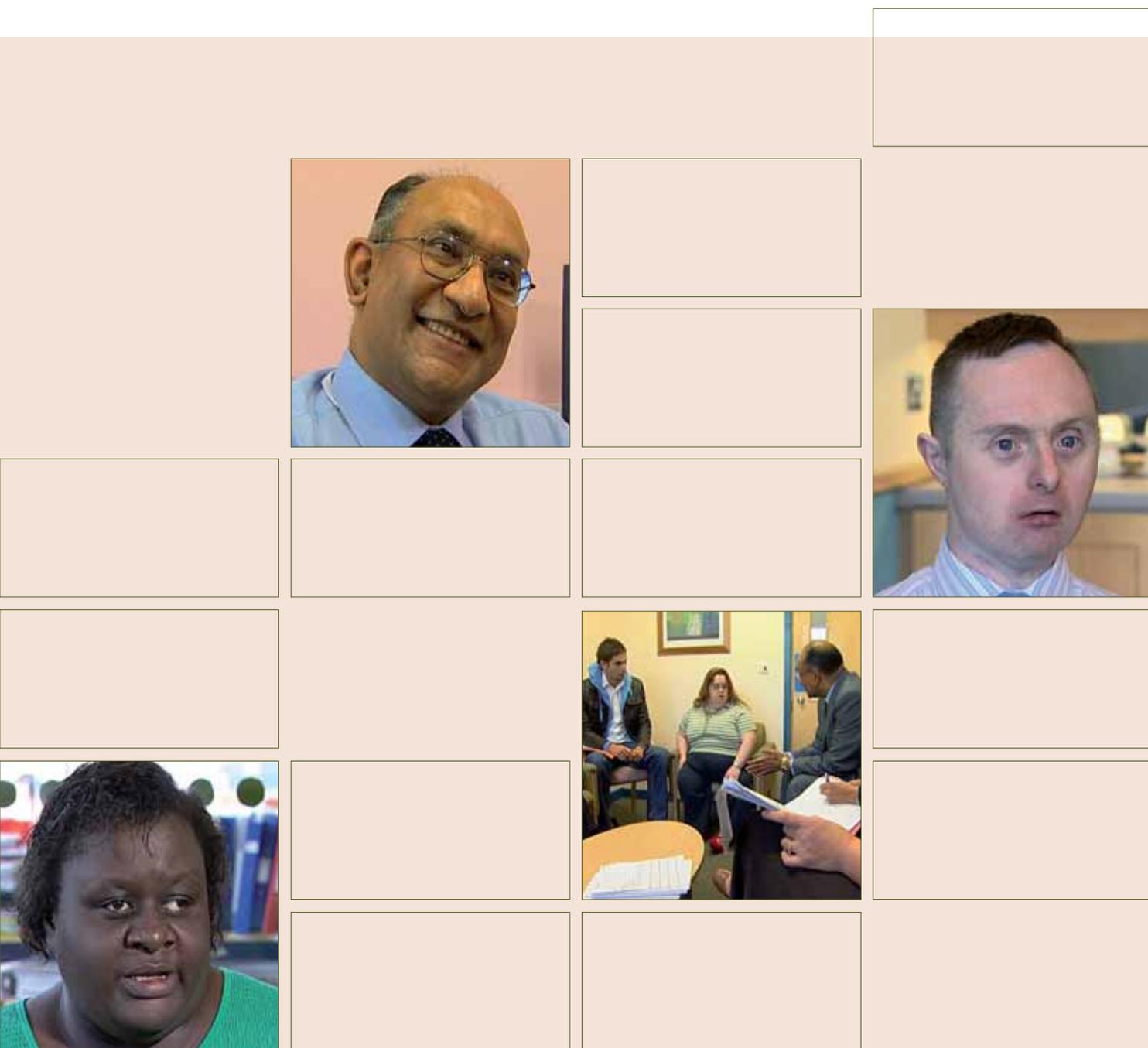


# A life like no other

A national audit of specialist inpatient healthcare services for people with learning difficulties in England



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# The Healthcare Commission

The Healthcare Commission works to promote improvements in the quality of healthcare and public health in England and Wales.

In England, we assess and report on the performance of healthcare organisations in the NHS and independent sector, to ensure that they are providing a high standard of care. We also encourage them to continually improve their services and the way they work.

In Wales, the Healthcare Commission's role is more limited. It relates mainly to national reviews that include Wales and to our yearly report on the state of healthcare. In this work, we collaborate closely with the Healthcare Inspectorate Wales, which is responsible for the NHS and independent healthcare in Wales.

The Healthcare Commission aims to:

- safeguard patients and promote continuous improvement in healthcare services for patients, carers and the public
- promote the rights of everyone to have access to healthcare services and the opportunity to improve their health
- be independent, fair and open in our decision making, and consultative about our processes

# 1. Executive summary

## Background

This is a national report following the Healthcare Commission's audit of specialist inpatient healthcare services for people with learning difficulties in England, carried out in 2007.

We use the term 'learning difficulties' rather than 'learning disabilities' in this report. Whenever we consulted with people with learning difficulties during the audit it was clear to us that this was the term they preferred. Its use here reflects the inclusive nature of the process we followed.

The audit followed two formal investigations into NHS services for people with learning difficulties, that we carried out, and our concerns in specific independent healthcare organisations. These identified unacceptable and failing standards of service, including abusive behaviour towards people with learning difficulties and institutional abuse.

As a result of these concerns, we instigated a national audit in 2006. Our reason for carrying out the audit was to uphold people's human rights. When those of us in positions of authority or responsibility decide that other people need to be cared for, or when people ask us to care for them, we have a duty to do that well, to help them remain or become as independent as possible, to achieve their maximum potential and to ensure that the right support is in the right place at the right time.

We wanted the audit to:

- provide the first detailed information on the extent and nature of services provided to people with learning difficulties by the specialist healthcare sector

This information would:

- start a process that will lead to improved services in the short and long-term, for the benefit of patients, users, family members who care for people with learning difficulties and staff. As far as possible we want to ensure that services for inpatients, including secure and NHS 'campus' provision for people with learning difficulties are provided in the safest possible environment
- help us to develop a performance framework to use when we are monitoring services in the future. It is striking that there are no indicators, specific to the healthcare of people with learning difficulties, in current assessment processes
- feed into our assessments of healthcare organisations and other core work
- support improvements by publishing national findings and other material and making recommendations to a range of audiences
- promote a national debate about the quality and appropriateness of services

Most people with learning difficulties who need care receive social care living either with their families, in their own home or in care homes regulated by the Commission for Social Care Inspection (CSCI). At any one time around 4,000 people receive care directly from organisations providing specialist healthcare services. There is a less clear performance framework in place with regards to services for people with learning difficulties than in other aspects of healthcare. For example, there are currently no national health targets and there is no national service framework specific to learning difficulties.

### How we carried out the audit

The audit was designed to be inclusive. We established an external steering group to ensure from the very beginning of the process that we heard the views of people with learning difficulties and family carers, clinicians and others with an interest.

The audit required all healthcare organisations providing specialist services to people with learning difficulties to respond to a questionnaire and potentially to be visited by a review team. We intended to promote change and improvement throughout the audit process by encouraging those who provide care to reflect on their services, by exposing people to services they would otherwise not see, and by organising inclusive training for our review teams.

We found 638 individual learning disability services that fell within the scope of the audit. These were provided in 72 NHS trusts and 17 independent healthcare organisations registered with the Healthcare Commission. This information was not previously known.

We thought it was important to visit services so that we could see what they were like for the people with learning difficulties who use them. We visited 154 services, covering 68 of the 89 organisations, providing care to adults and adolescents. The visiting team usually included a person with learning difficulties or a family carer.

### Our findings and conclusions

We describe what we found in some detail using headings that are important to us all: My choices; My day; My rights; Me and others; My wellbeing. It is important that we include this detail so that it can be used by those involved in care – people working in and commissioning services, local organisations and people with learning difficulties. We want them to see what we have found and, where necessary, take steps to improve their practices.

In six services, we had serious concerns about safety. These concerns were followed up immediately so that the necessary improvements were made without delay. Further information is shown in section 6. We sent a written report of our findings, including a list of the things that needed improvement, to every service we visited.

We found only a few services where the quality of care and the attention paid to the safety of people with learning difficulties were uniformly good across all aspects of care.

We know that staff can find this a challenging environment to work in, but have seen that services can be provided well. Where we saw better performing services, they:

- placed people with learning difficulties at the centre of care, particularly in relation to planning for their care and helping them to make choices
- provided care in an attractive environment
- had clear arrangements for safeguarding
- provided access to independent advocacy services
- were open to internal and external scrutiny, with the organisations' leaders playing an important role in this
- had good practices in place for the training of staff

Most services appeared to be providing basic standards of care and had, on the whole, committed teams of staff. There were unacceptably wide variances in the standards of care between services, both within an organisation and when compared to others. In most establishments, we have concerns about the quality of care overall.

In the main:

- procedures for the safeguarding of vulnerable adults are poor though we are assured that procedures in adolescent services are robust. We cannot be sure that the human rights of people with learning difficulties are always upheld. Having people acting as advocates on behalf of people with learning difficulties can provide valuable external scrutiny and shine a light on poor behaviours. We are concerned that access to advocacy services is patchy
- there is poor planning of care with people who have learning difficulties. We saw insufficient evidence that care plans are accessible to people with learning difficulties or that they are current and reviewed frequently enough. This is surprising given that our focus was largely on specialist health provision with professionals providing services
- the arrangements for the training of staff are often poor
- there is a lack of internal and external scrutiny. We saw limited evidence of engagement by those who commission services on behalf of people with learning difficulties (local authorities and primary care trusts, often working in partnership). We see this as a missed opportunity to influence the safety, quality, range and cost-effectiveness of services

- the provision of stimulating activities and opportunities was mixed. Many services provide good levels of stimulation and opportunities to take part in a range of activities, but others do not. We were careful to allow for the fact that some people with learning difficulties are formally detained, so their freedom is often curtailed
- physical intervention appears to be carried out appropriately. Many services were not undertaking physical intervention of any sort. The use of PRN medication to control behaviour is a more difficult area. (PRN medication is 'pro re nata' medication, given as required rather than routinely.) A large majority of services used PRN on a regular basis to control behaviour. The issue here is one of evidence-based practice. Does PRN or indeed regular doses of psychotropic medication have any basis as a response to the challenging behaviour of people with learning difficulties? It is our understanding that such evidence is extremely limited
- services are often old fashioned and institutional. Poor plans for care, an often poor physical environment, not enough attention given to training, a high use of agency and bank staff, and a lack of choice about who people live with and where they live all point to services being institutional
- we saw a lack of leadership in a general sense. There is little evidence to show

how boards and service managers are reassuring themselves about the standard of service provision

Another important finding is that, within the NHS, healthcare organisations are providing services that are substantially not specialist healthcare. Whilst the programme to close campus services is addressing this in the NHS, there is a potentially large, and hidden, issue whereby healthcare organisations continue to provide services that are residential, rather than specialist, in nature. Of people in specialist learning difficulty services, around 15% live in campus provision.

Our conclusion, at a general level, is that the quality of care in the majority of services for people with learning difficulties needs significant improvement. Our recommendations to services, when implemented, will ensure basic standards are met. This raises challenges for all of us. Not least, because there is a danger that these findings and conclusions could be seen as just the latest in a depressingly long line. We see the need for a more profound change.

### What happens next?

There needs to be a shift in the way specialist healthcare services are commissioned and provided so that we can be assured of the safety of people with learning difficulties and the quality of services they receive. We would like this change to take place swiftly, and for it to be enduring.

Long-term, sustainable change will involve a concerted effort, by a range of people and organisations, to work collaboratively and in a complementary way.

We want to see a strong performance framework in place for all those involved in commissioning and providing services for people with learning difficulties. We will seek the support of the Department of Health to achieve this.

We conclude by setting out the actions that the Healthcare Commission and others must take.

