people through common perception. There is confusion between stereotyping and labelling that comes with prejudice. Stereotyping can sometimes be positive and prejudice is negative about certain groups of people. Labelling means when people judge others simple based on specific characteristic or identifying other people in the form of prejudice and discrimination. It is important to provide appropriate definitions of, 'prejudice' and 'discrimination', and to distinguish between them. The terms 'prejudice' and 'discrimination' are often used interchangeably, but it is important to be clear about the difference between them. For our purposes, prejudice can be described as a type of attitude towards members of a social group, whilst discrimination can be described as behaviour or an action arising from that attitude and directed towards members of a social group. In other words discrimination is essentially 'prejudice in action'

Prejudice can be seen to have 3 aspects to it; the cognitive (what we think/perceive) this can draw upon stereotypes and labelling, the affective (the emotional aspect, often negative) and the behavioural (what people do, discrimination). The understanding of these concept enable carers to care, support and manage individuals and assist in enabling the framework of valuing people, person centred care and personalisation

EMPLOYMENT AND TRAINING

The first Employment Strategy for people with learning disabilities was completed in 2003; guided by the Valuing People White Paper 2001 which recognised the need for people with learning disabilities to have access work and employment opportunities. Since then significant progress has been made both nationally and locally to improve the chances of people with a learning disability to gain appropriate training and skills to gain employment including paid employment. Today's society understands that:

- people with a learning disability should have access to good-quality further education and training
- people with a learning disability should be properly supported to get into work, and in the workplace
- more employers should take on people with a learning disability
- employers must pay people with a learning disability at least the national minimum wage for the work they do
- the government must make sure people with a learning disability benefit from welfare reform and changes to the benefit system.

RESOURCES

As a result of changes over time, resources are available from a range of organisations in these subject areas, of which these are taken from:

- Abuse
- Advocacy
- Autism
- Black and minority ethnic communities
- Communication
- Employment
- Family Carers
- Food and health
- Good Support
- Government
- Hate Crime
- Health
- Human Rights
- Housing
- Learning disabilities
- Managing Money
- Mental Health
- Mental Capacity Act
- Offenders and the Criminal Justice System
- Other areas
- Parenting

- Personalisation
- Positive Behaviour Support
- Profound and multiple learning disabilities
- Safeguarding
- Sexuality and relationships
- Young people and transition
- Workforce

VALUING PEOPLE

Because of the need changes and progression of services, Valuing People came as a white paper in 2003 and formed the basis for future care and support, and although not enshrined in legislation, forms the backbone of how services are provided today.

Problems and Challenges

There are over 200000 people with severe learning disabilities in England, and about 1.2 million with a mild or moderate disability. Health and social services expenditure on services for adults with learning disabilities stands at around £3 billion. In the 30 years since the last White Paper Better Services for the Mentally Handicapped, progress has been made in closing large institutions and developing services in the community, but more needs to be done. There are major problems, including:

- Poorly co-ordinated services for families with disabled children especially for those with severely disabled children;
- Poor planning for young disabled people at the point of transition into adulthood;
- Insufficient support for carers, particularly for those caring for people with complex needs;
- People with learning disabilities often have little choice or control over many aspects of their lives;
- Substantial health care needs of people with learning disabilities are often unmet;
- Housing choice is limited;
- Day services are often not tailored to the needs and abilities of the individual;
- Limited opportunities for employment;
- The needs of people from minority ethnic communities are often overlooked;
- Inconsistency in expenditure and service delivery; and
- Few examples of real partnership between health and social care or involving people with learning disabilities and carers

Four key principles of Rights, Independence, Choice, Inclusion lie at the heart of the Government's proposals. Legislation which confers rights on all citizens, including the Human Rights Act 1998 and the Disability Discrimination Act 1995, applies equally to all people with learning disabilities, and the Disability Rights Commission will work for people with learning disabilities. New national objectives for services for people with learning disabilities, supported by new targets and performance indicators, to provide clear direction for local agencies's

INSTITUTIONAL HOSPITALS (a thing of the past)

The closure of long-stay hospitals started in the 1980s when people with a learning disability were moved to residential care homes in the community. Residents who had lived in long-stay hospitals reported extreme poor standards of care, which included being locked up; having no clothes of their own and sharing everything they did have with a large group of people.

People with a learning disability are increasingly able to live independent lives with choice. It is important that quality of care continues to improve and will only do so with sufficient investment in social care."

COMMUNITY SUPPORT SERVICES

There are now a range of community services to ensure that community living is enhanced and needs catered for.

Community support services provide behavioural interventions. Support plans are integral within the community services.

The community teams are multidisciplinary. They include:

- psychiatric services; a medical team including a consultant
- community learning disability nursing
- psychological therapies
- social workers (Hull)
- speech and language therapy
- occupational therapy
- physiotherapy
- epilepsy specialist services
- Continuum behavioural support services
- transition workers, supporting transfer into adult care
- creative therapies
- STR workers (support, time and recovery workers)

When someone is referred to the service, they will be assessed. The service user and their carers will work with the team to create a plan of targeted intervention. They will be kept involved in their treatment and support plans. These can include individual or combined services, such as:

- further specialist assessments, such as tests of cognitive functioning
- person-led assessments to determine levels of care required within support plan
- personalised services which support the individual at home
- psychiatric assessment
- supported assessment and admission to assessment areas
- enhanced nursing assessment
- enhanced therapy assessment
- behavioural management and support plans
- dementia assessment and support plans

- epilepsy management plans
- autism support and intervention
- psychological therapies, including systemic and family therapy
- intensive interaction with individuals who have profound and multiple disabilities
- equitable inclusion in local and national health priorities
- detailed communication work
- functioning, gait, mobility, parenting capacity, swallowing, continence
- focussed individual work, for example looking at bereavement, sexuality issues and capacity assessments
- health facilitation, health action planning and patient passports
- support to access acute care services
- general health through primary care services
- enhancing community presence and activities of daily living
- eating/swallowing assessments
- postural management plans
- complex nutritional interventions
- respiratory care
- complex bowel management
- health and wellbeing monitoring including medication reviews
- transition support for young people transferring into adult services
- carer assessments, in which all carers are encouraged to take part

EMPOWERMENT

Today, society empowers people with learning disabilities to make choices about how they live their lives. Whatever people's needs, preferences and goals, organisations work closely with them to help decide on the best type of support. This might include supporting someone find a job, build new relationships or get involved with activities in the local community. These are just examples.

- Working with people to help them decide exactly what support they need.
- Help with anything from using public transport, to cooking, or managing money.
- Helping people to find paid and voluntary work, or to set up their own business.
- Whatever type of leisure activity to get involved with in your community – from taking up a new sport to going to the pub with friends – support can be there to make it happen.
- Supporting people with learning disabilities to make new friends, or stay in touch with old ones, through friendship groups, events and activities.

SUPPORTED LIVING

Supported living is a concept that was developed as an alternative to institutional care for people with learning disabilities in the 1990's. The main principles of supported living are that people with learning disabilities own or rent their home and have control over the support they get, who they live with (if anyone) and how they live their lives. Supported living assumes that all people with learning disabilities, regardless of the level or type of disability, are able to make

choices about how to live their lives even if the person does not make choices in conventional ways. Supported living has no legal definition but has a commonly accepted set of principles that are defined as:

- I choose who I live with
- I choose where I live
- I have my own home
- I choose how I am supported
- I choose who supports me
- I get good support
- I choose my friends and relationships
- I choose how to be healthy and safe
- I choose how to take part in my community
- I have the same rights and responsibilities as other citizens
- I get help to make changes in my life

2.3 Understand the effects different sorts of provision of care have had on individuals with learning disabilities

PERSONALISATION

The personalisation agenda is leading some of the changes happening in social care today. It has come about as a direct result of the modernisation of social care services that has been happening over the past several years.

RESIDENTIAL CARE

Residential care refers to long-term care given to adults or children who stay in a residential setting rather than in their own home or family home.

There are various residential care options available, depending on the needs of the individual. People with learning difficulties are often cared for at home by paid or voluntary caregivers, such as family and friends, with additional support from home care agencies. However, if home-based care is not available or not appropriate for the individual, residential care may be required.

