

Position statement and action plan for learning disability

About the Care Quality Commission

The Care Quality Commission is the independent regulator of health and adult social care services in England. We also protect the interests of people whose rights have been restricted under the Mental Health Act.

Whether services are provided by the NHS, local authorities or by private or voluntary organisations, we make sure that people get better care. We do this by:

- Driving improvement across health and adult social care.
- Putting people first and championing their rights.
- Acting swiftly to remedy bad practice.
- Gathering and using knowledge and expertise, and working with others.

Contents

Background	4
How we developed this plan	4
What have people told us?	5
What does the Care Quality Commission need to do?	7
What we will do	7
Appendix 1 – Background and briefing paper	12
What is a learning disability?	12
How many people are there with a learning disability?	12
The service landscape	14
Prison population	17
Quality of life for people and families with learning disabilities	17
The extent of regulated services	18
Funding streams	18
What do we know about the quality of services for people with learning disabilities?	20
Appendix 2 – Numbers of people within tiers of service and quality of those services	24

Background

As the independent regulator of health and adult social care, the Care Quality Commission has a unique ability to influence the quality of care in England.

We are responsible for driving improvement and taking action if providers of care do not meet essential standards of quality and safety. We will also ensure people have the power to make informed choices about the care services they receive and access to services that offer a seamless experience of care.

We want to focus our activities to ensure they make a real difference to people. We are therefore consulting people on our five-year strategic plan, which sets out how we intend to approach our work.

We have identified **five** priorities where we believe our unique role as regulator will enable us to significantly enhance the quality of outcomes for people who use services:

- 1 Ensuring care is centred on people's needs and protects their rights.**
- 2 Championing joined-up care so that health and social care are more coordinated.**
- 3 Acting swiftly to help eliminate poor quality care.**
- 4 Ensuring and promoting high quality care.**
- 5 Regulating effectively in partnership.**

Our work to achieve improvement in these priority areas will always be underpinned by the principles of equalities and human rights. This will include a strong focus on differences in access to services, the safety and effectiveness of care, and people's rights to be treated with dignity and respect. We will pay particular attention to the needs of people in more vulnerable circumstances, including those with mental health problems, learning disabilities, physical disabilities or long-term conditions; older people; and children and young people.

This document sets out our early thoughts about our approach to ensuring not only that services for people with learning disabilities reach basic standards of quality and safety, but also improve. It provides some priority actions for CQC to take to ensure that, working with others, we can make a difference to services for people with learning disabilities. Appendix 1 gives supporting information about services for people with learning disabilities and about people's experiences of using them.

How we developed this plan

As well as reviewing information about the performance of services and recent reports about learning disability care, we have also worked with people with learning disabilities, family carers, and professionals from within and outside our organisation to help develop our thinking. We have tried to focus on what matters to the people who use the

services we regulate and to give a clear direction to our learning disability work as we go forward.

What have people told us?

We sought views from people at:

- A specific event we held for people with learning disabilities and their supporters.
- Existing consultation meetings held by, for example, the National Valuing People meeting and the joint meeting between Valuing People, National Forum, National Family Carer Network and National Advisory Group on Learning Disabilities and Ethnicity.
- A specific event held by the NHS Confederation for us to gain the views of senior staff.
- The first CQC advisory board meeting.

We also posted information about our role and a set of questions onto social care and health e-networks.

People's concerns varied (see table 1). However, most were about improving the quality of services and ensuring that we focus on people with learning disabilities and work with them and their family carers as much as possible.

Table 1: Concerns raised through consultation

<p>Safe care</p>	<ul style="list-style-type: none"> • Capacity, consent and deprivation of liberty issues. • Safety in general hospitals. • Restraint. • Values of some professionals. <p>“Staff who provide services to people with challenging behaviour need training in understanding and responding positively (preventatively) to the challenging behaviour.”</p>
<p>Improving outcomes</p>	<ul style="list-style-type: none"> • Treatment of people whose behaviour challenges. • Commissioning of services. • Transition. • Accessibility of mainstream services – especially people with more complex needs or people from black and ethnic minority groups. <p>“Health inequalities per se from GP appointments to hospital inpatient treatment. <i>Death by Indifference</i> was not an isolated situation. Ensure recommendations from <i>Healthcare for All, Six lives: the provision of public services to people with learning disabilities</i> are being shown up and down the country”</p>
<p>Value for money</p>	<ul style="list-style-type: none"> • Lack of monitoring of the recent recommendations from reports. • Commissioning practice. • Growth of large services in the private sector. <p>“World Class Commissioning, among other documents, highlights the importance of evidence in the commissioning cycle of high quality services. It would be good to see that the CQC has a role in ensuring that learning disability services are being commissioned in response to real evidence of local needs, whether this evidence be quantitative or qualitative in origin.”</p>
<p>Personalisation</p>	<ul style="list-style-type: none"> • Lack of person-centred care plans. • Lack of positive values, dignity and respect. • Lack of involvement of people in delivery, training and development of services. • Lack of person-centred care. <p>“How does CQC ensure that provider organisations are providing quality person-centred support, inspections don’t seem to pick this up!”</p>

What does the Care Quality Commission need to do?