### **The Healthcare Commission will:**

- work with the healthcare organisations, visited during the audit, to deliver their action plans. We asked each organisation to put monitoring arrangements in place so that their management boards can be assured that actions have been taken
- immediately begin to carry out unannounced inspection visits to services for people with learning difficulties. This is to provide assurance that the findings of this report have been noted, that any required action has been taken and that the human rights of people with learning difficulties have been upheld. We will also visit services that were not visited as part of this audit
- use the information gathered during the audit to cross-check the declarations made by NHS trusts as part of our assessment of

core standards in our 2007/2008 annual health check

- introduce a set of performance indicators around the provision of learning difficulty services as part of our 2008/2009 annual health check. We will involve others, including the Department of Health and interested organisations, in finalising the detail of these indicators. They will be announced during 2008, but will include measures, important in assessing quality of care, on:
  - the planning of care with and around people with learning difficulties
  - individual health action plans
  - progress towards the closure of NHS campuses
  - progress towards implementing the mental health national service framework for people with learning difficulties
- explore how best to assess the provision of independent advocacy services and arrangements for safeguarding
- work with others, particularly the Government's Valuing People team, to actively promote the findings from this audit
- carry out a joint programme of work with the CSCI in 2008/2009 to assess the quality of commissioning of services for people

with high support needs, including people whose behaviour challenges or with mental ill health needs. We will pay particular attention to the use of high cost, out of area placements both in terms of the quality of outcomes for people and the effective use of resources.

### **We also expect others to play a part in addressing the issues raised in this report.**

#### **Provider organisations**

We expect all provider organisations to evaluate and review their care and learn from these findings. We are greatly encouraged by the evidence from our externally commissioned evaluation that shows the audit has already triggered significant change in those organisations audited. We would like there to be an ongoing process of evaluation and reflection.

We want services for young people to be more active in putting systems in place to measure the impact of their care with regards to the outcomes experienced by young people.

We want provider organisations (NHS organisations and independent healthcare organisations subject to the Healthcare Commission's registration requirements) to reflect on the type of services they provide. We expect that some organisations, particularly those that are residential in nature, will consider that they are not best placed to provide some aspects of care. This may be appropriate from a risk or financial perspective but needs the agreement of

commissioning partners and partnership boards. Any changes need to be part of a managed process, to ensure that those organisations best placed to provide social care can do so, with healthcare organisations doing what they do best. We will work with the Department of Health, the CSCI and Valuing People team to provide assurance that the programme to close campus services progresses, taking into account the potential impact on the safety of people with learning difficulties and the need to ensure that all services fall within the appropriate regulatory arrangements.

#### **PCTs**

We want PCTs, their strategic health authorities, and local authorities – working together as appropriate – to play a more active role in commissioning learning difficulty services. This must take into account the recently published Department of Health guidance on commissioning specialist health services for adults with learning difficulties and in ensuring age-appropriate provision.<sup>1</sup> This audit has shown that a different, and more inclusive, approach is needed when examining the provision of care for people with learning difficulties.

We believe that commissioners, along with their strategic health authority partners, should review this report and consider how best to meet some of the challenges raised. They must explicitly consider this commitment as part of local area agreements to be published by the end of June 2008. We look forward to supporting this as, with the CSCI

and the Mental Health Act Commission, we focus on assessing the commissioning of services for people with learning difficulties in 2008/2009.

### **Strategic health authorities**

In addition to the points made in the paragraphs above, we want each strategic health authority to ensure that the programme to close campus services takes into account the views and needs of people with learning difficulties. This should be in line with the commitments made in the Government's *Our health, Our care, Our say*<sup>2</sup> together with the commitment made in the Government's comprehensive spending review, October 2007.

### **Department of Health**

During this audit we heard repeated calls for a national service framework for people with learning difficulties, on the basis that frameworks have been a powerful driver in other clinical areas. The Department of Health intends to introduce new registration requirements for all healthcare organisations under the legislation that sets up the new health and social care regulator. We call upon the Department of Health to take into account the risks presented in specialist learning difficulty services when it establishes national standards of performance.

### **Department of Health and training bodies**

People with learning difficulties expect staff working in services to be able to receive high-quality training that promotes individuals' human rights. We do not believe that such

training is generally available or promoted sufficiently by employers. We will explore this with strategic health authorities, the Department of Health, Skills for Health, universities and other interested parties and ensure there is sufficient leadership of this important aspect of care.

### **Learning disability partnership boards**

These were set up in each local authority to ensure improvements happen for people with learning difficulties. Members include people with learning difficulties, family carers and representatives from relevant organisations and agencies. The audit process has led to the development of tools including questionnaires, training packages and a DVD, and a cadre of people experienced in reviewing services for people with learning difficulties. We would like local learning disability partnership boards to consider whether they can adopt aspects of the audit to provide the external scrutiny that people with learning difficulties tell us is important.

We also call upon learning disability partnership boards to be active partners with commissioners in providing a vision for safe, high-quality services that uphold people's human rights.

We owe a debt of gratitude to all the people with learning difficulties that were at the centre of this work.

## 2. Introduction

This national report follows the Healthcare Commission's audit of healthcare services for people with learning difficulties in England, which was carried out in 2007.

Prior to the audit, we carried out two formal investigations into services for people with learning difficulties in Cornwall NHS Partnership Trust<sup>3</sup> and Sutton and Merton Primary Care Trust<sup>4</sup>. These identified unacceptable and failing standards of service including abusive behaviour towards people with learning difficulties and institutional abuse.

These investigations and other identified failures in learning difficulty services in the NHS and independent healthcare sector, led to a concern around whether such instances were isolated or more widespread.

We have a duty to protect patients, to ensure that the care they receive is as safe as possible and that care is provided to an appropriate standard. We could not provide any assurance that healthcare services for people with learning difficulties were meeting these requirements.

In 2006 we instigated a national audit. We wanted the audit to:

- provide the first detailed information on the extent and nature of services provided to people with learning difficulties by the specialist healthcare sector
- collect relevant information on learning difficulty services

This information would:

- start a process that will lead to improved services in the short and long-term, for the benefit of patients, users, family carers and staff. As far as possible we want to ensure that services for inpatients, including secure and NHS 'campus' provision for people with learning difficulties, are provided in the safest possible environment
- help us to develop a performance framework to use when we are monitoring services in the future
- feed into our assessments of healthcare organisations and other core work
- support improvements by publishing national findings and other material and making recommendations to a range of audiences
- promote a national debate about the quality and appropriateness of services

This report is part of a suite of publications and material produced by the Healthcare Commission to support the findings from this audit. A DVD accompanies the report and should be viewed alongside it. It illustrates the experience from the perspective of people with learning difficulties and the audit teams that visited the services. The DVD also shows positive practice in action. The recommendations made to each organisation as part of the audit are published on our website

**[www.healthcarecommission.org.uk](http://www.healthcarecommission.org.uk)**

## How the report is structured

- Section 3 provides background information on what we mean by the term learning difficulties. We provide a brief historical perspective and illustrate how poor practice in services remains commonplace.
- Section 4 explains how we carried out the audit and how we ensured that a range of people were involved. Throughout the process, we supported and challenged efforts to provide safe, high-quality care. It also describes how we balanced the rights of people with learning difficulties to have their personal information remain confidential with our desire to access such information, without consent if necessary. This was needed to provide a full picture on the quality of care.
- Section 5 describes the findings from the audit.
- Section 6 takes these findings and sets out our conclusions on the state of healthcare inpatient services for people with learning difficulties.
- Section 7 outlines the actions that the Healthcare Commission will take. It also sets out our expectations of others to make the necessary changes to the way in which healthcare services are commissioned, provided and monitored.

# 3. Learning difficulties background information

People with learning difficulties have the same rights as anyone else to pursue a fulfilling life. We all want to have homes, families, good health, prosperity and happiness and achieve our own goals. These are basic human rights, which apply to us all.

Without a relationship founded on these rights, and an acknowledgement that they are the most fundamental of expectations, then an environment is created that leads to poor and abusive treatment.

When those of us in positions of authority or responsibility decide that other people need to be cared for, or when people ask us to care for them, we have a duty to do that well, to help them remain or become independent, to achieve their maximum potential, to ensure that the right support is in the right place, at the right time.

## What does 'learning difficulties' mean?

It will already be apparent that the term learning difficulties, rather than learning disabilities, is used in this report. We are aware of the range of debates around terminology that have taken place over a number of years, but our reason here is simple. Whenever we consulted with people with learning difficulties during the audit it was clear to us that this was the term they preferred. Its use here is therefore a reflection of the inclusive nature of the process we followed.

This use does raise questions of prevalence. In the education sector, for example, learning difficulty is used to describe people with educational difficulties, such as children with dyslexia. In this report when we refer to people with learning difficulties we are referring to the group of people that healthcare services refer to as people with learning disabilities. Further information on prevalence is shown below.

There are several definitions of learning difficulties.

The UK Government, in its white paper *Valuing People*<sup>5</sup> interpreted the model to define people with learning difficulties as having:

- a significantly reduced ability to understand new or complex information and to learn new skills (impaired intelligence)
- a reduced ability to cope independently (impaired social functioning)

These are in evidence before adulthood and have a lasting effect on development.

The 'social model of disability' (put simply) sees difficulty as being the result of society's failure to adapt attitudinal views to meet growing expectations of the quality of life, of all people's needs – thereby 'disabling' rather than 'enabling' some people. This model, used by the American Association of Intellectual and Developmental Disabilities<sup>6</sup> (AAMR) in the US sees difficulty as an interaction between the

person and her or his environment. This model has been adopted by organisations including the World Health Organisation<sup>7</sup> and Mencap.<sup>8</sup>

## Prevalence

Estimates of current and future numbers of people with learning difficulties have recently been derived, based on information from registers and general population data.<sup>9</sup> These estimates suggest that:

- 169,000 people aged 20 or over (0.46% of the adult population) are known users of learning disability services in England. Of these, 26,000 are aged 60 or over
- overall, there will be sustained growth over the next two decades in both the numbers of people with learning difficulties known to services (11% over the decade 2001-2011, 14% over the two decades 2001-2021) and the estimated 'true' number of people with learning difficulties in England (15% over the decade 2001-2011, 20% over the two decades 2001-2021)
- in common with general life expectancy trends, within the 50+ age range there will be very marked increases in both the numbers of people with learning difficulties known to specialist services (28% over the decade 2001-2011, 48% over the two decades 2001-2021) and in the estimated 'true' number of people with learning difficulties in England (31% over the decade 2001-2011, 53% over the two decades 2001-2021)

People with learning difficulties face barriers in accessing the NHS in general. This in part has contributed to them experiencing more ill health and a greater chance of premature death than the general population.<sup>10</sup> However in general they are now living longer than previously and experiencing the increased health problems associated with old age. For some people, for example those with Down's Syndrome, this brings added risks of pre-senile dementia. Additionally, more children with complex needs are surviving into adulthood. This is in part due to changes in neonatal care and increased use of medical technologies, for example, assisted ventilation.

## Historical perspective

Attitudes to, and services for, people with learning difficulties have seen substantial changes over many years. In some ways these can be understood as gradual progress towards acceptance as full citizens. Institutional care designed specifically for people with learning difficulties has its roots in the Victorian era when many large hospitals were built for the express purposes of care, protection, segregation and congregation. Along with hospital care came a medical model of understanding learning difficulty and the institutions became known as specialist hospitals. In the middle of the last century the institutions were incorporated into the NHS, and at their peak there were about 65,000 people in them.

These large institutions providing long-term care were shut away from the rest of society. Procedures including dehumanising treatment, a massive imbalance of power, lack of individuality and lack of opportunity to make and maintain relationships were harmful to many of the people who lived there.

The campaign to move away from segregated institutions to care in the community was given a major boost by a series of scandals concerning ill treatment in long-stay hospitals. These, in turn, led to a series of white papers and reports emphasising the requirement to move away from a medical model of care. Accordingly hospital places were replaced by residential care homes. These were less institutionalised than the hospitals but too often the individual was not in control of his or her own life. This has led more recently to the expansion of supported living where people are tenants in their homes with more control over their lives.