OUTREACH

Outreach is an activity of providing services to populations who might not otherwise have access to those services. A key component of outreach is that the groups providing it are not stationary, but mobile; in other words they are meeting those in need of outreach services at the locations where those in need are.^{[1][2][3]} In addition to delivering services, outreach has an educational role, raising the awareness of existing services.

Outreach is often meant to fill in the gap in the services provided by mainstream (often, governmental services), and is often carried out by non-profit, nongovernmental organisations. This is a major element differentiating outreach from public relations. Compared to staff providing traditional services, outreach staff may be less qualified, but is more highly motivated.

After assessing individual needs we will then be able to identify if a person would require an intensive package of support that is flexible within its delivery.

Such people will benefit from our outreach service which is a tailored support package where people are collected from their homes and do not require a building based service. Innovations therefore ensure that all individuals have the opportunity to access and take part in activities within the community.

It is sometimes better for some service users who tend to have high support needs to go directly from their homes to activities of their choice.

VALUING PEOPLE

- All people with learning disabilities and their families will benefit from Valuing People Now
- All people with learning disabilities and their families will have greater choice and control over their lives and will have support to develop person centred plans
- All people with learning disabilities get the healthcare and support they need to lead healthy lives
- All people with learning disabilities and their families have the opportunity to make an informed choice about where, and with whom they live
- All people with learning disabilities and their families to have a fulfilling life of their own, beyond services that includes opportunities to work, study, and enjoy leisure time and social activities. This includes supporting more people into paid work, including those with more complex needs
- People with learning disabilities have the choice to have relationships, become parents and are supported to do so
- People with learning disabilities will be treated as equal citizens in society and supported to enact their rights and fulfil their responsibilities
- All people with learning disabilities can speak up and be heard about what they want from their lives – the big decisions and the everyday choices. If they need support to do this, they should be able to get it
- All people with learning disabilities and their families will be able to use public transport safely and easily, and feel confident about doing so
- People with learning disabilities will be able to lead their lives
- People with learning disabilities will be able to lead their lives in safe environments and will feel confident that the right to live in safely is upheld by the criminal justice system

INDIVIDUAL BUDGETS

People can get money from their local authority to choose and pay for support. This is called an individual budget or personal budget.

This means that people with a learning disability can choose to buy their support from people they already know or from learning disability support provider

SOCIAL CARE

Social care in England is defined as the provision of social work, personal care, protection or social support services to children or adults in need or at risk, or adults with needs arising from illness, disability, old age or poverty.

ISOLATION MANAGEMENT

Isolation is a major and prevalent health problem among community-dwelling older adults, leading to numerous detrimental health conditions.

Social isolation refers to a complete or near-complete lack of contact with people and society for members of a social species. It is not the same as loneliness rooted in temporary lack of contact with other humans. Social isolation can be an issue for anyone despite their age, each age group may show more symptoms than the other as children are different from adults.

Social isolation takes fairly common forms across the spectrum regardless of whether that isolation is self-imposed or is a result of a historical lifelong isolation cycle that has simply never been broken, which also does exist. All types of social isolation can lead to staying home for days or weeks at a time; having no communication with anyone including family or even the most peripheral of acquaintances or friends; and wilfully avoiding any contact with other humans when those opportunities do arise. Even when socially isolated people do go out into public and attempt social interactions, the social interactions that succeed — if any — are brief and at least somewhat superficial. The feelings of loneliness, fear of others, or negative self-esteem can produce potentially very severe psychological injuries

OWN ACCOMMODATION

With or without live-in support, someone with a learning disability and/or mental health problem can live in their own home, retain their independence and make choices about how to live their life. A primary benefit of live-in support is the versatility it offers as and when needs change – having a support worker living in the same household, means that it is possible for a person to have full-time support or extra support for a while, without changing their living arrangements or introducing new people into their home.

NEEDS ASSESSMENT

A **needs assessment** is a systematic process for determining and addressing needs, or "gaps" between current conditions and desired conditions or "wants". The discrepancy between the current condition and wanted condition must be measured to appropriately identify the need. The need can be a desire to improve current performance or to correct a deficiency.

A needs assessment is a part of planning processes, often used for improvement in individuals, education/training, organizations, or communities. It can refine and improve a product such as a training or service a client receives. It can be an effective tool to clarify problems and identify appropriate interventions or solutions. By clearly identifying the problem, finite resources. Gathering appropriate and sufficient data informs the process of developing an

effective product that will address the group's needs and wants. Needs assessments are only effective when they are ends-focused and provide concrete evidence that can be used to determine which of the possible means-to-the-ends are most effective and efficient for achieving the desired results.

3. Barriers to full citizenship

3.1 Understand how society acts in ways that create, add to and maintain disability

Prejudice

Prejudice literally means "prejudgment." Prejudice is an attitude about another person based on his or her perceived membership in a group. So people use the perceived group membership of another person to provide a ready-made attitude about the person.

Attitudes can be positive or negative, and we use our attitudes in general to manage our approach-avoidance behaviours. A positive attitude toward a brand of peanut butter might lead to purchasing that brand on a regular basis. A negative attitude about snakes might lead to avoidance of snake displays at a zoo.

Most psychologists focus on negative prejudice, or attitudes about members of perceived groups that have negative connotations and lead to avoidance. Clearly, these negative prejudices produce the most harm to their targets. Other psychologists acknowledge the existence of positive prejudices, or more favourable attitudes toward members of one group compared to others. While this does not seem to cause the social disruption of negative prejudice, it still conflicts with our desire to be seen and treated as individuals.

3.2 Understand how individuals with learning disabilities have been marginalised and socially excluded

The experience of most people with learning disabilities is generally reported as them having a poor quality of life, i.e. excluded from mainstream life, communities, employment, social and political participation and inadequate income for their basic and disability related needs. Valuing People, the Government's key strategy for people with learning disabilities, however, has social inclusion as a key principle; 'Inclusion means enabling people with learning disabilities to do those ordinary things, make use of mainstream services and be fully included in the local community' .

Inclusion means people being able to: participate in, benefit from and contribute to society; claim full human and citizenship rights, access the same opportunities, use the same facilities as other people for education, housing, employment, health and leisure and having the support to do so (Bradley, 2005). This principle is reiterated in the government consultation paper Valuing People Now: 'The aim is to support people with learning disabilities to live an ordinary life in the community alongside their fellow citizens as described by human rights legislation and the Disability Discrimination Act' (Department of Health, 2007:10).

3.3 Understand how social attitudes have contributed to discrimination against individuals with learning disabilities

Attitudes are feelings or predispositions held by people or individuals towards something or someone. Attitudes are seen to play a key role in achieving equality because they may translate into behaviour towards individuals and groups in society which have negative consequences (such as discrimination and hate crime).

Attitudes are linked to, but are not the same as, knowledge. It is often presumed that negative attitudes and behaviour come from people not having adequate knowledge. For example, people may avoid people with mental health conditions because they think they are prone to violence even though this is not true.

People with learning disabilities still face widespread prejudice and ignorance among the general population.

People with learning disabilities still face widespread prejudice and ignorance among the general population, a survey found one-third of people did not believe people with learning disabilities could live independently or carry out a full-time job, 23% of the public expected learning disabled people to live in a care home, while 8% said they would expect them to be cared for in a secure hospital. The survey also exposed public ignorance about what constituted a learning disability with almost one-third of respondents wrongly identifying mental illness as a learning disability.

Over half felt learning disabled people were the most discriminated against group in society, ahead of gay people and people from black and minority ethnic groups.

The sector, needs to work together to challenge preconceptions and show what a positive contribution to society people with a learning disability can make. This includes working, living independently and playing an active role within the local community.”

Medical Attitudes

Mark Cannon died in aged 30. After an operation to fix a broken thigh bone, he contracted an infection and suffered a heart attack. While his stated cause of death was bronchopneumonia, the local government and health ombudsmen found that the underlying cause was service failure, related to his severe learning disability.

Staff at Barking, Havering and Redbridge Hospitals NHS Trust did not make reasonable adjustments to meet his complex needs. His condition was inadequately assessed, monitored and recorded, and his pain inadequately managed.