Our five strategic priorities will guide our work over the next five years. The work we have done with people with learning disabilities and their families has helped us to think about what these priorities might look like for learning disability services.

We will use our regulatory powers to take these priorities forward and carry out a number of activities. Our core statutory functions include:

- The registration of health and social care providers to a common set of quality and safety standards, and checking ongoing compliance with these registration requirements.
- Powers of escalation and enforcement where services fall below essential quality standards.
- Visiting patients whose rights are restricted under mental health legislation to ensure their rights are protected.
- Carrying out periodic reviews of the performance of providers and commissioners.
- Undertaking special reviews and studies of particular aspects of care.
- Publishing information to drive choice, change and improvement.

For the first time, we will be able to use a single set of requirements when regulating the quality and safety of health and social care providers. We have ensured that our system for registration is focused on outcomes for people using services, promotes their rights and ensures that care is delivered in a way that is centred on people's needs.

We will also ensure that listening to the voices and experiences of people who use services is embedded across all of our activities.

We set out below how we will use our powers to promote change and improvement in services for people with learning disabilities, and how these relate to our strategic priorities. In doing so, we need to be realistic about what we have the capacity to deliver as we embed our new ways of working, and we also need to ensure that the actions we identify are capable of delivering the improvements we seek. There have been many reports recommending action to improve learning disability services (see appendix 1), so we need to focus on how we can use our core functions to drive improvement.

What we will do

On the basis of this consultation (see table 1) and previous reports, we have identified three key areas for improvement where CQC would like to make a difference over the next five years. These are:

- Ensuring that the care of people with learning disabilities becomes more person-centred, including a greater focus on person-centred care plans.
- Ensuring that people with learning disabilities receive care that is safe.
- Improving the commissioning of services for people with learning disabilities.

We have also identified two key activities that will enable us and our partners to make changes in this area. They are:

- Improving the information we have, and making sure it is more widely available in the system.
- Building our capability as an organisation to understand the learning disability field, and our capacity to engage with people who use services and their families.

Tables 2 and 3 set out how we will use our system of registration and reviews to deal with issues and concerns raised with us and what extra actions we might take to increase the impact of this work. We have also suggested some measures to help evaluate the progress of this work. We have established an internal steering group that will develop the action plan further and agree a framework for monitoring delivery. We will review our progress and present a report to our Board in 12 months' time.

Table 2: Actions to take forward enabling activities

Enabling activities	Specific actions	Measures
<p>Improving the information we have and making sure it is more widely available in the system</p>	<p>Work with the Department of Health/Information Centre to enhance the information available to CQC and others.</p> <p>Making sure our work on user voice is effective across all sectors.</p>	<p>National Minimum data set for learning disabilities established</p> <p>Relevant support to the public health observatory and the confidential inquiry</p> <p>Scored performance indicators updated for 2009/10 performance assessment</p> <p>Face-to-face interviews for patient surveys for people with learning disabilities developed and piloted</p> <p>Relevant information from Mental Health Act commissioners' visits is made available</p>
<p>Building our capability as an organisation to understand the learning disability field and our capacity to engage with people who use services and their families</p>	<p>Develop training and policy briefing for staff to promote better awareness about the needs of people with learning disabilities.</p> <p>To retain CQC's current advisory board for learning disabilities and ensure that there are governance processes to support it.</p> <p>Employ a person with learning disabilities to work with the strategic lead to work to raise awareness and support staff.</p>	<p>Training and policy briefing delivered and evaluated</p> <p>Regular board meetings and impact reports</p> <p>Person actively engaged in CQC activities</p>

Table 3: Actions against strategic priorities

Care Quality Commission priorities	Specific actions	Measures
<p>Ensuring care is centred on people’s needs and protects their rights</p>	<p>In assessing services’ compliance for registration, for both learning disability specific services and mainstream services, these regulations will be particularly important:</p> <ul style="list-style-type: none"> • Regulation 17 – respecting and involving people who use services. • Regulation 9 – care and welfare of people who use services. • Regulation 11 – safeguarding people who use services. • Regulation 23 – supporting workers. <p>Take full account of the need to involve people with learning disabilities and family carers in our programme of experts by experience.</p> <p>Ensure the circumstances of people with learning disabilities are fully reflected in our work on the mental capacity act.</p> <p>Pilot a joint service inspection of local authorities and primary care trusts on adult safeguarding.</p> <p>Consult on special reviews concerning restraint and the health and social care needs of offenders, as part of the 2010/11 programme of special reviews and studies.</p>	<p>Levels of involvement increased</p> <p>System appropriate to learning disabilities</p> <p>Learning disability concerns reflected</p>
<p>Championing joined-up care</p>	<p>Continue work on the special review of healthcare needs of people with learning disabilities and mental health needs, ensuring that there is robust follow up to the findings of the review.</p> <p>Develop our commissioning assessment over time, with a focus on ensuring that care is centred on people’s needs and delivering care close to home for people with learning disabilities with complex needs.</p>	<p>Review delivered with clear supporting action plan</p> <p>Assessment developed to pick up these issues</p>