#### Expectations today

The Government's white paper, *Valuing People: A New Strategy for Learning Disability for the 21st Century* is based on the premise that people with learning difficulties have equal legal and civil rights and should be supported in ways that promote their independence, increase choice and control and inclusion in their communities. It is a 'cross-government' white paper, which covers more than health and social care services, for example housing, work and education.

Learning disability partnership boards were established as the key mechanism to achieving the key objectives in *Valuing People*, with local authorities as the 'lead agency'.

In relation to healthcare, there is an emphasis on people with learning difficulties having access to mainstream NHS services and using them wherever possible. *Valuing People* acknowledged that specialist services may sometimes be required but their role and function needed to change. Importantly, it contained a specific objective to close the remaining long-stay hospital beds and look at NHS campus provision. This has been strengthened by an objective in the white paper, *Our Health, Our Care, Our Say* to close all NHS campus provision by 2010.

Every person is expected to have a choice of:

#### **Planning centred around them:**

Person-centred plans are the culmination of discovering how to listen to people with learning difficulties and understand what is most important to them and what they want from their lives. The plans are meant to be constantly reviewed and revised, focusing on what the person (with learning difficulties) thinks is important to them now and for the future, and acting upon this in alliance with family and friends. Whoever draws up a person-centred plan should ensure the person's choices and wishes are acted upon, and both listen and learn to understand their capacities and choices. Person-centred plans should be used as a basis for solving problems, negotiating and spending the

resources wisely to pursue the person's aspirations. These resources may be obtained from an individual's personal network, from service agencies, or from a range of non-specialist and non-service sources. Of course the things that are important are not always financially driven. For instance, having friends, being valued, playing an active part in society or just being able to have a good gossip may all be important. These have a societal cost – people need to care, have time to get to know people with learning difficulties and to want to become involved.

#### **A community care needs assessment:**

Community care assessments, led by social services departments, provide a record of needs from which person-centred approaches should be developed. Healthcare staff should assess any healthcare needs identified as part of this process. A risk assessment and care plan should be developed based on the community care assessment. A long-term person-centred care plan should also be agreed with each individual and their advocates.

**A health action plan:** *Valuing People* contained a key objective that people should be able to have a health facilitator and health action plan if they wished. Health action plans were developed to ensure the individual health needs of people with learning difficulties were fully understood, and importantly, acted upon. A health action plan should be centred around the person with learning difficulties, fully involve them and be available in a format that

is appropriate to their understanding. For some people, the results of a good health action plan can singularly transform their quality of life.

#### **Key policies for children and young people**

In 2004, the *National Service Framework for Children, Young People and Maternity Services*<sup>11</sup> was published. It sets out national standards that promote high-quality services that are centred around children. Two of the standards are of particular relevance to young people with learning difficulties:

- standard four concerns growing up into adulthood, and expects all services to work towards age-appropriate support
- standard eight focuses on disabled children and young people, and those with complex health needs. It states that they should receive co-ordinated, high-quality services centred around children and families that promote social inclusion and where possible, enable them and their families to live ordinary lives.

*Every Child Matters: Change for Children*<sup>12</sup> is a new approach to the wellbeing of children and young people from birth to age 19. This overarching Government policy aims to ensure that every child, whatever their background or their circumstances, has the support they need to:

- be healthy
- stay safe
- enjoy and achieve
- make a positive contribution
- achieve economic wellbeing

This means that the organisations involved in providing services to children – from hospitals and schools, to police and voluntary groups – should be working together in new ways and sharing information, to protect children and young people from harm and help them achieve what they want in life.

#### Who provides care and support?

The majority of people with learning difficulties who need care receive social care living either with their families in their own home or in care homes regulated by the Commission for Social Care Inspection (CSCI). (These services do not form part of the national audit – see *how we carried out the audit*.)

In England there are 134,000 people with learning difficulties known to social services. Of these, 103,000 people receive community-based services and 3,600 live in non-healthcare residential services. Currently 5,500 people with learning difficulties are

receiving direct payments. There are 6,708 care homes, registered with the CSCI, providing care to people with learning difficulties.

Primary care trusts (PCTs) commission services from the NHS and independent healthcare providers, which are classed as healthcare. There are over 4,000 people who are inpatients in accommodation provided by the NHS, in a variety of settings including 'old' long-stay hospitals, campus accommodation (due to close by 2010), within assessment and treatment services and in other services (shown on the next page).

The NHS has contracts with independent healthcare providers to provide secure services, residential services, and day services for people with complex needs. All independent healthcare services are registered with the Healthcare Commission under the Care Standards Act (2000).<sup>13</sup> There are approximately 1,154 places in these services. The audit did not review all services registered as mental health establishments, but we did review those where we knew people with learning difficulties were living.

A local authority may be funded by the PCT further to a partnership agreement, which it can use to commission social care from health providers. Local authorities are not permitted to commission health services. So in learning difficulty services those NHS services providing care not registered with CSCI are classified as

healthcare. Those that are long-term residential in nature are classed as a 'campus' and are to close under the programme to close campus services\*. If local authorities are commissioning social care from the NHS the service will either be registered with the CSCI or be unregistered social care – and therefore unregulated. The NHS should not be commissioning social care that is not registered with the CSCI or in services due for closure under the programme to close campus services.

At the time of the questionnaire, there were 44 young people in specialist services for adolescents and reported to be 309 adolescents in adult services.

Secondary care services currently available to people with learning difficulties are:

- acute assessment and treatment (inpatient services)
- specialist residential and day provision for people with more complex needs
- forensic services including low, medium and high secure services

- adolescent services
- short breaks
- community learning disability teams
- specialist teams that provide intensive support in people's homes

The glossary provides an explanation of these terms.

Specialist health professionals work with people with learning difficulties to promote access to mainstream NHS services and provide direct support to those with the most complex needs. *Valuing People* describes how "in addition to their clinical and therapeutic roles, specialist staff should take on roles in health facilitation, health promotion, teaching and service development".

The Department of Health issued guidance "all means all"<sup>14</sup> to NHS chief executives to highlight the health inequalities faced by people with learning difficulties and the need to ensure access to mainstream NHS services.

\* In most parts of England during the 1970s, health and social services negotiated arrangements to transfer people with learning difficulties from long-stay hospitals to services in the community. Initially, the cost of this transfer was supported by supplementary benefits from an uncapped Government fund for residential care (care homes and domiciliary care). However, this created an incentive for people to be placed in residential care, rather than receiving services in their own homes (which would be paid for by the local authority). It also contributed to a large increase in the number of independent residential and nursing homes.

#### Issues recently identified in healthcare services for people with learning difficulties

A number of surveys, investigations and reports as well as enforcement action have recently highlighted problems in healthcare (and other) services for people with learning difficulties. These include abusive care, neglect, poor access to a range of health services, deprivation and violation of people's human rights. A fuller account is shown in **Appendix 1**.

priority, areas. Services for people with learning difficulties are sometimes perceived as 'Cinderella' services – not constantly the focus of performance management and assessment attention.

#### The performance framework

We have now undertaken several reviews and investigations into services for people with learning difficulties. We see that there is a range of expectations placed on organisations that provide these services. Our investigation into services provided by the Cornwall Partnership Trust identified that services can become isolated from scrutiny and from an accepted understanding of what constitutes good practice. Whilst there has been a welcome focus of attention on services for people with learning difficulties following work by Mencap, the Disability Rights' Commission and the Healthcare Commission, its place in the 'performance framework' has not always been as dominant. For example, there is no 'national service framework' specifically for learning difficulties and national targets have not been established as they have for other,

## 4. How we carried out the audit

We established a set of principles that guided our work from the outset. We wanted to ensure that the audit met high ethical standards, including involving participants with learning difficulties and paying attention to issues of consent and confidentiality, and met high methodological standards including the use of pilot studies to maintain reliability and validity of data collection.

We also wanted the audit to improve services and enhance the work of the Healthcare Commission by:

- developing a comprehensive understanding of the type and range of services provided, as there was no nationally available information
- seeing each stage of the process as making a positive contribution to change
- encouraging self-reflection by people working in services
- training review teams so that skills and knowledge could be used in the future and transferred to others
- targeting follow-up visits using an approach based on risk and clearly reporting on what needs to happen at a local level
- evaluating what we learnt

**The process is described more fully in Appendix 2.**

We established external and internal steering groups to ensure that, from the very beginning of the process, we heard the views of people with learning difficulties and family carers, clinicians and others with an interest. The membership of the external reference group is shown in **Appendix 3**.

The audit included all specialist learning disability services for adult and adolescent inpatients in the NHS and independent healthcare. It looked at the provision of care in the following services:

- acute assessment and treatment centres
- short break (or respite) services
- individual residential services paid for by the NHS (but not regulated by the CSCI)
- low secure services
- medium secure services
- high secure services
- 'old' long stay services
- campus services
- specialist adolescent services

We did not include those services run by the NHS that were registered with the CSCI.

## 4. How we carried out the audit continued

Assisted by the external reference group, we designed two questionnaires: a questionnaire for an individual service, and a further questionnaire for an organisation's board.

We carried out a pilot of the process before the national phase to ensure that the method was as robust as possible. Following the pilot stage we changed many aspects of the audit including some of the questions and process for the visits and reports.

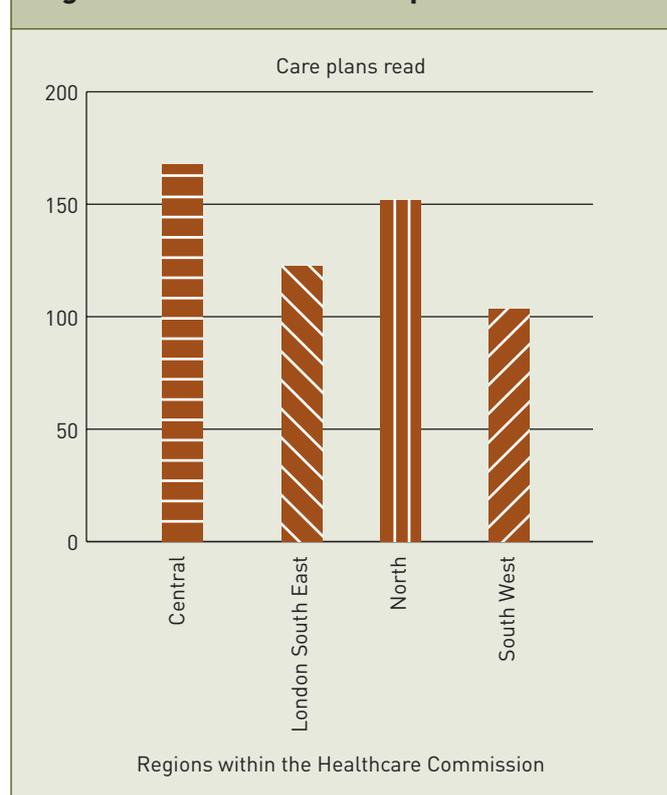
It became clear during the pilot phase that the review teams needed to look at patient files to gather important evidence.

Consequently a paper setting out issues relating to confidentiality and consent was presented to the Healthcare Commission's 'Committee on the use of confidential personal information' which, after careful deliberation, agreed to allow the review teams to access patient files without consent. This had some important caveats:

- to ask the person with learning difficulties if they wanted to look at the care plan with the assessment manager
- to document the numbers of care plans that were read
- to document if a patient specifically asked the review team not to read their plan and if there were exceptional reasons as to why their wishes were not met

The table below shows how many records we looked at (556). One person stated that they did not want us to look at their care plan, and their wishes were respected.

**Figure 1: Number of care plans read**



We identified 638 individual learning difficulty services that fell within the scope of the audit. They were provided in 72 NHS trusts, and 17 independent healthcare organisations registered with the Healthcare Commission. **Appendix 2** shows the organisations included within the audit.

The national phase started in January 2007 when we sent questionnaires to 638 services and a separate questionnaire to 89 boards of management. There was a response rate of 92% and 96% respectively.

From all services, 154 had a follow-up visit by a review team. These services were provided in 68 of the 89 healthcare organisations included within the audit.\* The 154 services visited included those that did not respond to our questionnaire. Each review team comprised three people: a family carer or person with learning difficulties, a Healthcare Commission manager and a clinician or manager from the field. A recruitment and selection process took place and the British Institute of Learning Disabilities provided training.