The trust apologised for Mark’s treatment and paid compensation to his parents. But a survey of over 1,000 doctors and nurses, showed the problems his case illustrates remain.

Almost half (46%) of doctors and 37% of nurses say learning disabled receive poorer care than others.

3.4 Understand how labelling, institutionalisation, stereotyping and exclusion affect individuals

What is a learning disability?

The term learning disability is a label. It is convenient in discussion and for planning services. But people who carry that label wear many others, such as friend, neighbour, relative, employee, colleague, fellow citizen. A label describes one aspect of a person, but does not capture the whole person

Labelling theory is the theory of how the self-identity and behaviour of individuals may be determined or influenced by the terms used to describe or classify them. It is associated with the concepts of self-fulfilling prophecy and stereotyping. Labelling theory holds that deviance is not inherent to an act, but instead focuses on the tendency of majorities to negatively label minorities or those seen as deviant from standard cultural norms. The theory was prominent during the 1960s and 1970s, and some modified versions of the theory have developed and are still currently popular. Unwanted descriptors or categorisations – including terms related to deviance, disability or diagnosis of a mental disorder – may be rejected on the basis that they are merely "labels", often with attempts to adopt a more constructive language in its place. A stigma is defined as a powerfully negative label that changes a person's self-concept and social identity.

Institutionalisation refers to the process of embedding something (for example a concept, a social role, a particular value or mode of behaviour) within an organization, social system, or society as a whole. The term may also be used to refer to committing a particular individual or group to an institution, such political sense to apply to the creation or organization of governmental institutions or particular as a mental or welfare institution. The term may also be used in a bodies responsible for overseeing or implementing policy, for example in welfare or development.

Stereotypes

Where prejudice involves attitudes, stereotypes are cognitions or beliefs. When making a stereotype, a person categorizes others in ways that are overly simplistic based on perceived group membership. For example, the stereotype that professors are absent-minded might be true of some, but is highly unlikely to be true of all professors.

Stereotypes reflect the very natural human capacity for forming categories and then making rules for what fits into a category. This is not an effort to excuse the application of stereotypes to groups of people, but simply a recognition that stereotyping is not an isolated, poorly understood type of cognitive process.

Like prejudice, stereotypes can be positive or negative. An example of a positive stereotype might be "Asians are good in math." Even a positive stereotype has the potential to be harmful, as a person who does not "fit" the positive stereotype might then feel isolated and less worthy. The impact of negative stereotypes is of course extensive. Claude Steele and his colleagues have chronicled the impact of stereotype threat, in which raising awareness of a stereotype produces a

self-fulfilling prophesy. Suggestions that a group to which you belong does not perform well in the current circumstances is a prescription for poor performance

3.5 Understand the effect discrimination has had on the life choices and opportunities of individuals with learning disabilities

As a result of discrimination the Disability Discrimination Act 2005 became law.

The Disability Discrimination Act

The Disability Discrimination Act (DDA) 1995 aims to end the discrimination that faces many people with disabilities. This Act has been significantly extended, It now gives people with disabilities rights in the areas of:

- employment
- education
- access to goods, facilities and services, including larger private clubs and transport services
- buying or renting land or property, including making it easier for people with disabilities to rent property and for tenants to make disability-related adaptations
- functions of public bodies, for example issuing of licences

The legislation requires public bodies to promote equality of opportunity for people with disabilities. It also allows the government to set minimum standards so that people with disabilities can use public transport easily.

Access to goods, premises and services

The Disability Discrimination Act 1995 (DDA) gives people with disabilities important rights not to be discriminated against:

- in accessing everyday goods and services like shops, cafés, banks, cinemas and places of worship
- in buying or renting land or property
- in accessing facilities such as becoming a member of a larger private club (25 or more members)
- in accessing the functions of public bodies – the issuing of licences for example – Access to everyday services

Rights in employment

It is unlawful for employers to discriminate against people with disabilities for a reason related to their disability, in all aspects of employment, unless this can be justified. Justification is only possible in certain circumstances.

- Employment rights and the Disability Discrimination Act

Rights in health

The DDA gives people with disabilities rights of access to health services and social services, such as doctors' surgeries, dental surgeries and hospitals.

You also have a right to information about healthcare and social services in a format that is accessible to you where it is reasonable for the service provider to provide it in that format.

- Rights of access to health and social care

Rights in education

The Special Educational Needs and Disability Order 2005 and subsequent Disability Discrimination Order 2006 (DDO):

- makes it unlawful for education providers to discriminate against pupils with disabilities, including students and adult learners
- makes sure people with disabilities are not disadvantaged in comparison with people who do not have disabilities
- Learning and your rights

Buying and renting property – your rights

Under the DDA it is unlawful for landlords and other persons connected with the selling, letting and managing of premises to treat disabled people less favourably for a reason related to their disability, unless they can show that the treatment is justified.

The Disability Discrimination (Northern Ireland) Order 2006 amends or extends existing provisions in the DDA 1995 and includes, for example, making it easier for disabled people to rent property and for tenants to make disability-related adaptations.

- Tax on property and rental income (money, tax and benefits section)
- Building regulations (property and housing section)

Mental health and rights

Many people with a mental health condition may not think of themselves as having a 'disability' – but they have rights under the Disability Discrimination Act.

Rights – motoring and transport

People with disabilities have rights of access in relation to motoring, transport and the travel infrastructure (such as railway stations and airports) under the Disability Discrimination Act.

The Disability Discrimination Act also means that you have a right to information about transport (timetables, for example) in a format that is accessible to you, where it is reasonable for the transport provider to provide it in that format.

Help and advice from the Equality Commission

The Equality Commission can provide free and confidential advice and assistance to people who believe that they have been discriminated against for a reason related to their disability.

It also provides free general advice to employers and service providers on recommended good practice under the DDA.

4. Legal framework

4.1 Understand the main aspects of law and government policy both national and local since 1990 which have affected individuals with learning disabilities

Disabled people are still struggling for the right to use public transport, get into buildings, go to school or college with their friends, or to get a job. Although civil rights legislation, the Disability Discrimination Act (UK 1995), have helped, disabled people still often feel that the dominant culture sees them as different from everyone else because of persisting stereotypes of disability.

Anyone can, at any time, become disabled, or develop a physical or mental impairment. Perhaps people's need to distance themselves from this harsh reality makes it convenient to rely on received negative attitudes and historical stereotypes of disability. These stereotypical images are less troubling than accepting the individuality, the joy, the pain, the appearance, behaviour and the rights of disabled people. This could explain why disability equality has been called 'the last civil rights movement'.

What disabled people want more than anything else is to be accepted for who they are and to have their rights guaranteed in law and in practice.

United Kingdom employment equality law is a body of law which legislates against prejudice-based actions in the workplace. As an integral part of UK labour law it is unlawful to discriminate against a person because they have one of the "protected characteristics", which are, age, disability, gender reassignment, marriage and civil partnership, race, religion or belief, sex, and sexual orientation. The primary legislation is the Equality Act 2010, which outlaws discrimination in access to education, public services, private goods and services or premises in addition to employment. This follows three major European Union Directives, and is supplemented by other Acts like the Protection from Harassment Act 1997. Furthermore discrimination on the grounds of work status, as a part-time worker, fixed term employee, agency worker or union membership is banned as a result of a combination of statutory instruments and the Trade Union and Labour Relations (Consolidation) Act 1992, again following European law. Disputes are typically resolved in the workplace in consultation with an employer or trade union, or with advice from a solicitor, ACAS or the Citizens Advice Bureau a claim may be brought in an employment tribunal. The Equality Act 2006 established the Equality and Human Rights Commission, a body designed to strengthen enforcement of equality laws.^[1]

Discrimination is unlawful when an employer is hiring a person, in the terms and conditions of contract that are offered, in making a decision to dismiss a worker, or any other kind of detriment. "Direct discrimination", which means treating a person less favourably than another who lacks the protected characteristic, is always unjustified and unlawful, with the exception of age. It is lawful to discriminate against a person because of their age, however, only if there is a legitimate business justification accepted by a court. Where there is an "occupational requirement" direct discrimination is lawful, so that for instance an employer could refuse to hire a male actor to play a female role in a play where that is indispensable for the job. "Indirect discrimination" is also unlawful, and this exists when an employer applies a policy to their workplace that affects everyone equally, but it has a disparate impact on a greater proportion of people of one group with a protected characteristic than another, and there is no good business justification for that practice. Disability differs from other protected characteristics in that employers are under a positive duty to make reasonable adjustments to their workplace to accommodate the needs of handicapped staff. For age, belief, gender, race and sexuality there is generally no positive obligation to promote equality, and positive discrimination is generally circumscribed by the principle that merit must be regarded as the most important characteristic of a person. In the field of equal pay between men and women, the rules differ in the scope for comparators. Any dismissal because of discrimination is automatically unfair and entitles a person to claim under the Employment Rights Act 1996 section 94 no matter how long they have worked.