<p>Acting swiftly to help eliminate poor quality care</p>	<p>Build better information into Quality and Risk Profiles, which reflect the concerns in the sector, including the use of information from third parties such as learning disability partnership boards.</p> <p>Make sure our risk processes are structured so that they can identify poor quality care in specialist services and residential care, and ensure that appropriate improvement actions are being taken.</p>	<p>Sector relevant Quality and Risk Profiles developed and delivered</p> <p>Resources identified and inspection delivered</p>
<p>Ensuring and promoting high quality care</p>	<p>Promote discussion at senior NHS level about the quality of learning disability services.</p> <p>Contribute to the development of leadership programmes aimed at encouraging non-executives to ensure the quality of care for vulnerable groups.</p> <p>Become active partners in Valuing People Now by our regional directors regularly attending regional valuing people now boards. Develop a standard format for sharing intelligence from these meetings.</p> <p>Monitor development of the Department of Health's autism strategy.</p>	<p>Meetings take place and support engaged for CQC activities</p> <p>Regular attendance at meetings</p>
<p>Regulating effectively in partnership</p>	<p>Contribute to the development of the Social Care Institute for Excellence's audit tool for care bought through individualised budgets, to be used by individuals or their circles of support.</p>	

Appendix 1 – Background and briefing paper

What is a learning disability?

The accepted definition of intellectual disability in the UK is set out in the Department of Health's original White Paper, *Valuing People*, published in 2001. *Valuing People* is based on the foundation that people with learning disabilities are people first. We focus throughout on what people can do, with support where necessary, rather than on what they cannot do.

Learning disability includes the presence of:

- A significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with:
- A reduced ability to cope independently (impaired social functioning), which;
- Started before adulthood, with a lasting effect on development.

This definition covers people with a broad range of disabilities. A low intelligence quotient, for example an IQ below 70, is not, on its own, a sufficient reason for deciding whether an individual should be provided with additional health and social care support. An assessment of social functioning and communication skills should also be taken into account when determining need. Many people with learning disabilities also have physical and/or sensory impairments. The definition covers adults with autism who also have learning disabilities, but not those with a higher level autistic spectrum disorder who may be of average, or even above average, intelligence – such as some people with Asperger's Syndrome. 'Learning disability' does not include all those who have a 'learning difficulty', which is more broadly defined in education legislation.

How many people are there with a learning disability?

Nearly one million people have a learning disability, and some 800,000 of these people are adults. This is essentially a statistical projection, based on samples of specific areas and the norms of different tests. About a quarter of the total (177,000) are known to services – these are broadly those people with more significant disabilities. The majority of people with moderate or mild disabilities do not have access to social care support or specialised healthcare support.

The reasons for the increasing numbers of people with learning disabilities are:

- Improved survival rates among young people with severe and complex disabilities.

- Reduced mortality among older people with learning disabilities.
- A rise in the number of young adults belonging to certain ethnic communities from South Asia.

Figures for incidence and prevalence of learning disability have been refined recently by comprehensive research carried out by Eric Emerson and his colleagues at the University of Lancaster. His estimates come from a systematic analysis of pupil records in the annual Schools' Census data on the prevalence of learning disabilities among the current school population aged 4-15. Per 1,000 children, the prevalence was 41.6. Table 4 shows the breakdown by level of disability.

Table 4: Incidence of categories of learning disabilities according to Pupil Level Annual School Census data

Category of learning disability	Incidence per 1,000
Profound and multiple learning disabilities (PMLD)	1.14
Severe	4.63
Moderate	35.8
Total	41.57

From this information, the number of children entering adult services each year up to 2026 has been estimated, with allowances made for mortality, to arrive at the estimated total population of adults in each category.

Emerson forecasts the average annual rate of increase over the next five years to be at least 3% and potentially 5.5 %. After that, the rate of increase declines due to lower birth rates.

Table 5: New users of services

New users with critical and substantial needs (50% of those with moderate needs also included)	Number of eligible users – middle estimate	Average increase per year – middle estimate
2008	137,000	-
Average annual growth rate 2009-13	167,679	4.1%

The numbers of people receiving formal support from health and social support services regulated by the Care Quality Commission are also likely to increase, because:

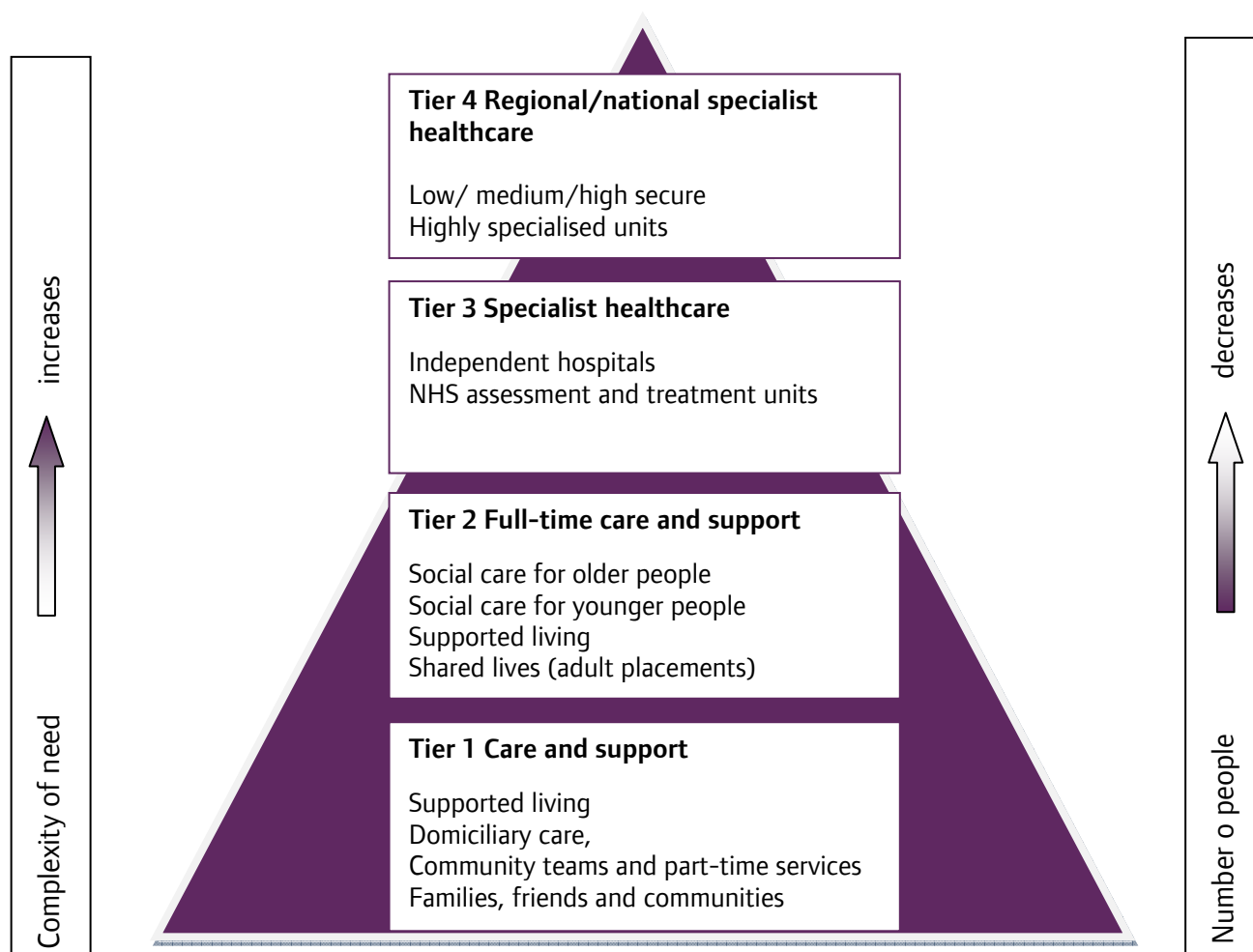
- The number of infants with profound and multiple learning disabilities surviving into adulthood is likely to increase (by 1.8% per year, according to Emerson's estimates).
- People on the autistic spectrum are proving hard for services to support effectively into adulthood, and so are developing increasingly severe challenging behaviour.
- There are 26,000 people aged 60 or over (approximately 15% of all adults with learning disabilities) known to services in England. The number of adults with learning disabilities aged over 60 is predicted to rise. Older people with learning disabilities live with their families, in residential homes or in their own homes. They need the same kind of support as younger people, but they often receive less help. People with Down's syndrome are more likely to develop early onset dementia.

The uptake of personal budgets may well change the landscape for this group of people, but it is currently unclear what the uptake will actually be. During the pilots, 25% of the uptakes were from people with learning disabilities.

The service landscape

Before moving to the specific challenges in respect of quality and the role of the CQC it is important to understand the array of support and services that are received by people with learning disabilities and their families. The estimated numbers of people and services involved will follow a brief explanation of the different tiers and how they relate to each other (see figure 1 and below).

Figure 1: Tiered model of services for people with learning disabilities



Tier 1: Families, friends and communities

As mentioned earlier, the majority of people with learning disabilities are not known to services and rely upon their families and others for support. For a number of people, family and informal systems of support are sufficient for most areas of life. Sometimes, families can access various support services, often through social services departments or through community teams (generally, professionals in joint teams, combining health service clinicians with social workers and care coordinators). Examples range from access to college or part-time support workers (or personal assistants), through to short breaks.

The majority of services this group of people will access are mainstream public services.

Tier 2: Full-time support

A smaller group of people live independently of their families and receive support for most, if not all, of the day and night. There are a number of different models for this.

- **Supported living** – individuals or occasionally small groups receive support in their own home, or as a tenant of a home

provided by a housing provider. Sometimes a number of tenants who have learning disabilities will share a group of flats or apartments. The homecare provider (as opposed to the housing provider) gives support through personal assistants. These arrangements can be used by people with the full range of disabilities and challenges and can involve very intensive support packages right down to occasional visits.

- **Social care** – in many cases, full time support is provided in traditional residential care homes. This is generally in small or medium-sized groups. There are also a number of young and middle-aged adults with learning disabilities who live in care homes for older people. The care can be totally social or have a nursing component.
- **Shared Lives** (formally known as adult placement) – here a person can live in people's own homes as part of a family unit or ordinary individuals and receive care and or support from the person approved and trained for this role.