Each review team held a meeting to discuss issues in advance of the visit, which usually took place over a day. Following the visit, we produced a report that identified recommendations for improvement and good practice.

## Evaluation

In any programme of activity such as this, we evaluate the process, methodology and outcomes of the work.

To support this evaluation, we organised:

- an external event for all of the review teams involved in the audit

- an internal event for all Healthcare Commission staff involved
- an externally commissioned, independent, evaluation

We commissioned the Office for Public Management to carry out an independent evaluation. It designed and sent out a questionnaire to all services that received an audit questionnaire from us and collated the responses.

The questionnaire survey was sent to 529 individuals in total. Full responses were received from 242 people, an overall response rate of 46%.

The majority (85%) of respondents stated they had made or planned some changes as a result of the audit. This included some respondents who did not make any changes as a result of the original Healthcare Commission questionnaire or receive a visit, but did make some longer term plans, which they attributed to the audit.

Half of all respondents (51%) made actual changes as a result of the audit.

Table 1 shows how many respondents stated “the audit has prompted important changes for people in my service”.

\* Two organisations, part of the audit pilot stage, are not included in this figure.

## 4. How we carried out the audit continued

**Table 1: Number of respondents that had or were going to make changes as a result of the audit**

|                   | n          | %   |
|-------------------|------------|-----|
| Strongly agree    | 82         | 35% |
| Tend to agree     | 115        | 50% |
| Tend to disagree  | 30         | 13% |
| Strongly disagree | 4          | 2%  |
| <i>Don't know</i> | 11         | -   |
|                   | <b>231</b> |     |

Those who received a visit as well as a questionnaire were more likely to have implemented changes than those who received a questionnaire alone (36% against 14%).

The changes staff implemented and planned were wide ranging and 'real'. They included an increase in the involvement of people with learning difficulties, improved staff training and the development of plans for people with learning difficulties. There were many others. The following are indications of the types of activities that staff said they had changed or were going to change/improve as a result of the audit:

- staff training (50 mentions)

- the levels of involvement by people with learning difficulties (40 mentions)
- evaluations/reviews of policies (24 mentions)
- physical environment (14 mentions)
- person with learning difficulties independence (10 mentions)
- registration with CSCI (10 mentions)
- provision of activities (8 mentions)
- work more closely with service providers (7 mentions)
- governance (4 mentions)
- staff resources (3 mentions)

The external event was well attended by people engaged in the audit process. Below are some key points about the audit that emerged during the event:

What worked well:

- working as a team: everybody liked working as a mixed group of people
- some aspects of the training
- the process as a whole
- visiting other services

What we could have done better:

- timescales: sometimes the visits were too rushed and not enough time was spent in some of the services
- more involvement of people with learning difficulties
- better organisation of benefits, expenses and setting up of the teams

Outcomes people involved in the process want to see:

- indicators/benchmarks for monitoring the service
- a repeat of the audit or something like it
- the opportunity to use the skills of people in their own locality
- reassurance that some of the individual people that they visited were being better cared for
- an improvement in the services

A full evaluation paper will be available on our website at the end of 2007.

# 5. Our findings

This is the first time that an exercise like this has been undertaken in England. As such, we are reliant on the data supplied to us following our request.

## Number and type of services

The provision of services is summarised below. **Appendix 2** categorises services in more detail.

- In the NHS, the most prevalent types of services were ‘residential services,’ (not including campus), commissioned by the NHS, comprising 33% of all provision.
- Campus provision comprised 16% of all NHS services.
- There were 130 acute assessment and treatment services comprising 20% of all provision.
- Within independent healthcare services, secure services comprised 62% of all independent learning difficulty provision.
- Both NHS and independent healthcare services were operating at nearly full capacity, just over 86%. As expected, lower capacity rates were observed in ‘old’ long-

stay services, provided by both the NHS and the independent healthcare sector.

## Number and characteristics of people receiving care

The characteristics of the people receiving care in these services is summarised below. **Appendix 4** provides further detail of population characteristics.

- At the start of the audit around 4,000 people with learning difficulties were receiving care in these services.
- The average number of people using the services at the time of the questionnaire was 6.2 people per service in the NHS and 12.2 people in independent healthcare services.
- Of these individuals, most were men (63%). In low, medium and high secure services there were 625 men to 127 women. This is skewed, as there are no specialist NHS high secure services for women with learning disabilities.
- The proportion of people from different ethnic groups reflects the general population in England.

- Age ranges also broadly reflect the pattern from national census data. There was a concentration of people aged 25-44 using services and fewer younger and older people. The distribution was very similar in both the NHS and independent healthcare with slightly more younger and older people using NHS services.
- There were 1,223 people detained under the Mental Health Act. Of these, 40% were in 'low secure' services with 22% in acute assessment and treatment services. Of those detained, 901 were in NHS services and 323 people in independent healthcare services.

## Areas examined

With the external reference group we identified 12 question areas. These were the most critical indicators of the likely safety and quality of a service and were followed up in all organisations selected for a visit. Additionally, review teams selected areas for additional scrutiny relevant to each service. They used three criteria: potential problems, indications of good practice and unusual answers. This allowed us to react to the information provided and ensure a greater breadth and depth of evidence.

Our visit teams therefore asked varied questions, which makes direct comparisons more difficult. We considered it was more important to ensure that within a service, the quality of care, quality of life and outcomes for people were of an appropriate standard.\*

A description of why adults or adolescents receive care from specialist inpatient health services is shown in Table 2.

\* Our findings in relation to the questions identified for routine follow up in all services are therefore expressed in definitive terms for example, "the majority of services..." Our findings in relation to evidence collected from tailored questions determined by the peer review teams are qualified, for example "we found 39 services that..." It does not, therefore, follow that the remainder did not have these issues because that question may not have been followed up in all services.

**Table 2: Reasons why adults or adolescents receive care from specialist inpatient health services**

**Adult services background**

The adults who find themselves in these services do so for many reasons. For example, a break down in the placement where they are living, a mental health problem, a need to be assessed for changes to medication, or they may have come into contact with the legal system. Many adults are also in residential services, further to the move away from institutional care in hospitals to the provision of campus style provision. As such, people with learning difficulties here are not in need of health provision but could be accommodated within the community in a model of care that centres around their needs – hence the closure programme in place for campus services.

**Adolescent services background**

Little information has been collected or is known about the care of young people in adolescent services, who have different needs to those of adults.

Young people admitted to adolescent services have complex needs, typically with behaviour that is challenging for those providing services. All services visited specified that for admission, a person’s primary need must be their learning difficulty.

Several young people were described by staff and in case files as having a developmental disorder, most often an autistic spectrum disorder. Often, young people in adolescent services also had mental health problems.

Reasons for people coming into the services were varied, but often, managing the young person’s behavioural needs had become such that placement in the family home was no longer safe or sustainable. Several young people had a history of offending or were admitted because they were felt to be at risk of offending in the future. Some services would accept referrals from the criminal justice system for assessment and/or treatment.

The results are grouped around five themes that we all consider important.

- My choices
- My day
- My rights
- Me, and others
- My wellbeing

We illustrate the evidence with quotations from the written visit reports.

## My choices

Here we wanted to find out if people with learning difficulties are being supported to make everyday choices, and actively listened to in order to make them. We also wanted to find out how involved people are in daily and life-changing events and the extent of their independence and the support available.

### Independence and choice

- We saw limited evidence, during our visits, to confirm the findings from the questionnaire that independence is always promoted. In around half of services the questionnaire findings were not supported.

- Conversely, in a similar number of services we found that people with learning difficulties were given significant amounts of choice in their day-to-day lives, with choice well supported.
- In a small number of the visits we found there was little or no choice in the food available to people using the learning difficulty services.

*“Although the service is referred to as a low secure hospital facility more effort could be made to promote a less institutional environment and to encourage greater independence and choice for people with learning difficulties.”*

*“This included instances of lack of choice with food “they had to eat it or go without”, through to being locked out of their bedrooms during the day, and toilets being locked, so they had little choice in where they spent most of their day.”*

*“During our visit we observed people having lunch. I sat beside one young man but he didn’t want what was on offer. He was offered no other choice and therefore did not eat and spent the rest of the afternoon trying to take biscuits from the kitchen.”*

*“The bungalow was purpose built in 2002 with the input of staff and people who were going to live there. It was divided up into two gender specific areas and there were signs of choice and individuality throughout.”*

*“The approach to choice facilitated by staff seen in the service supports the empowering of people, thereby preparing them for a more independent lifestyle.”*

### **Summary of areas for recommendations:**

We made 27 recommendations to adult services that they should give people using their services more choice in their day-to-day lives. This will maximise their independence – allowing for their circumstances. We made five similar recommendations to adolescent services.

### **Communication and making information accessible to support choices**

- The evidence from the visits to adult services showed most staff felt an interpreter was available if requested and knew where to find one. However approximately 40 services (all service types) provided little information or training to staff to enable understanding and communication with people using the services.
- About 30 services provided good, appropriate information to people using the services in easy read format or including pictures. We also saw examples of people using communication techniques including Makaton\*, symbols and pictures to help people using the services to make choices. Notably this did not include medium and high secure services or a long stay hospital. It was also low in campuses (10%).

\* See glossary of terms

The majority of good practice was in acute assessment and treatment services (31%).

*“Patients appear to have very little influence in the choices they have in everyday life and this is partly due to the lack of information that is presented in a format that the patients can understand.”*

### **Summary of areas for recommendations:**

We recommended to 44 services, mostly in campus, that communication methods should be made more accessible to people using the services. This included written material and interactions, for example using Makaton or pictures and symbols where appropriate.

### **My day**

Here we wanted to establish how people lived their day-to-day lives, activities carried out during the day, how often they ‘went out’ from the service, and how they were supported to be active members of their local community.

- Services for adolescents provided many good examples of engaging young people in a range of positive activities and experiences. Several involved young people in planning day trips linked to their teaching sessions, or bought season tickets for the local football team and took young people to matches.

- From our visits to adult services, half were not engaging people with learning difficulties in activities at a sufficient level. This is much lower than our expectations following the evidence from the service questionnaires.
- Although nearly all people with learning difficulties had left the site in the last month, this was mainly to go shopping or eat out. We identified 29 services that had planned extensive and varied activities enjoyed by the people there.

*“During our visit, there was very little evidence of activity or of choice being given, communication between staff and people with learning difficulties was limited, although staff informed us that they were able to understand people’s wishes and likes and interests.”*

*“We do health we don’t do social.”*

*“It was positive to note during the visit that people were complimentary about activities they were involved in, which included outdoor pursuits, trips out planned in conjunction with them, educational work, living skills and for some, a holiday.”*

**Summary of areas for recommendations:**

We made 29 recommendations to an even range of services, that they make activities more meaningful and frequent.

## My rights

Here we wanted to discover:

- how people were treated in the services
- how they were supported to understand things
- if they were able to access the services of an advocate
- if they were able to receive information in a format that they could understand
- if they were placed at the centre of their care
- if they were treated with dignity and respect and their human rights were upheld

We also wanted to know the standard of plans for people’s discharge from the service and how complaints were dealt with.

## Independent advocacy

- The majority of services (both adult and adolescent) did not provide independent advocacy. Just over a quarter of people using the learning difficulty service had spoken to an independent advocate in the last six months. The remaining three quarters apparently had no access to advocates. We identified services where there was no awareness of the availability of advocacy services, where advocacy was

not used by any of the people with learning difficulties and where no evidence of advocacy could be provided during the audit visit. In 38 services however, we identified good advocacy provision.

*"We used them [independent advocacy organisation] before but they had unrealistic views of what our people can do."*

*"...a lot of people didn't understand what advocacy was for or what independent meant."*

*"Independent advocacy is well established in the area and service users have timely access to advocacy services. Positive relationships between the trust and advocacy service are well developed. PALS (Patient Advice and Liaison Service) has involvement with learning disability services and is currently engaged in discussions with the trust regarding enhanced involvement with learning disability services."*

### **Summary of areas for recommendations:**

In 78 services we highlighted the importance of advocacy and recommended the implementation of adequate independent advocacy arrangements. Of the 78 services, the highest number of recommendations were made to residential and campus provision. We made similar recommendations in three adolescent services.