4.2 Understand how these changes have affected individuals with learning disabilities, families, carers and the way services are offered

Access to services

The Disability Discrimination Act (DDA) gives you rights in the way you use services or receive goods.

It is **unlawful** for service providers to treat you less favourably because of your disability, and they must make 'reasonable adjustments' for you, such as giving you extra help or changing the way they provide their services. Following changes to the law in 2004, service providers must consider making changes to physical features of their premises so that there are no physical barriers which prevent you from using their services, or make it unreasonably difficult for you to do so.

It doesn't matter whether or not you pay for the service; it's providing the service that matters. Services include going to a restaurant, shopping for clothes or food, using the local library, going to church or visiting your solicitor or doctor.

A service doesn't have to be impossible to use before a service provider has to make changes. They also have to make changes when it's unreasonably difficult. They should think about whether any inconvenience, effort, discomfort or loss of dignity you experience in using the service would be considered unreasonable by other people, if they had to endure similar difficulties.

What are goods and services?

Most services are covered by the DDA. Anyone who provides a service to the public or a section of the public is a service provider. There are a few exceptions: private clubs that have a meaningful selection process for members; transport (but only the transport vehicle, not everything else connected with it such as stations, airports and booking facilities); and education.

Accommodation

Most providers of accommodation are service providers, including:

- private landlords
- housing associations
- estate agents and managing agents
- local authorities providing housing

This means they must make reasonable adjustments if you find a service unreasonably difficult to use.

Not all manufactured goods are covered. The maker of a bathroom suite does not have to make the bath accessible for you, but the shop selling it has to make sure that it is not unreasonably difficult for you to use its services.

Making reasonable adjustments to services

There isn't a clear answer that can be given to the question 'what is reasonable'? The law uses this phrase to allow different solutions in different situations, and it is ultimately up to the courts to decide in each situation. However, what is reasonable may vary according to the type of service and the nature of the service provider, its size and resources.

Some of the factors that service providers might have to take into account when considering adjustments may include:

- whether taking particular steps would overcome the difficulty that you face in accessing their service:
- how practicable it is to take these steps
- the financial and other costs involved
- how disruptive it would be
- how much money and other resources they have available
- how much they have already spent
- what financial help is available to them.

If a service provider does nothing until you are unable to use their services, they could well be in breach of the law.

Is it all right for service providers to wait until I cannot use their services before making changes?

No. Their duties are anticipatory and continuing. In other words, service providers should be thinking ahead and continually looking at the way they provide services, the physical features of their premises and services, and how they can make improvements for disabled people.

Can service providers just make changes for people with particular disabilities?

No. Service providers should consider the full range of access needs of disabled people and the ways in which their services may be difficult to use.

How should a service provider deal with a physical feature that is making it difficult for me to use a service?

Once a service provider has identified the physical features that may make it difficult for you to use their service, then the law gives them a choice. They can remove that feature, alter it, find a way of avoiding it or provide the service another way.

We recommend that service providers first consider removing the physical feature or altering it. This is often the safest option because it is more likely to make the service accessible, meaning that you receive the services in the same way as other customers. This is called an 'inclusive' approach.

Where a service provider does decide to avoid a feature or provide the service another way, then the service must not be unreasonably difficult for you to use.

4.3 Understand the main aspects of current law which protect and promote the rights of individuals with learning disabilities

Many situations experienced by disabled people involve human rights. However, there is little information available about human rights and how they relate to disabled people.

Too often a person may not realise that they are able to do something about their situation, or even that there is something wrong with the way they are being treated. It is therefore vital that disabled people are able to access information about their human rights and challenge bad treatment.

This section provides practical information about human rights, and their relevance to disabled people. It is written directly for disabled people. The section will also be useful for people working with learning disability or those wanting to learn more about the impact of human rights on disabled people.

Why is the Human Rights Act important for people with learning disabilities.

Human rights are not just about the law. The Human Rights Act influences the way public services are delivered to disabled people. The Human Rights Act says that providers of public services, such as staff at residential homes, educational bodies or hospitals, or carers in your own home, must make sure that they do not breach your human rights.

Which human rights are relevant for learning disabilities?

All of the human rights protected by the European Convention belong to and may be relevant for disabled people. This guide will concentrate on the four human rights that are often the most relevant:

- the right not to be tortured or treated in an inhuman or degrading way;
- the right to respect for private and family life, home and correspondence;
- the right to life; and
- the right not to be discriminated against in relation to any of the rights in the European Convention.

These four rights raise a range of issues that can be relevant for learning disabled, which are discussed below. However, the relevance of human rights for them is not limited to these issues. The Human Rights Act is still a relatively new law and has great potential to empower disabled people in many areas of life.

- Your right not to be treated in an inhuman or degrading way

Article 3 of the European Convention on Human Rights says that no one shall be tortured or treated in an inhuman or degrading way. This right is an absolute right. This means that you should not be tortured or treated in an inhuman or degrading way in any circumstances, as this right may never be breached, restricted or limited. Article 3 is not just about torture. The ban on inhuman or degrading treatment can be very relevant for disabled people.

- inhuman treatment means treatment causing severe mental or physical harm
- degrading treatment means treatment that is grossly humiliating and undignified

Situations in which disabled people may experience inhuman or degrading treatment are considered below. However, only the most serious kinds of ill treatment are covered by this right. Whether the treatment is serious enough to be inhuman or degrading will always depend on the particular circumstances of your case, taking into account factors such as your age, whether you are male or female, your state of health, and the length of time you were subjected to the treatment.

To illustrate this, compare the difference between a frail, older person being refused anything to eat or drink for 24 hours with a young healthy person being refused anything to eat or drink for 24 hours. Neither situation is acceptable, but the frail, older person is likely to be more severely affected.

The treatment does not need to be deliberate – it is the impact it has on you that matters. For example, if staff in a care home unintentionally leave residents in soiled bed sheets for long periods of time because they are understaffed, this may still amount to inhuman or degrading treatment.

At the core of this right is human dignity.

For disabled people, this right may be relevant in a number of situations:

Abuse or neglect

Abuse or neglect in residential or nursing homes, hospitals or during home care may in some circumstances breach the right not to be treated in an inhuman or degrading way. Unacceptable practices such as leaving you for long periods in your own bodily waste, washing you in a way that leaves you inappropriately exposed in front of other people, or leaving trays of food without helping you to eat if you are unable to feed yourself may be serious enough to be inhuman or degrading treatment. On each occasion this will depend on the particular circumstances of your case, including how 14 Section 2

4.4 Understand current and proposed government policy initiatives affecting individuals with learning disabilities, their families and the way services are offered

- There have been some key improvements in both the socio-economic experiences of disabled people in the last 20 years, and in related government policies. Nevertheless, few disabled people are optimistic about what the future holds.
- Some aspects of the arguments made by disability organisations have been capitalised on by the politics and ideology driving recent and current policies in ways which disadvantage disabled people. In particular this has happened with the social model of disability and concepts of ‘independent living’, ‘user involvement’ and ‘co-production’.
- In engaging with dominant policy agendas, we may risk losing touch with more fundamental issues concerning the welfare state. This may unintentionally contribute to the undermining of collective responsibility and redistribution.
- In campaigning for policies to tackle disabling barriers and enable equal access, we need to explicitly and vigorously promote the welfare state and the concept

of social security in its broadest sense. People of all ages who experience impairment and/or illness are at a disadvantage in a society and an economy where the market is the sole arbiter of opportunities and life chances.