Tier 3: Specialist healthcare

For a small number of people with learning disabilities, their additional needs and complex behaviour can mean that more specialist services are required. In some cases, this reflects the complexity of their disability; in many cases it reflects the poverty or inappropriateness of the services they have received. This is often in the context of a lifetime of neglect, broken relationships and inadequate provision. There are two main providers of these services:

- **Local NHS assessment and treatment services** – intended to be relatively short-term placements with access to clinical support and nursing care.
- **Independent hospitals** – also seeking to provide specialist assessment and intervention with the support of nursing and other health professionals. Placements are often longer in the independent sector and some are not in the local area for the person and their family. All people are detained under the Mental Health Act.

Tier 4: Regional and secure services

There are an increasing number of secure settings for people with learning disabilities. There are also a number of people with learning disabilities who access generic tier 4 services. There is likely to be important liaison and professional relationships between Tier 3 services and the very specialist services at Tier 4, in order to facilitate movements both ways and to ensure collaborative and positive risk management. There are 1,223 detained patients under the Mental Health Act who may not all be on wards specifically designated for people with learning disabilities. There may be patients who are on supervised community treatment – but figures for these at the moment are likely to be inaccurate.

Prison population

There is a growing concern that people with mild learning disabilities are increasingly found in mainstream prison services. Since no screening takes place during admission to prison for people with learning disabilities it makes it difficult to judge how many are in this group, though the Prison Reform Trust estimate it to be 30% (approximately 17,000), which has been calculated for people with learning disabilities and learning difficulties.

The Bromley files from the Prison Reform Trust suggest that people with learning disabilities are not well accommodated in prison, and that some should not be in prison, but the court diversion schemes are often under-resourced and staff are poorly trained to pick up learning disability issues. Many people often find themselves repeat offenders and there is little support, both in prison and externally, to help them move away from offending behaviour.

A survey run by the Prison Reform Trust showed that over half the prison staff believed that prisoners with learning disabilities or difficulties were more likely to be victimised or bullied than the other prisoners.

It is very important to recognise that this should not be a static landscape, but that people will often move between the different services. When a person is unwell they may need more support, but after successful rehabilitation they will be able to reach a different potential. Many people find themselves in services not through choice, or indeed need, but many through historic commissioning practices.

Quality of life for people and families with learning disabilities

Individuals' quality of life varies significantly. We do know, however, that most people live with their families who say they get little support, or receive support that is not useful or timely.

We know from the survey of learning disabilities that the majority of people are unemployed, have little money, have problems accessing housing and have higher health inequalities than the general population.

Those in the national forum for people with learning disabilities have also said that they are often bullied, harassed and prejudiced against by a population who knows little about their lives and who do not seem to want to get involved or stand up for people's rights. This is seen in the recent coverage of a mother who took her own and her daughter's life due to continual harassment from the local population because her daughter had a learning disability.

Family carers will often talk about the struggle they have with their loved ones, exhaustion that they face and worry about their future when they die.

Many people with learning disabilities say that they are not looking to be treated differently, but want services and support that are centred around their needs, staff that listen and react to their issues, and flexible support. Family carers want similar issues, but also want staff to understand that they do know about the needs of their family members and would like to be taken seriously.

The extent of regulated services

Table 6 summarises the services that we regulate, in relation to learning disabilities. (For a full break down of services and areas of performance of these areas see appendix 2.)

Table 6: Services currently regulated

National minimum standards – healthcare	NHS performance ratings	National minimum standards – social care	Performance judgements for adult social services
Independent healthcare specialist inpatient services – low and medium secure.	Mainstream NHS services, such as acute hospital provision. Specialist NHS provision, including assessment and treatment services, campus provision, community learning disability teams and specialist inpatient services High, medium, low secure settings – prison health.	Social care for older people, adult placements, domiciliary care, social care for younger people, nursing agencies.	Aspects of council learning disability services, including partnership boards, person-centred care, advocacy. Intelligence from themed service inspections are used towards councils' assessments of performance.

Funding streams

The support of people with learning disabilities is funded in different ways in different parts of the country, but there are some general principles which guide the way that funding streams tend to operate. Considering the definitions and types of service in the different tiers shown above, funding arrangements continue to reflect the complexity of a person's need.

Initially (Tier 1), most people with learning disabilities do not meet eligibility criteria for any funded services and arrange their support with their families, friends and communities. They may also access voluntary sector services that are centrally funded, such as sports or leisure activities.

Once people have more complex needs (Tiers 1 and 2) and require more formal supports, the local authority will hold the budget for commissioning these services either through self-directed support or through traditional care management. From April 2009, all social care commissioning has been transferred to local authorities, and primary care trusts are not now expected to be involved in the funding.

As disability becomes more complex, (Tiers 2 and 3) people may require the support of health service professionals and settings. The funding streams for this are generally shared between the Health (PCT) and Local Authority Commissioners. This may be in the form of health funded community professionals, supporting Local Authority funded services, or shared funding of a more specialist package of support such as a residential home with nursing. Some areas have pooled budgets for this type of funding, usually with a lead in the Local Authority. Other areas have different joint funding arrangements.