### **Locking of doors**

People using services should only have their freedom of movement restricted when there has been a definitive assessment of risk.

- In services for adolescents we found locked door policies were not flexible and may have been overly restrictive for some young people. No people with learning difficulties held keys to their own bedrooms, or other areas of the service.
- In the majority of services for adults (including 20 residential services and campuses) we found evidence of inappropriate restrictions on freedom. This included not offering people with learning difficulties the choice of whether to lock their bedroom doors.
- Fewer services were praised for their approach to locking doors. A formal assessment of the relative risks had taken place. Some people using the services had been provided with keys as a result of the assessment of risk.

*“All doors except bathrooms were locked as a matter of policy, which had a negative impact on people using the services. Patients had no ready access to drinks or snacks without requesting them from staff. There was no patient supervised access to the ward kitchen and staff acknowledged that patients’ skill and ability in drink and basic meal preparation, identified prior to admission, were not recognised.”*

**Summary of areas for recommendations:**

We made recommendations concerning access to 51 services. These promoted the use of risk assessment and review of policies and practices on locking doors. 45 of the services were acute assessment and treatment services, with the remaining six, adolescent services.

**Access to healthcare**

Evidence from our visits suggests that people with learning difficulties mostly do have good access to healthcare professionals.

- According to the unit questionnaires, 81% of people have had a routine health check.
- The evidence from 34 services also suggests that, in some places (including a third of assessment and treatment centres), people using the services had problems accessing healthcare specialists on a timely basis.

- Some delays were reported in accessing specialist trust services such as psychology, behavioural therapy and speech and language services. This may have a detrimental effect on people with learning difficulties, particularly those detained under the Mental Health Act 1983, who, aside from medication therapy, may be left without any active treatment.
- Generally young people’s health needs were well met, with systems in place to ensure access to primary care and specialist health input (such as speech and language therapy) without delay.

*“The service accesses a wide range of specialist services for individual residents, on a needs-led basis. Services include a range of holistic and complementary therapies. There is also evidence that service staff identify residents’ general health needs.”*

*“Whilst general healthcare needs appeared to be adequately met, access to specialist services was more limited and not provided on a routine basis.”*

**Summary of areas for recommendations:**

We made 49 recommendations to services to ensure people have correct and timely access to healthcare.

### Planning care with and around the person receiving care

All people with learning difficulties that use services should have their care centred around them in an individual way.

- Most adolescent services had not adopted a formal person-centred approach to care planning. Plans relating to the care of adolescents did not often reflect the young people's views.
- For a small minority of detained young people, their solicitor had appointed an independent social worker, as their 'home' local authority was unable to provide support.
- Staff described how for some young people their continuity of social care had been broken as they were being transferred to adult social services. This had caused delays in accessing support, or in some instances had delayed discharge.
- All the adolescent services we audited provided educational opportunities inhouse. Links with local colleges and vocational training were highly variable. Some – especially secure services – were noteworthy for having organised plans around learning and training, and appeared to be delivering a range of options around the learning needs of young people.

- We saw little evidence that plans for the care of adults with learning difficulties were carried out with their full involvement.
- In just over half of all services, people with learning difficulties did not a copy of their care plan that was accessible and easy to understand.
- Our visits revealed only a minority of services had care plans in place that were accessible and easily available. We saw little evidence that care plans were audited regularly or kept up-to-date.
- The questionnaires stated that over half of all people had their own health action plan, however the visits did not substantiate this.

*“There was little information to support the board statement that person-centred planning, and essential lifestyle planning, are foundations for the service to respond to the needs of individuals and the development of the service.”*

*“Plans for care, community care assessments and well developed person-centred health action plans were in place for people with learning difficulties ...the files for people's care were systematically organised ensuring that information was accessible with ease.”*

**Summary of areas for recommendations:**

We made over 200 recommendations around ensuring that people with learning difficulties were better involved in planning their care. The plans need to be more easily understandable and accessible to them. They should be regularly reviewed to ensure that they reflect the current needs of the person. We made 11 recommendations around care planning in adolescent services.

**Arrangements for the discharge of people from services**

- In adolescent services several staff we interviewed were concerned about finding an appropriate way out of the service for young people. Lengths of stay could exceed two years, even if young people were ready to move on.
- Our analysis from the questionnaires reveals that 81% of people using learning difficulty services were receiving active treatment. Whilst this is positive, active treatment of the remainder of people (857 people, of which 17 were in independent healthcare services) had finished, and there were no plans for them to leave the services.
- We found evidence in only seven services of efficient procedures for arranging discharge. In nine we encountered difficulties illustrated by the following quotations:

*“The audit team was particularly concerned about the lack of long-term plans for a person with a learning difficulty who is a young adult.”*

*“People were detained under the Mental Health Act but receiving no active treatment.”*

*“Most of the patients on the service have been there for several years and no patients have been discharged from the service since opening four years ago. Although some of the patients had made progress and felt ready to move on there was no evidence of a plan for any of the patients to move on.”*

**Summary for areas for recommendations:**

We made several recommendations around discharge, which included ensuring people were not delayed and that appropriate services were found for individuals.

**Voice of people with learning difficulties in the design of the service**

- Our evidence here, gathered mainly from our visits, showed an even split regarding performance in this area. We noted in visits to 50 services that people were not involved in the planning of their care, recruitment of staff, or changes to services. Around half of these were services that acted as the home of the person with learning difficulties. The remainder were assessment and treatment centres and low secure services.

## 5. Our findings continued

- Equally, other services for people with learning difficulties provided a wide range of opportunities to enable people with learning difficulties to contribute and collaborate on the design of the service. This was demonstrated through the use of forums for people with learning difficulties, involvement in consultations and changes in services in response to feedback.
- Young people were not usually involved in developing service policies, although many services had begun to hold meetings with them where they could raise issues that mattered to them.

*“There was no evidence that a full re-provision consultation had been undertaken with people with learning difficulties, family members advocates and staff.”*

*“....it was unclear how the staff ensured that less able people with learning difficulties have as much choice and influence in daily living in the house as more vocal people with learning difficulties.”*

*“Opportunities are established for people with learning difficulties, families and carers to become involved in trust activity. These include sub-groups to the board, a self-advocacy group and representation on the partnership board. At local level people with learning difficulties and carers can provide feedback via feedback questionnaires and participating in the service meetings.”*

### **Summary of areas for recommendations:**

We made 56 recommendations around ensuring people's views were listened to. The highest number was in campus and acute assessment and treatment services.

### **Complaints**

- Analysis of questionnaires from adult services shows the majority had received no complaints from people who use the services, family carers and relatives or others in the last six months.
- During the audit visits there were 23 service reports where issues around accessibility of information regarding complaints were raised. In 12 services we saw good provision of information on complaints, with language in a user-friendly format, such as easy read and/or pictures. Eleven services had little or no provision of accessible information about complaints for the people using their services.

*“It was of concern that the trust and local authority could apparently conduct a complaint investigation with respect to care provided on the service without the service staff being involved or knowing the outcome.”*

*“Information on how to complain is not available.”*

### Summary of areas for recommendations:

We made 28 recommendations, mostly around services formalising their process for minor or informal complaints. The process should ensure staff and the person filing the complaint are fully engaged from the time the complaint is raised to the outcome, following investigation.

## Me, and others

In this part of the audit we wanted to understand how people with learning difficulties were supported to maintain contact with family and friends. We wanted to understand the relationship between people with learning difficulties and staff, how staff were supported and how the service was monitored both internally and externally.

### Friends and family

Access to family and friends is an important part of all our lives.

- Young people's needs and rights to maintain relationships with their families were generally very well supported. Family carers were usually invited to case reviews, unless there were relevant safeguarding issues.
- Being placed a long way from home presented some challenges for maintaining contact with families. In spite of this, many young people enjoyed visits home for a

single night or weekend. Some services organised financial support and even travel arrangements to enable parents to visit young people who could not leave the service.

- Young people described few relationships with people outside of their immediate family or services. Opportunities to socialise with people outside the service were often very limited, particularly because education and recreation was often delivered onsite, or in other health service facilities.
- While around half of people using services for adults with learning difficulties had received a visit from family or friends in the last month, many had never received a visit. In acute and assessment centres only 11% of people had been visited by family or friends.
- Very few people had friendships apart from those with paid staff.
- There was evidence from around half of the visits that some staff worked actively to maintain relationships between the person that uses the services and their family and friends.

*"Family records were kept for people with learning difficulties and nurses or social workers made contact with families and relatives to encourage attendance."*

### Summary of areas for recommendations:

Recommendations were made to services to try to support people with learning difficulties to maintain family contact and encourage friendships.

### Staffing and sickness

- Around one in three staff members were reported to be agency or bank staff. This figure is skewed by a small number of establishments with high rates of agency and bank staff. It was less evident in services for adolescents.
- Our visits raised concerns about the over-reliance on bank and particularly agency staff in 40 services. Often, such staff did not receive any introduction to the service and employee checks were not always carried out. We were also concerned about the excessive hours that bank staff worked and often the amount of overtime was not monitored.
- There was also evidence of high levels of vacancy and sickness among staff in some services, with an average vacancy rate of 10% over all services.
- A quarter of all staff in adult services had had a sick day in the last month – a higher level of sickness than might be expected. The national rate of staff sickness for all NHS organisations (2005) is 4.5%, with rates in mental health and community trusts being 5.3%.<sup>15</sup>

*“The service was utilising high levels of bank/agency staff on a weekly basis in order to maintain safe staff levels. On average this calculated to be five bank/agency staff per day. This situation had been ongoing for some months.”*

*“A feedback system for comments to the agency following the placement of any agency staff had recently been withdrawn. There were no policies with regard to agency or bank staff procedures available in the service. There was no formal induction mechanism for agency staff and up-to-date policies were not available on site for reference. There was no system in place to ensure induction was routinely reviewed or actually takes place.”*

### Summary of areas for recommendations:

We made 78 recommendations mainly around ensuring that sufficient staffing levels are reached to enable services to be provided safely and effectively. We also recommended that services carefully manage the use of bank and agency staff. Most recommendations were made to residential and campus services. We made seven recommendations to services for adolescents around safe staffing levels and protecting the time of staff to allow them to take part in development activities.

## Supporting staff

- The majority of services for adolescents appeared to provide staff with opportunities for mandatory and more advanced training, and all of those visited had systems in place to ensure that training – and records – were up-to-date.
- Responses to all service questionnaires show that 56% of staff had received mandatory training in the last 12 months, with 67% receiving an appraisal in the last 12 months. The evidence from visits suggests staff had failed to attend mandatory training in the last year in 118 of the adult services visited (77%). There was also evidence that files on staff training were not maintained appropriately. The quality of record keeping for training was poor with managers of services not always being able to tell what training was required and when.
- Of particular concern was the lack of training around the protection of vulnerable adults.
- In a minority of services visited, we raised concerns about whether staff had received regular appraisals and had appropriate management or clinical supervision to undertake certain tasks.
- In a little over a quarter of the services visited, staff reported feeling isolated from the management tier and board and from other services. We were particularly

concerned about managers' failure to cascade information or interact with staff.

*"The mandatory training was very narrow in focus and didn't seem to address what was really needed.....they might know the temperature of the fridge but don't know how to communicate with people."*

*"Some people wanted to do training but there were never enough staff to release them."*

### Summary of areas for recommendations:

We made 124 recommendations relating to training, supervision and appraisals. Many of these recommendations focused on making sure that staff have access to regular supervision and receive appraisals (including performance development plans) and that all mandatory training takes place. We made four recommendations around training in services for adolescents.

## Monitoring services

An important component of ensuring that services are of a high-quality and that rights are upheld is the arrangements in place for local monitoring.

- All of the services for adolescents we visited participated in the Quality Network for Inpatient Care (QNIC). This is an annual peer-reviewed audit, which results in a local report and action plan.