- In order to experience equal access to full citizenship, disabled people require some kind of collective and redistributive mechanism. Such redistribution needs to be in the context of a value system which values diversity and in which disabled people are treated as belonging and contributing to the communities in which they live.
- There is little room for making progress within the ideological framework driving current disability policies. We need to develop more radical challenges to the current disability policy agenda and engage in wider debates, particularly those which question the continuing pursuit of economic growth regardless of the damage done to the environment, to values and to humanity.

For many, those who have a learning or other disability, future planning is an issue. The population of older parents who have children with a learning disability is growing and many of their children are likely to outlive them. In many cases the caring role can span up to seven decades, ending only with their death. Governments and other service providers cannot ignore the pressing needs of this population and their parent and sibling carers. In most countries, family carers provide inexpensive care for a person with a learning disability and other disabilities. This trend is set to continue in England. Demographic changes and the health needs of these two growing populations must be considered against government policy constraints and limited in-home and external care options in order to avoid a crisis. The consequences of not supporting these family carers will lead to crisis management, increase in distress and care giving burdens, and increased spending on unsuitable crisis placements. Housing and financial guidance are issues for carers

Future Plan

A future plan is a structured plan for a carer's relative who has a learning disability covering all aspects of well-being of that person. Clarifying and sharing the future plan for the relative is very important. A clear written statement of the carer's future plan enables key people to understand the relative's perspective. It allows others to understand what is involved and provides new opportunities for the family to contribute to the plan. Plans are often not put in place as a result of denial by parents or carers of their own mortality and of the fact that they won't be able to help. Carers have referred to a lack of support and guidance and are reluctant to ask for help.

Housing

It is uncomfortable for family carers to explore out-of-home placements (housing) and support (or personal care) options for their relative with learning disabilities. Research has shown that older parents or sibling carers want their relative to stay within their own home either with family or professional support, or move into a home of a sibling. Residential care is a lesser preferred option. Housing and support in Northern Ireland can be either provided separately by different organisations or offered together by the same organisation. Such services were provided by Health & Social Care Trusts, although recently there are a number of alternative providers. These

offer people with learning disabilities different living and support arrangements. The majority of people with learning disabilities in Northern Ireland and the United Kingdom live with their family. Family carers have limited knowledge about the different housing options that are available. Potential housing options in Northern Ireland include supported living, residential care, nursing home accommodation, adult placements and intentional community.

Funding

There are different methods to fund housing and support options (in Northern Ireland). Direct payments from social services are payments made to the family carer or the person with the learning disability to buy care services. Direct payments give the family carer money instead of social care services. Carers have a greater choice and control over the life of a person with a learning disability, and are able to make decisions about how care is delivered. Disability Living Allowance (DLA) is paid at different rates depending on how a disability affects someone. Disability Living Allowance is in two parts: the care component and the mobility component. Attendance Allowance is, in 2013, paid weekly at two different rates. It depends on the level of help required. Extra Pension Credit or Housing Benefit is also available. Incapacity Benefit, which has been replaced by Employment and Support Allowance, is money for people who cannot work because they are sick or disabled. Independent Living Fund (ILF) provides money to help disabled people live an independent life in the community rather than in residential care

4.5 Know how to explain to individuals you support, their families and carers the impact and relevance of current law and policy

Access to legal advice and representation is an important aspect of citizenship and of the rights to justice enshrined in the Human Rights Act and various international conventions. People with learning disabilities may use legal services for the same reasons as any other citizen, but may also require legal advice to deal with issues that are more likely to affect them than other sections of society, for example getting the right level of community care support, challenging an assessment of their health, social or educational needs, or establishing their capacity to make a decision for themselves.

People with learning disabilities are also more likely than the general population to be victims of crime and suffer harassment or bullying because of their disability and therefore come into contact with the police, courts and lawyers. There is evidence to suggest that people with mild learning disabilities are more likely to be in contact with the criminal justice system as offenders. While progress has been made in improving legal support for the victims, witnesses and perpetrators of crime who have a learning disability through the involvement of 'appropriate adults' and application of special measures in court, legal professionals have registered concern about the limitations of these measures. Adults with learning disabilities who lack capacity to make some or most decisions for themselves are protected by the Mental Capacity Act. Legal assistance may be required by them, or on their behalf, to challenge an assessment of capacity or best interest's decision, to seek authorisation for a deprivation of liberty safeguard, or to apply to the Court of Protection for substitute decision-making powers.

Survey evidence suggests that people with a long-term illness or disability are more likely to need help dealing with legal issues compared to the general population and are less likely to know their rights. Family carers have a vital role to play in this respect by ensuring that people with learning disabilities know when to seek legal advice and how best to access legal services. Family carers often support a person with learning disabilities when they have been the victim of a crime, while the Winterbourne View scandal has also drawn attention to the consequences of excluding families from safeguarding the interests of vulnerable adults. Although we have a good sense of how the legal system can impact upon the lives of people with learning disabilities and, as a matter of principle, the role that legal services should play in upholding their rights to justice, we have relatively little empirical evidence about what happens in practice when people with learning disabilities seek help with a legal issue.

5. Ways in which change has been brought about

5.1 Understand how the concept and profile of human rights has contributed to change

Human rights can contribute to change by:

- **Campaigning** – human rights add highly effective moral and legal weight when influencing policy makers.
- **Advocacy and advice-giving** – human rights provide a powerful language and additional tool in challenging poor treatment and service provision.
- **Empowering communities** – communities who understand what their rights are can use this knowledge to strengthen their voice and influence with service providers and decision makers.
- **Service provision** – human rights provide a practical planning and decision-making framework for designing and delivering better quality services.
- **Internal processes** – applying human rights internally can help bring a fresh approach to the challenges of involving activists or service users in shaping your priorities and work.

5.2 Understand how changes in the concept of learning disability have been brought about

From Workhouses to Institutions towards Residential care and more recently, Supported Living and independent living projects, the concept of personalisation has now come to the fore and is now the lead for of person centred care and support.

PERSON CENTRED PLANNING: KEY FEATURES AND APPROACHES

What is Person Centred Planning?

We all think about, and plan our lives in different ways. Some people have very clear ideas about what they want and how to achieve it, others take opportunities as they arise. Some people dream and then see how they can match their dreams to reality. Sometimes it is useful to plan in a structured way, and person centred planning provides a family of approaches that can help do this.

These approaches share common values and principles, and are used to answer two fundamental questions:

- Who are you, and who are we in your life?
- What can we do together to achieve a better life for you now, and in the future?

Person centred planning is a process of continual listening, and learning; focussed on what is important to someone now, and for the future; and acting upon this in alliance with their family and friends. It is not simply a collection of new techniques for planning to replace Individual Programme Planning. It is based on a completely different way of seeing and working with people with disabilities, which is fundamentally about sharing power and community inclusion.

Key features of person centred planning

There are five key features of person centred planning. For many self-advocates, families and friends leading person centred planning, they will happen naturally. For example, if someone is organising their own planning, it will be difficult for them not to be at the centre, which is the first key feature of person centred planning!

However, many people are dependent upon service systems and we need to struggle with the problems and dilemmas of sharing power in person centred planning. The following assumes that a member of staff is supporting someone to plan their life, and illustrates how for many of us person centred planning reflects a different way of thinking about people with disabilities, rather than a new technique.

1) The person is at the centre

'Person centred planning begins when people decide to listen carefully and in ways that can strengthen the voice of people who have been or are at risk of being silenced.' John O'Brien

Person centred planning is rooted in the principles of shared power and self-determination. Power is an issue because many people are limited in their power in comparison to others. Others control their lives. They direct how people spend their time, what they eat, how they behave, even what they say. In this context, planning can become just a further indignity. Person centred planning can be used to redress this balance as far as possible. People using person centred planning make a conscious commitment to

sharing power. Built into the process of person centred planning are a number of specific features designed to shift the locus of power and control towards the person. Where person centred planning is used within services, the following issues should be thoughtfully considered as ways of keeping the person at the centre, whilst remembering that having meetings, involving the person and making the plan is not the outcome. The outcome is to help the person to get a better life on her own terms.