As the complexity of the person's disability increases (Tier 3) the health component of their support tends to increase. Here the funding stream is likely to transfer to the PCT as part of NHS continuing healthcare (NHS CHC) provision. Eligibility for NHS continuing healthcare is determined by whether a person's primary need is for healthcare, rather than for accommodation and related support. Where a person is entitled to NHS CHC, the NHS takes responsibility for their assessed health and social care needs. The revised National Framework for NHS Continuing Healthcare (www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_103162) sets out that NHS CHC can be provided in any setting, including a person's own home and that the commissioning of it should maximise personalisation and individual control and should reflect the individual's preferences as far as possible.

The final level of complexity (Tier 4) means that people may be detained under the Mental Health Act and/or require a range of specialist health resources. Funding transfers to regional specialist commissioning groups who are health service-led teams that seek to make appropriate arrangements across their region.

The breakdown of funding in these different arrangements is not currently reported. However, the Department of Health Report for 2008 (www.official-documents.gov.uk) gives the total NHS spend on people with learning disabilities as £2.49 billion. Clearly this is in addition to their access to generic NHS services. For local authorities, the figure was £3.121 billion. Again, this excludes general spending initiatives such as £1.4 billion for Supporting People and £0.5 billion for self-directed support implementation.

What do we know about the quality of services for people with learning disabilities?

Much has changed in recent years – from the building of large Victorian asylums accommodating thousands of people in open wards in rural locations, to Community Care which brought legislation to close the hospitals and support people to live more independent lives, predominantly in care homes.

Valuing People Now

Valuing People (2001) was the first major policy statement for almost 30 years to outline the strategic direction for people with learning disabilities. This focused on people's rights, choices, independence and inclusion into mainstream society. *Valuing People Now* (2009) was published and confirmed the founding principles of *Valuing People*. It set the key principles within a human rights framework and stressed issues such as having the right to access good quality treatment in health services, people with very complex needs and full and fair access to services for people from different ethnic groups. It has a plan of action to monitor progress.

Putting People First – The Transformation of Social Care

Putting people first is a concordat that sets out a commitment to finding new ways to improve adult social care in England. Personalisation will mean people thinking about individuals first, rather than traditional service provision. It will require the transformation of health and social care.

In 2005, the Cabinet Office Strategy Unit proposed individual budgets as part of its paper, *Improving the Life Chances of Disabled People*. This was followed by a Green Paper on Community Care promoting the importance of individualised support where power is held by the person and his or her family. This is the background for the growth of supported living services and the increased use of personal assistants and other homecare-type support. The quality, inspection and regulation of these services are likely to become an important issue during the period covered by this plan.

Despite government strategies, much guidance and many 'tool kits' to support change, there are still major issues of poor quality care and support being faced by people with learning disabilities and family carers on a daily basis.

We know this from the many recent reports that highlight abuse and poor practices, lack of leadership, and lack of challenge and will to regularly monitor these services to ensure good quality is maintained.

The lack of good physical health, both in primary and secondary care, has come under scrutiny in recent years. Mencap's *Treat Me Right* (2005) and The Disability Rights Commission's *Closing the Gap* (2006) highlighted:

- Poorer health outcomes for people with learning disabilities.

- Poor communication between professionals and people with learning disabilities.
- A lack of understanding of people's health needs.
- Poor training for professionals.
- Poor access to primary care.
- A lack of health screening.
- Poor treatment in general practice.
- A lack of user-friendly literature to support informed choices.

Mencap's most recent study, *Death by Indifference* (2007) highlighted the pathways of six individuals with learning difficulties. It examined the care and response they received from the acute hospital sector. It was Mencap's view that these six people would still be alive today if they had received the standard of care afforded to the general public. This prompted an independent inquiry into access to healthcare for people with learning difficulties that was chaired by Dr Jonathan Michaels, and an Ombudsman's investigation into the six deaths.

The Sir Jonathan Michael's enquiry, *Healthcare for All* (2008) called for sweeping changes in the NHS, finding that people with learning disabilities had:

- Poorer health than other people.
- Higher levels of unmet need.
- Experience of unequal treatment.
- A lack of 'reasonable adjustments' being made for them.

The six deaths were investigated by the Ombudsman, and their report *Six lives: the provision of public services to people with learning disabilities* (2009) found:

- The culture that underlies people's basic human rights was "not in place in the experience of most people involved".
- "On many occasions in the lives of the people concerned, basic policy, standards and guidance were not observed, adjustments were not made, and services were not coordinated."
- The complaints of "Four of the six cases we upheld, stating that the person concerned was treated less favourably, in some aspects of their care and treatment...for reasons of their learning disability". That is to say, because these individuals had a learning disability, staff working in the NHS could not see past their disability and treated them in a manner that was poorer than if they had not had a learning disability.

Within the specialist arena of healthcare for people with learning disabilities, a range of important and concerning issues of quality have been identified in the Healthcare Commission's national audit in 2007

and our follow-up audit in 2009. While there were some good services, many were characterised by some or all of the following features:

- Poor safeguarding procedures.
- Patchy access to advocacy services.
- Poor care planning.
- Lack of internal and external scrutiny and specifically, limited evidence of commissioner engagement.
- Limited provision of stimulating activities during the day and evening.
- Concerns about the use of physical intervention and PRN (medication given to people as required).
- Institutional regimes.
- Poor leadership and lack of appropriate training for staff.