## 5. Our findings continued

- On the whole, services for adolescents carried out very little monitoring of the outcomes for young people with learning difficulties.
- In the majority of services for adults there were good arrangements for managers from within an organisation to visit a service without notice. This was less likely to take place in residential services.
- The information obtained during our visits indicated that some of the services had clear reporting structures to the board. However, in a similar number, the boards were not fully engaged with the service and where there were mechanisms for communication, staff were not always aware of them.
- Services for adolescents reported much variation in their involvement with commissioners.
- In general we found little involvement by those commissioning adult services. In the majority of services it was stated that the commissioners had not visited in the last six months.
- In a few services the relationship with commissioners was commended, with evidence that they were actively involved in monitoring services. This included making both announced and unannounced visits, attending meetings and reviewing performance. These were predominantly

in acute assessment and treatment services and medium secure services. It was reported that this involvement had improved the quality of services.

*“Commissioners don't know what they are commissioning, they hadn't even seen the service.”*

*“An area of notable practice is the commissioner for learning difficulty services' proactive involvement with the service. The commissioner makes both announced and unannounced visits, attends meetings and monitors issues such as the length of stay for individual people with learning difficulties. In addition the commissioner liaises with social services to make sure that people move on and do not become stuck in the service.”*

### **Summary of areas for recommendations:**

We made 37 recommendations that the commissioners of services are more proactive in managing the service level agreement, knowing the needs of individuals they are buying services on behalf of, and have structures in place to monitor these.

- It was evident that some services had action plans in place arising from the Healthcare Commission investigations in Sutton and Merton and in Cornwall and that they had considered the key recommendations of the reports.

- We also found an evenly mixed picture with regard to 'clinical audit' activity. Some services had good arrangements in place but others showed little evidence of services being reviewed. Good examples included:

*"A Service Improvement Plan with weekly targets. An infection control audit and a CPA (Care Programme Approach) care plan audit had taken place."*

*"The registered manager carries out regular audits of services provided, and has processes in place to obtain feedback from staff and people with learning difficulties."*

#### **Summary of areas for recommendations:**

Recommendations were made to nine services (one for adolescents) that they review and monitor their action plans arising from the Sutton and Merton, and Cornwall investigations. A further 43 recommendations were made that audit activity should be broadened to take account of national guidance to provide greater assurance of the quality of services.

## **My wellbeing**

Here we wanted to be reassured that people were safe and free from abusive situations, and that services were appropriately implementing policies including those on health and safety, safeguarding and physical interventions. Additionally, that people's privacy, dignity and cultural needs were being addressed and their environment was of an appropriate standard.

### **Safeguarding – adult and child protection arrangements including referrals**

Following their visits, our review teams referred six safeguarding concerns to the relevant local authorities under the Healthcare Commission's Safeguarding Adults' Protocol. We have followed up these referrals in each case and are assured that the necessary action has been taken.

- In the adolescent services we visited, young people appeared to be safe from harm and exploitation. All managers were confident that their staff had undergone a Criminal Records Bureau (CRB) check and would not be allowed to work without clearance. The organisational leads for safeguarding were often cited as being involved in staff training, reviewing incidents and having regular contact with the service team. Several managers and more senior staff reported constructive links with the local safeguarding children board.

## 5. Our findings continued

- All adolescent services reported that staff received mandatory training on safeguarding, and records and interviews with staff confirmed this. Access to more advanced training on safeguarding was an issue for one service. Staff were sometimes less clear about protection of vulnerable adult (POVA) arrangements, or which safeguarding route – adult or child – should be followed with older adolescents/ young adults.
- Services for adolescents made few child protection referrals. According to service managers, those that were made most often concerned a person with learning difficulties alleging an assault from another person with learning difficulties. There was evidence that incidents or causes for concern had been acted upon appropriately.
- Very few young people had formal ‘looked after child’ status with local authority children’s services.
- 73% of adult services declared their staff knew how to make child or adult protection referrals. Information from our visits did not support this and suggests that a sizeable minority of organisations are falsely reassured about the level of their staff’s knowledge. Our analysis suggested that fewer than half of services had adequate procedures/policies around safeguarding.
- There was mixed evidence as to whether staff had CRB and POVA checks. We did not see evidence that all relevant staff were consistently checked.
- There were low levels of reporting under ‘whistle-blowing’ procedures with only 46 services declaring one or more incidents.

*“The training record file as well as staff files sampled demonstrated that staff had not received training on POVA and staff interviewed did not know how to make an adult protection referral.”*

*“Staff have not had training in the protection of vulnerable adults and their understanding of the process to report a concern was not fully in line with that outlined in trust policy. The policy on the protection of vulnerable adults was due for review in December 2006.”*

*“They understood protection and how to make a referral but if it was one person with a learning disability hitting another, they didn’t understand that this also needed dealing with.”*

*“A whistle-blowing policy is in place but not all staff have an awareness of it.”*

*“Some staff were too scared to say anything.”*

### **Summary of areas for recommendations:**

A total of 126 recommendations were made around the issue of safeguarding in all areas of services.

### Practices for physical interventions

- From the evidence gained from questionnaire responses, fewer than 10% of services had used interventions other than physical (that is mechanical intervention using for example wheelchair straps or splints, or 'seclusion' in a special area) and more than half of services had not used physical intervention at all in the last six months.
- Conversely just over 80% of services had used 'pro re nata' (PRN) medication (medication given as required rather than routinely), mostly to control behaviour.
- From our visits we found several services where policies for using physical interventions were not in place or not accessible to staff. In two services we saw inappropriate policies for the use of physical intervention. Recommendations followed these themes directly emphasising that policies must be put in place or reviewed and accessible to staff. We made the highest number of recommendations to campus and residential services.
- Where we looked at records of physical intervention there was an equal split between positive and negative findings. Our recommendations centre around the need for services to accurately record instances of physical intervention and use clear definitions of what constitutes physical intervention.
- In several visits we found a positive approach to physical and mechanical intervention. There was active planning for its use, staff were well trained and had good knowledge around dealing with behaviours that challenge. There was also a culture to use it as a last resort, placing an emphasis on de-escalation. However, a smaller but still significant number of services used physical and mechanical intervention with little planning and often inappropriately. There were indications that staffing levels were not appropriate for its use, including insufficient numbers of qualified nurses available. Conversely, sometimes physical intervention was used as a result of low levels of staffing. In a significant proportion of services (mainly campus and residential) staff showed a lack of awareness of what constitutes physical intervention and had inappropriate or out-of-date training around its use.
- We found appropriate arrangements in services for adolescents with all staff receiving mandatory training around managing behaviour, with regular updates. Levels of physical restraint were highly variable but the majority of incidents in a service often involved a small proportion of young people with learning difficulties. No examples of mechanical restraint were reported or observed during visits. In general, the case files we reviewed showed clear plans for managing individuals' behaviour, identifying the signs of impending incidents and how to reflect on the incident with the young person

afterwards. Seclusion was rarely used and only secure services had designated facilities for seclusion.

*“The service does not use physical intervention. A review of training records and discussion with staff showed that they are skilled in de-escalation techniques and use them.”*

*“Physical intervention is used in the service and there is a purpose built seclusion room. However, the ward manager feels that physical intervention and seclusion is a last resort and this view was reflected by the ward staff and in the relatively low numbers of incidents.”*

### **Summary of areas for recommendations:**

We made 16 recommendations to services on the need for documented management systems and for the use of physical intervention to be based on risk. Recommendations were also made around the need to audit the use of physical intervention.

We made eight recommendations around managing young people’s behaviour.

### **PRN medication**

- We identified a proportion of services with poor systems and processes to support the appropriate use of PRN medication. However, in a greater number of the services we visited, teams were satisfied that there was good documentation to support the use of PRN and the services made appropriate assessments of need before using it.

### **Summary of areas for recommendations:**

33 recommendations were made around the use of PRN medication. These focused on using alternative methods to manage behaviour, rather than relying on medication. They also emphasised the need for services to review policies, procedures and practice to build assurance that PRN medication was used appropriately and in line with best practice. The majority of these were made to campus and acute assessment and treatment services (51%).

### **Seclusion**

- We commented on the use of seclusion in a small number of services with positive and negative findings evenly distributed. In some services there was evidence that seclusion was used in a way that was supported by assessment and planning. In others there was evidence that staff were not supported through training, planning and assessment, to use seclusion effectively.
- The highest reported level of incidents we identified in a single service was 25 incidents within six months. In nearly half of the services no people using the services had been hurt by another person using the services or by a member of staff in the last six months.

*“Physical intervention and the use of seclusion/de-escalation were used frequently. All the patients involved in seclusion/de-escalation were informal patients that were not being held under Mental Health Act requirements. Interviews with patients and staff demonstrated that the seclusion/de-escalation room was used for any episode of “bad behaviour” and could last anything up to one hour ten minutes. The records entered in an individual’s case notes showed that patients were sent to the seclusion/de-escalation rooms as a result of “bad behaviour”. There was no evidence that any of the patients sent to seclusion were cautioned under the requirements of mental health legislation for deprivation of liberty.”*

*“All the staff spoken to by the team stated that no forms of physical intervention were used in the service. There was documentary evidence seen to suggest that physical intervention and PRN medication were used regularly to manage the behaviour of people with learning difficulties in this service.”*

**Summary of areas for recommendation:**

We made 11 recommendations around the use of seclusion including the need to ensure it is carried out within the requirements of the Mental Health Act.

**Culture and faith**

- This area did not emerge as a strong theme, only 12 services had applicable evidence from the visits. A small number of services made little attempt to address wider cultural needs with little provision of training for staff in this area.
- Several services for adolescents described, or demonstrated during a visit, sensitivity and respect for young people’s culture and faith. Some displayed posters, notices or other materials about a range of diverse beliefs and practices. These displays were sometimes devised or initiated by people with learning difficulties. Some services had good links with local spiritual leaders.
- The recommendations we made in this area stressed the importance that services (predominantly short break services) make arrangements to meet the various cultural and religious needs of people with learning disabilities.

**Access to personal money**

- Responses provided to our questionnaire were more positive than our findings during visits. Overall, it appeared from our analysis of the questionnaires that people with learning difficulties were, where possible, encouraged to manage their own finances and to be involved in financial decisions. Secure internal banking facilities were often reported to be available, managed by the finance officer.

## 5. Our findings continued

- During our visits we noted that several of the services did not support people with learning difficulties to be in control of their own finances. We identified a lack of training in how to encourage independence.
- There was confusion over who was responsible for paying for activities.
- Several services lacked effective systems to ensure money was being used correctly (particularly whether it was appropriate for people using the services to pay for equipment and certain staffing costs). Several people with learning difficulties did not have access to independent bank accounts. We also identified issues surrounding access to money and choice over its use.
- Young people did not have secure storage to hold their own money. In case files, there was little evidence of formal plans to develop people's skills with money.
- For 'older' young people, staff were sometimes unclear about benefit entitlements and believed that it was the role of the person's social worker to advise and make arrangements.

*"Quite large amounts of money have been spent on holidays and although the service is very thorough about its financial processes and checking with the PCT, there appears to be lots of assumptions made about what residents want and are communicating to staff."*

*"The financial records of the people with learning difficulties suggest they have little opportunity to spend their money."*

*"People with learning difficulties do not look after their own money whilst in the service and staff have not been trained in supporting people to manage their own money, the principles of Valuing People are not being followed in this respect. Staff have had no training on managing (personal and service) accounts, therefore the trust cannot be confident that expected accounting procedures are followed or that record keeping is adequate".*

### **Summary of areas for recommendations:**

We made 18 recommendations to services to introduce or develop appropriate arrangements for encouraging people with learning difficulties to have financial independence and control.

### **Environment**

- Most services we visited were well cleaned, with only six services identified where cleanliness was a problem.
- Around one fifth of the services visited were in need of redecoration. Problems included decoration being outdated, tired or shabby. Review teams noted that in 20 services there was an institutional rather than a homely feel. We also noted a similar number of services that were particularly pleasant.