The person is consulted throughout the planning process

If the person has been involved in planning before then it makes sense to talk to her about how s/he wants to plan, if s/he wants a meeting, and if so, what kind of meeting, and how she wants to be involved. If the person is new to planning, it is important to spend time with her explaining the purpose of planning and looking at different options.

The person chooses who to involve in the process

Unlike traditional models of planning, it is for the person to decide who she wants to include in the planning process, and how. This is easy to say, but within services this is highly counter-cultural to the way meetings are typically organised. If the people around the person cannot find a way to help her make and communicate that decision for herself, then they have to decide in good faith who they think the person would want to involve. A good starting-point is 'people who know and care about the person'. This may well yield a different list from 'people who provide a service to this person'.

The person chooses the setting and timing of meetings

If a meeting does take place it is at a time convenient to the individual and those she wishes to invite and it is in a place where she feels at home. The planning is carried out in a way that is accessible to the individual as far as possible. Graphics, tapes, video or photos are often used.

Using person centred planning involves finding creative ways to involve people whilst recognising that some people will have limited experience on which to base a choice and others will have limited ability to follow and contribute to the process.

Family members and friends are partners in planning

'Person-centred planning celebrates, relies on, and finds its sober hope in people's interdependence. At its core, it is a vehicle for people to make worthwhile, and sometimes life changing, promises to one another.' John O'Brien

Person centred planning puts people in the context of their family and their community. It is therefore not just the person themselves that we seek to share power with, but family, friends and other people from the community who the person has invited to become involved. These represent two of the most important challenges for services using person centred planning: how can we share power with the person and support them to participate as much as possible?, and how can we encourage and include family, friends and non-service people?

The plan reflects what is important to the person, their capacities, and what support they require.

Person centred planning seeks to develop a better, shared understanding of the person and her situation. A person centred plan will describe the balance between what is important to the person, their aspirations and the supports that they require.

Focus on capacities

The focus of professional effort in the lives of people has traditionally been on the person's impairment. People are channelled into different services depending on the category of their impairment, for example, learning difficulty, sensory impairment or loss of mobility. This leads to a process of assessment, which analyses and quantifies the impairment and its impact on the person's ability to undertake a range of tasks. This assessment results in a description of the person in terms of what she cannot do: her deficits. Professionals then set goals for people to try and overcome these deficits.

Identifying supports

Professionals have been training people towards `independence` for years. It is said that there are two definitions of independence. The first is the familiar rehabilitation model where people are trained to be able to meet their own basic needs with minimum assistance. The second is a `support model` which sees independence as choosing and living one's own lifestyle – regardless of the amount and type of assistance necessary. Independence would therefore not be measured by the number of tasks which people can do without assistance but the quality of life a person can have with whatever support they need.

A person centred plan clearly records what support someone requires, on her own terms.

The plan results in actions that are about life, not just services, and reflect what is possible, not just what is available.

The focus of person centred planning is getting a shared commitment to action, and that these actions have a bias towards inclusion. By articulating the tension between what is important to the person and what is happening now, person centred planning creates a sense of urgency and a commitment to work for change.

The plan results in ongoing listening, learning, and further action.

Person centred planning should not be a one off event. It assumes that people have futures; that their aspirations will change and grow with their experiences, and therefore the pattern of supports and services that are agreed now will not work forever. It is often described as a promise to people. To fulfil this promise we need to reflect on successes and failures, try new things and learn from them and negotiate and resolve conflict together. Acknowledging and resolving conflict is important if people are to really work together to make change. Person centred planning is based

on learning through shared action, about finding creative solutions rather than fitting people into boxes and about problem solving and working together over time to create change in the persons life, in the community and in organisations.

What are the different approaches to person centred planning?

There are several different approaches or styles of person centred planning. Each style is based on the same principles of person centred planning: all start with who the person is and end with specific actions to be taken. They differ in the way in which information is gathered and whether emphasis is on the detail of day to day life, or on dreaming and longer term plans for the future.

Different styles of planning

Each planning style combines a number of elements: a series of questions for getting to understand the person and her situation; a particular process for engaging people, bringing their contributions together and making decisions; and a distinctive role for the facilitator(s).

Conclusion

Person centred planning is defined as a process of continual listening, and learning; focussed on what is important to someone now, and for the future; and acting upon this in alliance with their family and friends. There are different approaches, however, good person centred planning is always recognisable because the person will be at the centre; working in partnership with family and friends, the plan will clearly identify what the person's capacities are, what is important to her and what support she requires; there will be actions that have a bias towards inclusion, and the learning and reflecting are ongoing. There are issues presented here to be debated and discussed, and ways forward to agree. It is vital that we do this, as person centred planning creates opportunities for us to change our lives and our relationships, to share power and listen in a deeper way, and discover to what inclusive communities are really about

- it is important to define personalisation in terms based on the principles of independent living
- this should include service users and carers having choice and control and the freedom to live their lives in the way they want to
- many users and carers have positive experiences of personalisation and there are examples of good practice
- however, the number of people receiving truly personalised services remains very low and cuts to services may make this situation worse
- more needs to be done to ensure that everyone involved in service provision understands personalisation
- there needs to be better coordination of resources and services
- there needs to be more co-production with service user and carer organisations
- a stronger vision based on a return to the principles of independent living is needed to ensure that personalisation delivers better outcomes for service users and carers at the same time as ensuring resources are used as effectively as possible

5.3 Understand how those changes have affected the way individuals with learning disabilities are perceived and the services provided

Personalisation

The personalisation agenda is leading some of the changes happening in social care today. It has come about as a direct result of the modernisation of social care services that has been happening over the past several years.

Find out more about personalisation and the development of individual budgets below.

Personalisation for community learning disability staff means:

- all staff work to develop a partnership between themselves and those who want a personal budget
- staff perform an enabling role which gives people with learning disabilities choice and control
- work to support users to undertake a self-assessment, make best use of the Resource Allocation System to secure funding and help people to develop a support plan
- ensuring people have the right information about what they can purchase
- collating unmet needs and giving this information to commissioners to help them develop greater choice in the market
- the task includes the development of community and natural supports to promote people's independence, autonomy and active citizenship
- all staff should have good training, support and development opportunities to enable

What are the implications for community learning disability staff?

Personal budgets and self-directed support

There is emerging evidence, for instance from the IBSEN evaluation of the individual budget pilots, that people with learning disabilities have a lot to gain from increased choice and control over their support arrangements. Support available to date has often been inadequate, unsuitable or unacceptable. The benefits of choice will be most effectively realised through greater integration of health and social care resource. However, perceptions about risk have sometimes compromised access to, and uptake of, options like direct payments

The Department of Health is starting personal health budgets. These will build on the experience of personal budgets in social care, and test ways of giving people greater control over the health services they use.

A direct payment is only one way to receive a personal budget. The following points are crucial for understanding how personal budgets work:

- personal budgets should be focused primarily on funding ongoing support and care needs, and normally only considered after looking at relevant preventative and enabling options

- personal budgets can be offered as a direct payment, or as an 'account' managed by the council or a third party
- personal budgets should be implemented within the framework of self-directed support – this involves self-directed assessment, 'upfront' allocation and support planning, to ensure maximum choice and control.

Community learning disability staff have a vital role to play in the successful implementation of personalisation. Care managers and social workers who work within these services provide a statutory role in allocating a personal budget. They will need to have the skills to work in a person-centred way and be aware of the difference between the old and new ways of working. Community learning disability staff will be key in achieving targets set by the Department of Health which aim to have 30 per cent of people on personal budgets by 2011. Workers will need to ensure that support, proper learning and reflection on how to improve the process is on offer. Their role in making best use of finite public sector resources while getting the best for the disabled individual can be difficult and needs to be clearly agreed with their line managers and their adult social care department. Workers will need support, particularly when there is risk involved or criticism from users/families about decisions that have been taken. Staff's role in personalisation involves both statutory duties and the core tasks of developing partnerships with people with learning disabilities, sustaining long term relationships with people who may be in the social care system for all of their lives and undertaking shared decision making with each person.