It is not, however, just health services that have come under the spot light. The *First National Survey of People with Learning Disabilities* (2005) by Eric Emerson highlighted the disadvantages people with learning disabilities faced when compared to the general population:

- Social isolation.
- Lack of jobs.
- Poorer health outcomes.
- Lack of money for basic needs.

Mansell 2

For people whose behaviour seriously challenges services, the second Mansell Report (2007) reiterated the need to enhance local specialist support for people with these difficulties to significantly reduce the amount of poor quality high cost out of area placements. It found:

- A lack of monitoring of placements.
- Poor care planning.
- Poor forward planning to prevent crisis.
- Increased burden on family carers.
- Lack of local resources.

Commissioning has also played its part in ensuring outdated care and support is sustained. The joint commissioning review for people with learning disabilities and complex needs (2009), carried out by the Healthcare Commission, Commission for Social Care Inspection and Mental Health Act Commission highlighted:

- A lack of forward planning for people with learning disabilities.
- A lack of monitoring of placements/support.
- A lack of involvement of people with learning disabilities and family carers.

- Very few people got annual health checks from their doctor.
- People and their family carers had bad experiences of services while they were in general hospital.

People with learning disabilities that find themselves involved in the criminal justice service have also been reviewed. Lord Bradley produced his independent review of people with mental health problems or learning disabilities in the criminal justice system (2009). He found:

- A lack of early intervention work.
- Poor court diversion.
- A lack of training for most staff in the criminal justice service.
- No screening for people with learning disabilities.
- No support to stay out of the criminal justice sector.
- Bullying and a lack of support while in prison services.

All the recent reports have highlighted important issues concerning people with learning disabilities and their families, and we are starting to see some change, but there is still much to do.

Appendix 2 – Numbers of people within tiers of service and quality of those services

The following tables set out the numbers of people thought to be receiving services in tiers 1 and 2 (2008 figures) and the quality of those services.

Table 7: Tiers 1 and 2

Tiers 1 and 2 – from family and friends to residential care	
Family, friends and community	Unknown – est 575,000
Part-time support	Unknown – est 125,000
Shared Lives	1,300
Supported living	40,000*
Residential home	46,298
Residential home with nursing	4,863
Local authority	3,381
NHS	3,223

*Supported Living data is available from the Housing Corporation in the form of statistics provided by registered social landlords. However they do not distinguish between different client groupings.

Table 8: Tier 2

Tier 2 – residential homes and residential homes with nursing			
Home type	Number of places for people with learning disabilities	Number of homes	Average size
Residential home	46,298	6,221	7
Residential home with nursing	4,863	319	15*

*as noted previously, a number of people with learning disabilities are placed within large elderly care homes. This affects the average size.

Table 9: Star ratings

Quality of Tier 2/3 residential services		
Star rating	Homes registered to provide care for people with learning disabilities alone	Homes registered to provide care for people with learning disabilities and other types of care
0 Stars - Poor	48	16
1 Star - Adequate	693	246
2 Stars - Good	2,934	933
3 Stars - Excellent	865	295
Not yet rated	403	105
Rating suspended	1	1
TOTAL	4,944	1,596

We also know that for the last two years we have issued 159 statutory notices against homes registered for learning disability and cancelled 18 registrations for homes of the same.

Tier 3: Specialist healthcare

Once again it is difficult to ascertain definitive figures and to ensure that these are kept up to date. The most reliable source of data remains the 2007 Healthcare Commission national audit, although these figures may be subject to the following trends

- Growth in the independent hospital sector – the number of people placed in these settings continues to grow. They are currently all registered under mental health which leaves it difficult to extrapolate the learning disability services.
- Reduction in NHS campus provision – while the goal of no long-term care in the NHS is yet to be achieved, the numbers of people in these settings are reducing.
- Parallel to the closure of campus accommodation is a continued rise in the number of assessment and treatment units.

Notwithstanding these issues, the National Audit figures remain substantially accurate.