- We observed few issues relating to the privacy and dignity of people with learning difficulties. However in some services there was a lack of separate areas for men and women where these were needed. Some people had to share bedrooms and there was a lack of private places to meet with visitors or to go to be alone.
- Given the building and space constraints on some services, staff generally gave examples of being sensitive to the needs of young people to have private time. Most bedroom doors had peepholes, but staff stated that they used these discretely. Bathroom doors were not usually lockable, and some young people washed and dressed with staff within sight, due to concerns about risk. Most young people could use their bedrooms during the daytime and no young people reported issues around privacy to the audit teams.
- Some visits revealed several inadequate health and safety arrangements. These included blocked fire exits, poor environmental assessment of risk, poor arrangements for clinical waste, and unsafe fridge and freezer temperatures. This was particularly evident in a third of all campus services.
- There was evidence that the design of some services did not meet the needs of people using them. This is because they did not appear to be compliant with the Disability Discrimination Act (1995), there was a

shortage of space, or areas were not sufficiently accessible to people using the services.

- No causes for concern about the health and safety of young people were raised through audit visits.

*“The environment and amenities are dated and in need of immediate refurbishment. The overall impression is one of having changed little since the service opened in the 1970s.”*

*“The female person with a learning difficulty has to use a bathroom in the male person with a learning difficulty’s flat.”*

*“Eight residents have been allocated to twin bedded rooms and so have to share with another person. This impacts on their care and has led to an increased number of incidents of residents harming each other.”*

*“The respite service was found to be clean in all areas, although it is not fully compliant with the Disability Discrimination Act 1995, some work has been done to try to meet people with learning difficulties’ needs, within the limits imposed by the building. There is no lift to the first floor.”*

*“The people using the service have out grown the building and urgent attention needs to be considered, it is unacceptable that individuals cannot access the sink in their rooms because they require the use of a wheelchair.”*

## 5. Our findings continued

*“Fire doors are currently locked and create a hazard for egress in the event of a fire. It is not clear if this has been reviewed as part of the service’s fire risk assessment.”*

*“One room has been padded throughout including the emergency exit thus making the exit unusable.”*

### Summary of areas for recommendations:

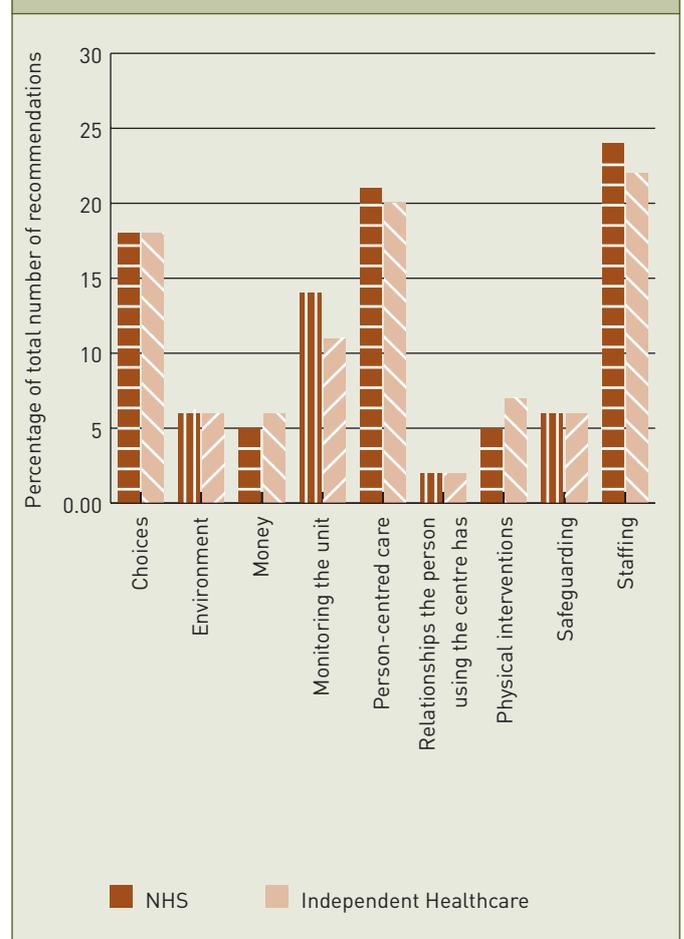
Recommendations to improve the physical appearance of buildings were made to 59 services particularly campus and residential. We also made 97 recommendations to improve the environment, health and safety, privacy and dignity and the state of the building.

## Overall number of recommendations

Taking all service types we made 2,548 recommendations in total for improvements to the 154 services. These ranged from fairly minor suggestions to where we identified breaches (in relation to areas where there are clear expectations, for example around the safeguarding of children or adults) of a more serious nature. There was only a small range in the mean number of recommendations made per service type. See table 3 on the following page.

There was no significant difference in the volume and type of recommendations made to services run by the NHS and services run by independent healthcare providers. See figure 2 below.

**Figure 2: Recommendations for improvement by volume and type**



| <b>Table 3: Recommendations for improvement by type of unit</b> |  |                                  |                            |                        |
|---|--|----------------------------------|----------------------------|------------------------|
| <b>Unit type</b>  | <b>Number of unit visits per unit type</b> | <b>Number of recommendations</b> | <b>Percentage of total</b> | <b>Mean no. of rec</b> |
| Acute assessment and treatment                                  | 24   | 382                              | 15.0%                      | 15.9                   |
| Short break (or respite)  | 22   | 386                              | 15.1%                      | 17.5                   |
| Individual residential services paid for by the NHS             | 31   | 562                              | 22.1%                      | 18.1                   |
| Low secure services   | 18   | 278                              | 10.9%                      | 15.4                   |
| Medium secure services  | 7  | 73                               | 2.9%                       | 10.4                   |
| High secure services  | 1  | 19                               | 0.7%                       | 19.00                  |
| 'Old' long stay provision                                       | 5  | 80                               | 3.1%                       | 16.00                  |
| Campuses  | 31   | 549                              | 21.5%                      | 17.7                   |
| Specialist adolescent services                                  | 6  | 76                               | 3.0%                       | 12.70                  |
| Other   | 9  | 143                              | 5.6%                       | 15.9                   |
| <b>Total</b>  | <b>154</b>                                 | <b>2548</b>                      | <b>100.00%</b>             |                        |

A report on the findings in services for adolescents will be published in early 2008.

# 6. Our conclusions on the state of healthcare services for people with learning difficulties

The fundamental purpose of the audit was to provide information on the extent to which healthcare services for people with learning difficulties were safe and provided to an appropriate quality. Are there any services that might be comparable to the standards of care identified in our investigation in Cornwall?

## Immediate concerns

Further to our visits we identified services that were a cause for concern.

- We identified six safeguarding concerns in five organisations. We referred these to the relevant local authorities using our protocol for safeguarding adults and are satisfied that the local authorities are dealing with them. None of these services gave rise to concern in the way that services in Cornwall did. Table 4 provides more information.
- The Healthcare Commission investigation team worked directly with Bromley Primary Care Trust to bring about improvements in the services provided following our escalation process.

## Themes from our findings across all services

We issued 154 reports, each making recommendations of a greater or lesser importance. A summary of recommendations made to each organisation is available on our website.

During this process we encouraged organisations to publicise our findings relating to their services. To date, we have not made our findings in individual services publicly available. This is to protect the confidentiality of people with learning difficulties, who often live in services where there are only a few people. We have had to balance these concerns with understandable calls for us to be open and transparent with our findings for the benefit of family carers. We will continue to discuss this with those concerned.

We found only a few services where the quality of care and the attention paid to the safety of people with learning difficulties were uniformly good across all aspects of care.

We know that staff can find this a challenging environment to work in, but have seen that services can be provided well. Where we saw better performing services, they:

- placed people with learning difficulties at the centre of care, particularly in relation to planning for their care and helping them to make choices
- provided care in an attractive environment
- had clear arrangements for safeguarding
- provided access to independent advocacy services

**Table 4: Services where a referral was made to the local authority**

| Name of organisation  | Number of referrals |
|---|---------------------|
| <p>Bromley PCT</p> <p>We visited four services in this trust. The teams were concerned with the quality of care and referred the trust to the Healthcare Commission's investigation team under our escalation process. We are publishing a detailed report on our findings.</p>   | 2                   |
| <p>Care Principles Ltd</p> <p>We were concerned about inappropriate care given to a person with learning difficulties, which was not recorded in their care plan. A 'protection of a vulnerable adult' referral was made to the local authority. Care was improved in line with best practice and the person concerned is now experiencing better health outcomes.</p>  | 1                   |
| <p>Coventry and Warwickshire Partnership NHS Trust</p> <p>The referral followed a serious allegation of abuse by a person with learning difficulties. We immediately informed the police and reported the incident to the local authority, further to arrangements for vulnerable adults. The allegations were investigated thoroughly and not upheld.</p>  | 1                   |
| <p>North Lincolnshire PCT</p> <p>We had wide-ranging concerns about poor standards of care and that vulnerable adults were not being sufficiently protected. We were concerned about the lack of stimulating activities, the absence of good quality plans for people's care and poor processes for the training of staff. We were also concerned about the poor environment, how confidential information was stored and fire safety arrangements.</p> <p>We are working with the PCT, together with the local authority and the strategic health authority, to ensure that immediate improvements are implemented. If we are not convinced that the PCT is making good progress with the necessary improvements, we will consider an escalation to the Healthcare Commission's investigation team for further action.</p> | 1                   |
| <p>Sandwell Mental Health and Social Care Trust</p> <p>We reviewed a person's care plan and were concerned about the acceptance of their behaviour in relation to another person with learning difficulties. This suggested the service had a poor understanding of appropriate behaviours. We made a 'protection of a vulnerable adult' referral to the local authority and at a local safeguarding meeting it was agreed that staff were working well with the people living there.</p>   | 1                   |

- were open to internal and external scrutiny, with the organisations' leaders playing an important role in this
- had good practices in place for the training of staff

Most services appeared to be providing basic standards of care and had, on the whole, committed teams of staff. There were unacceptably wide variances in the standards of care between services, both within an organisation and when compared to others. In most establishments, we have concerns about the quality of care overall.

From the evidence set out in section 5 of this report, we believe that:

- most services pay insufficient attention to safeguarding vulnerable people across all aspects of their care
- on the whole, care is poorly planned with individuals with a learning difficulty
- there are inadequate arrangements, both internally and externally, for the scrutiny of services
- some services have good levels of stimulating activities and opportunities for people with learning difficulties to take part, but in others the range of choice is limited
- on the whole, services have appropriate practices for physical intervention, but we have

some concerns about their use of medication, particularly where there is evidence that care plans are not in place or not monitored

- there is often a lack of leadership and little evidence to show how boards and service managers can be assured about the standard of care that their organisation provides

An additional important finding is that residential care is being provided by health services in largely institutionalised settings.

We take each in turn and consider in more detail.

### **Poor procedures for safeguarding vulnerable people**

We are concerned about the findings here. This shows that in most services there are inadequate arrangements for safeguarding people although there are instances of good practice, particularly in services for adolescents where we are assured that procedures are robust.

There appears to be a lack of awareness of what constitutes abuse, and we remain concerned that this leads to under reporting of incidents with the potential for abusive practices being allowed to continue unchallenged. The audit visits did not identify specific examples of physical abuse but many institutional failings were noted.

This goes to the heart of human rights. Until there are appropriate safeguarding arrangements we cannot be assured that the human rights of people with learning

difficulties in specialist inpatient healthcare settings are being upheld.

This could be addressed partly by services adhering to appropriate policies and procedures and by training staff to be more sensitive to abusive behaviours. More fundamentally by ensuring that people who work with people with learning difficulties can relate to them as they relate to their friends and family, the culture of “them and us” begins to dissipate.

Skilled people advocating on behalf of people with learning difficulties can provide valuable external scrutiny and potentially shine a light on poor behaviours. However, we are concerned that access to such services is patchy at best.

### **Poor planning of care for people**

We saw insufficient evidence that plans for the care of a person with learning difficulties are accessible to that person, current and reviewed on a frequent enough basis.

This is surprising given that our focus was largely on specialist health provision with trained professionals providing services. Assessment and treatment centres are just that. If people with learning difficulties are to lead more independent lives following assessment and treatment, then the planning for this must be improved, updated frequently and made more relevant to the individual. This is the case in both the NHS and independent healthcare.