Successful personalisation will depend on community-based staff having:

- an increased focus on outcomes
- doing less crisis work and more long term planning e.g. helping learning disabled adults to move to their own home before parents can no longer offer support
- a balanced view between risk taking (which promotes development) and safeguarding the person
- a commitment to helping people overcome a sense of powerlessness
- the ability to challenge risk averse cultures
- an awareness that their own continuous learning and support are essential to getting good outcomes for all.

The success of personalisation and mechanisms like personal budgets will depend on a significant culture shift in local authorities. Changes in culture and practice can only happen if staff at the front line have the confidence and take responsibility to challenge and change traditional methods of working. Staff will need to demonstrate new ways to take and manage risk, let go of some power, focus on prevention and find community-based solutions. In parallel, senior managers, policy makers and local politicians will need to support these changes and learn lessons from the new processes that are in place. Lessons learned from crisis situations should be used as a means of improving the process rather than creating restrictions or curtailing the autonomy of frontline staff.

Workers in the service will have an important role in making the process non-bureaucratic and accessible to people with learning disabilities, as well as contributing to methods of reviewing the process and monitoring satisfaction levels of those holding personal budgets.

Where personalisation works well, the host organisation has a strong culture of seeing people with learning disabilities and their families as leaders and experts through experience; employ them as trainers and service providers and uses their skills to influence elected members and partnership boards.

Staff working to help implement personalisation have a real opportunity to influence change, improve the quality of life for people with learning disabilities and help people through creative means to make best use of the important changes now being offered

5.4 Understand the roles of outside agencies and individuals in changing attitudes, policy and practice

VALUING PEOPLE

Valuing People and *Valuing People Now* whilst highly significant, they are not Acts, but White Papers. The role and status of White Papers is the matter of some debate, but a broad definition might be 'a means of presenting government *policy preferences* or inviting consultation, often prior to the introduction of legislation'.

A New Strategy for Learning Disability for the 21st Century

"Good services for people with multiple and complex needs will by definition be highly personalised and thus central to implementing personalisation policy."

What is good practice?

Good practice includes:

- People working together
- People with learning disabilities should help plan their own services and in some cases, make them happen
- Looking at people's strengths and skills
- Helping people to live in the community
- Services working together (social care, health, housing and leisure)
- Planning services around people's skills and interests

Good practice is about what people with a learning disability and their families think, not what the Department of Service Providers say.

The strategy has been strengthened to ensure that it is inclusive of those groups who are least often heard and most often excluded. This reflects concerns expressed by respondents to the consultation on Valuing People Now that service providers, Commissioners and policy makers were not specifically addressing the needs of these groups, including:

- people with more complex needs;
- people from black and minority ethnic groups and newly arrived communities;

- people with autistic spectrum conditions; and
- offenders in custody and in the community.

The Department of health will take forward programmes of work around ethnicity and complex needs and with families. These will be underpinned by regional and local action to support partnership working, particularly through Learning Disability Partnership boards. We have worked closely with family carer groups to ensure that this strategy reflects the concerns they raised during the consultation – that they be seen as expert partners in the care of their loved ones and that the particular needs of people with more complex conditions are met.

Personalisation

Person centred planning, advocacy and direct payments to give people more choice and control in their lives were at the heart of the original Valuing People. In December 2007, the cross-sector concordat Putting People First set out a vision for transforming social care. At its heart is the commitment to giving people more independence, choice and control through high-quality and personalised services. Putting People First is about empowering people to shape their own lives and the support they receive by allowing them to use resources more flexibly to suit their needs and lifestyle.

Delivery of this vision will depend upon central and local government working together with partners across the sector. Putting People First recognises that services across transport, leisure, education, health, housing, community safety and the criminal justice system and access to information and advice are vital to ensuring people’s independence and overall quality of life.

For people with learning disabilities and their families, transformation should mean using person centred approaches (such as person centred planning and support planning) and improved outcomes in terms of social inclusion, empowerment and equality. More people with learning disabilities should be able to commission their own services to live independently and have real choice about the way they live their lives. The Government will take action to ensure that this transformation programme includes the needs of people with learning disabilities and their carers.

6. Changes in healthcare for individuals learning disabilities over time

6.1 Understand how the healthcare available to individuals with learning disabilities has changed over time

Legislation & Policies – History of legislation on disability

Developments in Learning Disability Law: To understand developments in Learning Disability Law it is first necessary to understand that the law derives from two main sources, which are:

- ***Acts of Parliament and Statutory Instruments*** enacted under powers given by the Acts. These are known as statutory sources and include European Community Legislation, which automatically becomes part of UK Law statutory sources take precedence over other laws.

- **Common Law – often known as case law.** This includes decisions by judges in individual cases, which are often, but not always, interpretations of statutory sources. Common Law can include decisions by Tribunals. A pre-requisite of Common Law is a reliable system of reporting decisions. There is a system of precedence in Common Law, based on a hierarchy of Courts, with the Supreme Court as the ultimate UK Court. The Supreme Court is bound by relevant decisions of the European Court of Justice.

Learning Disability Law does draw a distinction between learning disability and mental illness, but there is considerable overlap, which this chronological account will attempt to explain.

1713–44: Common Law drew distinction between learning disability and mental illness before the first statutory sources, which began with the Vagrancy Acts between 1713 and 1744. The Vagrancy Acts allowed detention of “*Lunaticks or mad persons*”, which was the 18th century definition of mental illness.

1774–1845: Further legislation followed in 1774 with an Act to regulate private madhouses and the 1845 Lunatics Act included “*Person of unsound mind*”.

1886: The 1886 Idiots Act provided separately for idiots and imbeciles, which was the Victorian definition of learning disability, but the 1890 Lunacy (Consolidation) Act ignored the distinction.

1913: In 1913 the Mental Deficiency Act provided for the segregation of “*mental defectives*” in an ascending order of vulnerability;

1927: The 1927 the Mental Deficiency Act emphasised the need for care outside institutions. It also provided a definition of mental deficiency as “*a condition of arrested or incomplete development of mind existing before the age of 18 years whether arising from inherent causes or induced by disease or injury*”. This definition is very close to the definition of learning disability in Section 1 (4) of the Mental Health Act 1983, as amended by the Mental Health Act 2007. The Section states that learning disability means “*a state of arrested or incomplete development of the mind which includes significant impairment of intelligence and social functioning*”.

1930: In 1930 the Mental Treatment Act allowed for voluntary admissions, which was the first time that Parliament considered that anyone might of their own free will, require admission to a psychiatric hospital.

1946: The formation of the National Health Service by the 1946 NHS Act ended the distinction between paying and non-paying patients.

1948: In 1948 the National Assistance Act made provisions in the community, or residential settings for those in need, which came to include people with a mental disorder.

1959: The 1959 Mental Health Act defined mental disorder, which is mental illness as distinct from learning disability. The definition was “*mental illness; arrest or incomplete development of mind; psychopathic disorder; and any other disorder or disability of mind*”. There were further

classifications for long term compulsion which were “*mental illness; severe subnormality; subnormality; psychopathic disorder*” but there were treatability tests for the last two categories. 1970:

1970: *The Chronically Sick & Disabled Persons Act 1970* introduced by North West MP Alf Morris was the first in the world to recognise and give rights to people with disabilities. Alf Morris, later Lord Morris of Manchester, went on to become the first Minister for the Disabled

1983: *The Mental Health Act* retained the broad definition of mental disorder referred to in the 1959 Act but the classifications changed to “*mental illness (undefined); severe mental impairment; mental impairment or psychopathic disorder*”. It has been amended by the 2007 Mental Health Act where there will be a further description.

1986: *The Disabled Persons Act 1986*: required social services to provide a written assessment of disabled people and to look at the abilities of informal carers when deciding on the level of care needed.

1990: *NHS and Community Care Act 1990*. The Act was brought in to promote community care. Local social service departments have an overall responsibility for community care and have to publish a regular plan about how this care will be delivered. The responsibility places a duty on authorities to assess people for social care and provide the support they require. The act established the familiar procedures of ‘care management’ (social services) or ‘care programme approach’ (NHS) which the statutory departments now operate to. A mixed economy of care was promoted with the independent, private and voluntary sectors being encouraged to provide resources.