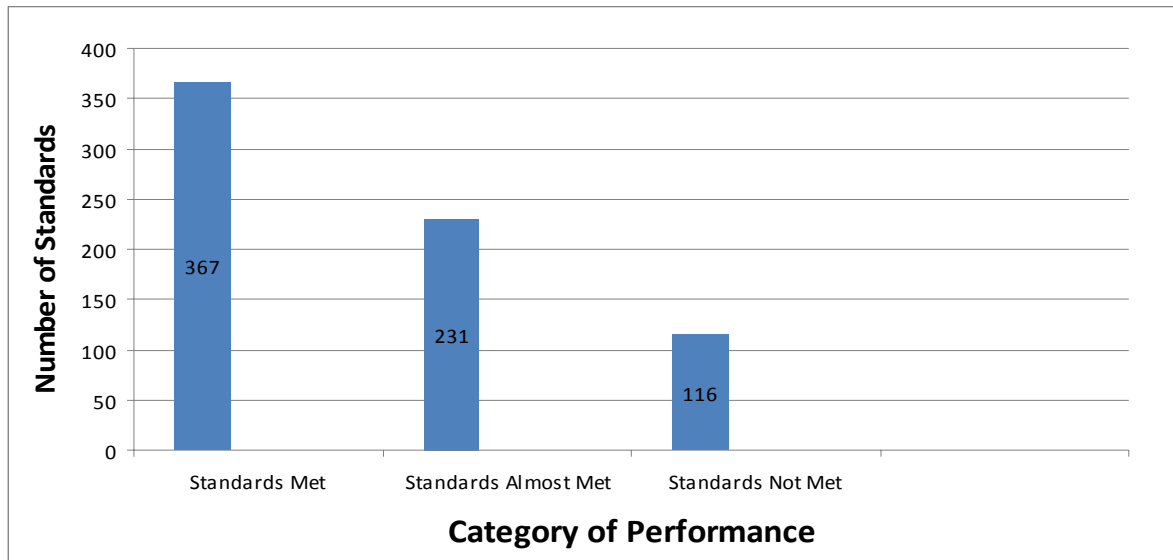
Table 10: Specialist health

Tier 3 Specialist healthcare	
Number of people receiving specialist healthcare	4,000
People under section for the Mental Health Act	1,223
Number of independent healthcare services**	55
Places in independent sector services	1,038
Number of assessment and treatment services	120

** This has risen from a reported 19 in 1987

Analysing the independent learning disability health sector performance on the Department of Health Minimum Standards for Independent Healthcare, we can find that the overall performance of the sector is in the mid range – with a few exceptions – both positive and negative.

Figure 2: Overall performance of the independent sector – the number of standards in each category of performance



We can also see that there is significant numbers of standards not fully met by a number of different services.

Figure 3: Independent sector performance – the number of services in each range of performance across all standards

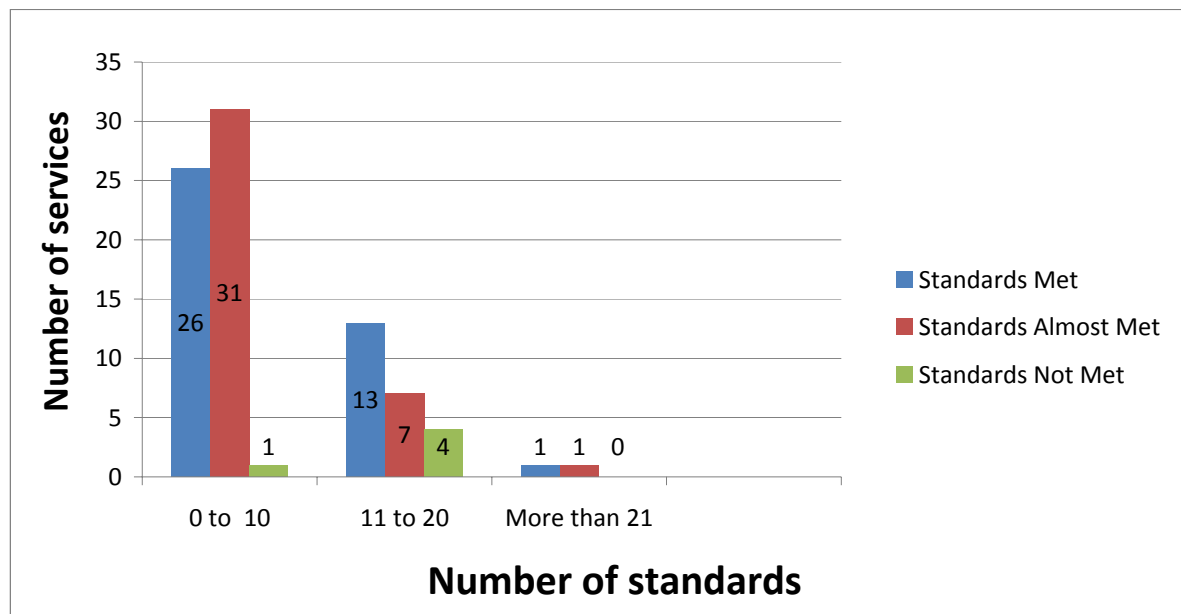


Table 11 shows that the standards that were not met seems to be mainly related to ensuring the work force was recruited appropriately, fitness to work (in terms of appropriate training and/or supervision) and the maintenance of buildings.

Table 11: Standards at risk – standards that have been ‘not met’ five or more times

Standard number	Standard – description	Number of services where not met
C09	Human resource policy	9
C17	Preventative maintenance planning	8
C04	Monitoring quality	5
C25	Resuscitation policy	5
M04	Clinical audit	6
M07	Risk assessment and management	6
M22	Informing patients	6
M15	Use of ECT	5

An easy read summary of this document is available on our website
www.cqc.org.uk

© Care Quality Commission 2009

Published December 2009

This document may be reproduced in whole or in part in any format or medium for non-commercial purposes, provided that it is reproduced accurately and not used in a derogatory manner or in a misleading context. The source should be acknowledged, by showing the document title and © Care Quality Commission 2009.

How to contact us

Phone: 03000 616161

Email: enquiries@ccq.org.uk

Registered Office:
Care Quality Commission
Finsbury Tower
103–105 Bunhill Row
London EC1Y 8TG

Please contact us if you would like a summary
of this document in other formats or languages.