1995: *The Disability Discrimination Act 1995* gives rights to disabled people to prevent discrimination on the grounds of disability. It is unlawful to discriminate in relation to employment, the provision of goods and services, the management, buying or renting of land or property, education and transport. The act was introduced over a period of time. In 2000 the Disability Rights Commission was established with the task of upholding the rights enshrined in the 1995 act.

1995: *Carers (Recognition and Services) Act 1995*: Carers’ needs are recognised in this legislation. It gives the right to have their needs taken into consideration when services are being assessed under the NHS and Community Care Act for an individual they care for.

1996: *Community Care (Direct Payments) Act 1996*: This gives authority for local social service departments, after assessing a person’s need, to make grants instead of giving a service. This then enables an individual to purchase and administer their own care services.

1998: *The Human Rights Act 1998*: This legislation adopted the European Convention on Human Rights into British law when it came into force in October 2000. There are 18 articles or protocols which explain fundamental human rights. It makes it unlawful for a public authority to

breach the rights set out in the convention. The act is not designed to bring actions against individuals.

2000: *Care Standards Act 2000*: The National Care Standards Commission arose from this act and they took over the responsibility for the registration and inspection of services from local authority departments. Services were inspected against a national standard with sanctions being imposed on those providers who did not meet the necessary criteria. The National Care Standards Commission was replaced in April 2004 by the Commission for Social Care Inspection and the Commission for Healthcare Audit and Inspection.

2000: *Carers and Disabled Children Act 2000*: Young disabled people aged 16 and 17 became eligible to receive direct payments to purchase their own care support. Carers are also given the right to be assessed and for this to be taken into consideration when supplying services to a disabled person. Their ability to continue caring long-term together with their own health or disability needs is identified. In addition the local authority can now directly support the carer by offering them services to facilitate their caring role (this was not available under Carers (Recognition and Services) Act 1995).

2005: *The Mental Capacity Act 2005*: this important legislation is discussed separately here.

2007: *Mental Health Act* amended and reformed the Mental Health Act 1983. It defines mental disorder as “*any disorder or disability of the mind*”. The definition is wide enough to include not only mental illness, but also learning disability and personality disorders. The definition of learning disability in Section 1(4) is “*a state of arrested or incomplete development of the mind which includes significant impairment of intelligence and social functioning*”. Because this definition would place learning disability within the definition of mental disorder, Section 1(2A) provides that learning disability will not constitute mental disorder unless it is “*associated with abnormally aggressive or seriously irresponsible conduct*” on the part of the patient. This proviso is important because neither Sections 3 nor 7 of the Act will apply to a learning disabled person unless the Section 1 (2A) qualification is met. Section 3 allows admission of a patient to hospital and detention there in pursuance of an application. The application must include a written recommendation by two registered medical practitioners. Section 7 allows receipt of a patient of 16 or over into guardianship in pursuance of an application. As with Section 3 the application must include a written recommendation by two registered medical practitioners. The Section 1 (2A) requirement does mean that guardianship will not always be available for a patient with learning disability. Accordingly, the provisions of the Mental Capacity Act 2005 may be more appropriate for patients with learning disability.

2008: United Nations introduced the ***UN Convention on the Rights of Persons with Disabilities***, which obliged members to promote equal rights and root out discrimination.

2012: On 27 March, 2012 the Coalition government’s Health and Social Care Bill gained Royal Assent to become the ***Health and Social Care Act (2012)***.

6.2 Understand how these changes have affected the life expectancy and opportunities of individuals with learning disabilities

The life expectancy of people with learning disabilities has increased over the course of the last 70 years. This is despite the fact that people with learning disabilities are 58 times more likely to die before the age of 50 than the rest of the population (Emerson and Baines 2010).

People with learning disabilities face many disadvantages in relation to health (Emerson and Baines 2010, Department of Health 2001). However, better social conditions and access to medicines like antibiotics have meant that more people are surviving beyond childhood and adulthood into older age. For example, people with Down's syndrome have seen a dramatic rise in their life expectancy from seven years in the 1930's to their late 50's today (Holland et al 1998).

The number of people with learning disabilities aged over 60, in England, is predicted to increase by over a third between 2001 and 2021 (Emerson and Hatton 2008). Recent evidence suggests that older people are one of the fastest growing groups of the learning disabled population (Emerson and Hatton 2011). The most recent predictions suggest that by 2030 the number of adults aged over 70 using services for people with learning disabilities will more than double.

However, this is likely to be an underestimate of the actual numbers of older people with learning disabilities both now and in the future as many people with learning disabilities are either not known to services or indeed do not use learning disability services in adult life.

6.3 Understand the health planning approach to securing high quality healthcare for the individuals you support

People with learning disabilities often have poorer physical and mental health than other people. This doesn't need to be the case.

The Annual Health Check scheme is for adults with learning disabilities who need more health support and who may otherwise have health conditions that go undetected.

Who will get an Annual Health Check?

People aged 18 and over who have been assessed as having moderate, severe or profound learning disabilities, or people with a mild learning disability who have other complex health needs, are entitled to a free annual health check.

What are the benefits of an Annual Health Check?

People with learning disabilities often have difficulty in recognising illness, communicating their needs and using health services. Research shows that regular health checks for people with learning disabilities often uncover treatable health conditions. Most of these are simple to treat and make the person feel better, while sometimes serious illnesses such as cancer are found at an early stage when they can be treated.

The Annual Health Check is also a chance for the person to get used to going to their GP practice, which reduces their fear of going at other times.

How long does an Annual Health Check take?

The health check can take up to one hour, although it can be much quicker depending on:

- how often the person normally visits their doctor
- their overall health and wellbeing
- their lifestyle (for example, whether they drink alcohol or smoke)
- how much of the consultation they decide to consent to

How do you get an Annual Health Check?

Adults with learning disabilities who are known to their local authority social services, and who are registered with a GP who knows their medical history, should be invited by their GP practice to come for an Annual Health Check.

What happens at an Annual Health Check?

The Annual Health Check lets the person with learning disabilities go to their GP practice and have aspects of their health checked, it also allows them to talk about anything that is worrying them.

During the health check, the GP or practice nurse will carry out the following for the patient:

- a general physical examination, including checking their weight, heart rate, blood pressure and taking blood and urine samples
- assessing the patient's behaviour, including asking questions about their lifestyle, and mental health
- a check for epilepsy
- a check on any prescribed medicines the patient is currently taking
- a check on whether any chronic illnesses, such as asthma or diabetes, are being well managed
- a review of any arrangements with other health professionals, such as physiotherapists or speech therapists

If the person's learning disability has a specific cause, the GP or practice nurse will often do extra tests for particular health risks. For example, for people with Down syndrome they may do a test to see whether their thyroid is working properly.

The Annual Health Check may also be a good opportunity to review any transitional arrangements that took place when the patient turned 18.

The GP or practice nurse will also provide the patient with any relevant health information, such as advice on healthy eating, exercise, contraception or stop-smoking support.

How will the Annual Health Check be tailored to the patient's needs?

People with learning disabilities have lots of different needs. Sometimes these are written down in a health profile or health action plan that the GP or nurse can refer to. Putting "reasonable adjustments" in place can help people to have a successful health check. Reasonable adjustments mean changing services so they are easier to use.

These adjustments can include:

- using pictures, large print, and straightforward language to help explain what is happening
- booking longer appointments

- scheduling an appointment that starts at the beginning or end of the day so people don't have to wait

Is it compulsory to have an Annual Health Check?

No. All parts of the health check are voluntary. Anyone who is having the health check, or their carer, can ask the GP or practice nurse for more information about the process. The patient can then give their consent before any tests or procedures are carried out.

Is it the same as the NHS Health Check scheme?

No. The NHS Health Check programme is for all adults aged 40–74. It assesses their risk of heart disease, stroke, kidney disease, diabetes and dementia every five years. For more information, visit the NHS Health Check mini-site.

How many people have Annual Health Checks?

In 2011–2012, more than 86,000 people with learning disabilities had an Annual Health Check.