### **Lack of internal and external scrutiny**

On the whole we saw limited evidence of engagement by those (local authorities and primary care trusts – often working in partnership) commissioning services on behalf of people with learning difficulties. We see this as a missed opportunity to influence the safety, quality and cost-effectiveness of service provision.

Many service managers had little idea of the arrangements contained within the contract and had limited understanding of commissioners’ expectations. Similarly most commissioners, for example, do not undertake visits to services and, as such, miss an opportunity to understand better the quality of services being purchased. For many of us, commissioning is an abstract concept. If we think about choosing something to buy with our money or selecting a school with our children, we take in lots of information, we weigh up various options, we make a selection and review our decisions. We believe that in purchasing services for people with learning difficulties commissioners should consider doing so in a different way than they do for the commissioning of other services.

Sadly, our evidence shows that people with learning difficulties have few opportunities to make or maintain friendships. Moreover, family contact is often made more difficult by placements a long way from the family’s home. This appears widespread. Again, this is something we would like commissioning authorities to pay more attention to.

### **Lack of stimulating activities and opportunities**

There were mixed results here with many services providing good levels of stimulation and opportunities to take part in a range of activities. Approximately half of the services were providing people with some opportunity to move around and leave the site. We were careful to take into consideration that some people with learning difficulties are formally detained, so their freedom is often curtailed. Taking this into account, the range of activities offered was limited. We found limited evidence of access to higher education, paid employment and similarly enriching activities. For many people the opportunity to go swimming was considered to be a highlight of the week.

We believe that creativity and energy must be applied to identifying opportunities for exciting activities. However, the very real pressures that staff are under – often due to vacancies, reliance on agency staff, and overtime – make this a challenge for many services.

### **Physical intervention practices**

On the whole, we found physical intervention was undertaken appropriately. Many services do not undertake physical intervention of any sort. During our visits we found ‘de-escalation’ techniques were applied thoroughly and staff were committed to practising this rather than physical intervention. This is to be commended.

The use of PRN medication is a more difficult area. A large majority of services used PRN

on a regular basis to control behaviour. Records were maintained appropriately and understanding and administration good. In some services we noted that the high usage of PRN seemed appropriate.

The issue here is one of evidence-based practice. Does PRN or indeed regular doses of psychotropic medication have any basis as a response to the challenging behaviour of people with learning difficulties? It is our understanding that such evidence is extremely limited.

Where medication is being used in response to specific and identified mental health need, it must be prescribed and administered according to the best evidence currently available. Due consideration must be given to its application for people with learning difficulties. Such medication would generally only be used in conjunction with other therapeutic interventions, but where care plans are not in place, we cannot be certain. This area of concern was identified in *Valuing People* but has perhaps received insufficient attention since its publication.

### **Lack of leadership**

We are concerned that there is little evidence to show how boards and senior managers responsible for services can be assured about the standard of service provision. Sometimes this is due to a lack of information, or where information is available, it often demonstrates unacceptable performance and poor practice.

Fewer than half of the management boards considered their own monitoring arrangements to be adequate. While there is evidence that some board members visit services to see first hand the quality of care provided, staff teams had little understanding of the purpose of the visits or of any action taken as a result.

The uptake of mandatory training is often poor. Arrangements for appraisal and supervision are often inadequate and many services have very high rates of vacancy and sickness among staff. We are concerned that in many services, staff may feel disempowered and under-valued. It is not difficult to see the relationship between this and the feeling of disempowerment, not being listened to and lack of control over most parts of their lives that people with learning difficulties have.

### **Residential care provided by health services in institutionalised settings**

We found a significant volume of service provision (around half of all services categorised as 'campus' or residential provision) where the person with learning difficulties views it as their home. It is unclear however whether some of these services are commissioned by a local authority under a partnership agreement.

People with learning difficulties that live in such services are not receiving active treatment as a consequence of their learning difficulty. Due to several factors of history, culture and practice – rather than active decisions taken by commissioners – a philosophy of institutionalised care is evident. The evidence relating to the

volume of recommendations made to campus and other residential provision is of significant concern to us. Indeed the Government has indicated that by 2010 all campus provision should be closed. Around 15% of all people in specialist learning difficulty services live in campus provision. We want to see improvement in these services regardless of their closure date.

During the audit process itself, further to representations made by healthcare organisations, we directly referred three organisations to the Commission for Social Care Improvement (CSCI) to confirm whether they should register with the CSCI as care homes. Furthermore, we took the decision to remove 91 services across three NHS providers from the audit. These services were potentially applicable for registration with the CSCI, and the NHS providers suggested that they were in the process of registration. To date, one NHS provider has registered all services referred together with an additional service; one has registered some services and one has not attempted to register any services. The CSCI is following up with this organisation.

This is a confusing state of affairs suggesting that healthcare providers and their commissioning partners must put in place improved and more transparent arrangements. This is partly addressed by the programme to close campus services, nevertheless we have residual concerns about a range of other services – outside the programme of closure.

Our conclusion, at a general level, is that the quality of care in the majority of services for people with learning difficulties needs significant improvement. Our recommendations to services, when implemented, will ensure basic standards are met. This raises challenges for all of us. Not least, because there is a danger that these findings and conclusions could be seen as just the latest in a depressingly long line. We see the need for a more profound change.

There needs to be a shift in the way specialist healthcare services are commissioned and provided so that we can be assured of the safety of people with learning difficulties and the quality of services they receive. We would like this change to take place swiftly, and for it to be enduring.

# 7. What happens next?

Any historical analysis of how society has reacted to people with learning difficulties shows that there has been progress, but sometimes the change has been slow.

We now need a shift in the way specialist healthcare services are commissioned and provided so that we can be assured of the safety of people with learning difficulties together with the quality of services they receive. We would like this change to take place swiftly, and for it to be enduring.

There are no easy solutions but it is important that organisations work together for long-term solutions.

We want to see a much clearer set of performance expectations in place for all of those involved in commissioning and providing services for people with learning difficulties. We will work closely with the Department of Health to pursue this.

We want to promote improvement founded on the rights of individual people with learning difficulties. We are anxious that some might respond to a challenging national report by conceding that the risks are too great, that they are going to stop being involved in these services altogether – passing the responsibility on to others. We see an alternative way forward.

As instigators of the audit we will take a number of actions, which are listed below. There are also several actions that we expect others to consider and take forward, for example people with learning difficulties, their family carers, voluntary and patient groups and local communities. We expect to play a part in helping to take these forward.

## **The Healthcare Commission will:**

- work with the healthcare organisations, visited during the audit, to deliver their action plans. We asked each organisation to put monitoring arrangements in place so that their management boards can be assured that actions have been taken
- continue to use the findings from the audit in our regulation of the independent healthcare sector. The audit complements and supports the assurance mechanisms we have in place with regards to compliance by independent healthcare organisations with the Private and Voluntary Health Care (England) Regulations 2001. The audit does not form part of the routine regulatory activity undertaken by the Healthcare Commission. However, if during the course of the audit any material breaches of the national minimum standards were found in independent healthcare organisations, they were, and will continue to be followed up in the routine inspection process. Similarly, we followed up any immediate serious concerns with regard to NHS providers, to ensure appropriate action was taken and we will continue to monitor them

- immediately begin to carry out unannounced inspection visits to services for people with learning difficulties. This is to provide assurance that the findings of this report have been noted, that any required action has been taken and that the human rights of people with learning difficulties have been upheld. We will also visit services that were not visited as part of this audit
- use the information gathered during the audit to cross-check the declarations made by NHS trusts as part of our assessment of core standards in our 2007/2008 annual health check
- introduce a set of performance indicators around the provision of learning difficulty services as part of our 2008/2009 annual health check. We will involve others, including the Department of Health and interested organisations, in finalising the detail of these indicators. They will be announced during 2008, but could include scored measures, important in assessing quality of care, on:
  - the planning of care with and around people with learning difficulties
  - individual health action plans
  - progress towards the closure of NHS campuses
  - progress towards implementing the mental health national service framework for people with learning difficulties
  - explore how best to assess the provision of independent advocacy services and arrangements for safeguarding
  - work with others, particularly the Government's Valuing People team, to actively promote the findings from this audit
  - carry out a joint programme of work with the CSCI in 2008/2009 to assess the quality of commissioning of services for people with high support needs, including people whose behaviour challenges or with mental ill health needs. We will pay particular attention to the use of high cost, out of area placements both in terms of the quality of outcomes for people and the effective use of resources.

### **We also expect others to play a part in addressing the issues raised in this report.**

#### **Provider organisations**

We expect all provider organisations to evaluate and review their care and learn from these findings. We are greatly encouraged by the evidence from our externally commissioned evaluation that shows the audit has already triggered significant change in those organisations audited. We would like there to be an ongoing process of evaluation and reflection.

We want services for young people to be more active in putting systems in place to measure the impact of their care with regards to the outcomes experienced by young people.

We want provider organisations (NHS organisations and independent healthcare organisations subject to the Healthcare Commission's registration requirements) to reflect on the type of services they provide. We expect that some organisations, particularly those that are residential in nature, will consider that they are not best placed to provide some aspects of care. This may be appropriate from a risk or financial perspective but needs the agreement of commissioning partners and partnership boards. Any changes need to be part of a managed process, to ensure that those organisations best placed to provide social care can do so, with healthcare organisations doing what they do best. We will work with the Department of Health, the CSCI and Valuing People team to provide assurance that the programme to close campus services progresses, taking into account the potential impact on the safety of people with learning difficulties and the need to ensure that all services fall within the appropriate regulatory arrangements.

### **PCTs**

We want PCTs, their strategic health authorities, and local authorities – working together as appropriate – to play a more active role in commissioning learning difficulty services. This must take into account the

recently published Department of Health guidance on commissioning specialist health services for adults with learning difficulties and in ensuring age-appropriate provision.<sup>1</sup> This audit has shown that a different, and more inclusive, approach is needed when examining the provision of care for people with learning difficulties.

We believe that commissioners, along with their strategic health authority partners, should review this report and consider how best to meet some of the challenges raised. They must explicitly consider this commitment as part of local area agreements to be published by the end of June 2008. We look forward to supporting this as, with the CSCI and the Mental Health Act Commission, we focus on assessing the commissioning of services for people with learning difficulties in 2008/2009.

### **Strategic health authorities**

In addition to the points made in the paragraphs above, we want each strategic health authority to ensure that the programme to close campus services takes into account the views and needs of people with learning difficulties. This should be in line with the commitments made in the Government's *Our health, Our care, Our say*<sup>2</sup> together with the commitment made in the Government's comprehensive spending review, October 2007.

### **Department of Health**

During this audit we heard repeated calls for a national service framework for people

with learning difficulties, on the basis that frameworks have been a powerful driver in other clinical areas. The Department of Health intends to introduce new registration requirements for all healthcare organisations under the legislation that sets up the new health and social care regulator. We call upon the Department of Health to take into account the risks presented in specialist learning difficulty services when it establishes national standards of performance.

### **Department of Health and training bodies**

People with learning difficulties expect staff working in services to be able to receive high-quality training that promotes individuals' human rights. We do not believe that such training is generally available or promoted sufficiently by employers. We will explore this with strategic health authorities, the Department of Health, Skills for Health, universities and other interested parties and ensure there is sufficient leadership of this important aspect of care.

### **Learning disability partnership boards**

These were set up in each local authority to ensure improvements happen for people with learning difficulties. Members include people with learning difficulties, family carers and representatives from relevant organisations and agencies. The audit process has led to the development of tools including questionnaires, training packages and a DVD, and a cadre of people experienced in reviewing services for people with learning difficulties. We would like local learning disability

partnership boards to consider whether they can adopt aspects of the audit to provide the external scrutiny that people with learning difficulties tell us is important.

We also call upon learning disability partnership boards to be active partners with commissioners in providing a vision for safe, high-quality services that uphold people's human rights.

# Appendix 1

## Issues recently identified in healthcare services for people with learning difficulties

- Commission for Health Improvement 2003<sup>16</sup> investigation into secondary health services for people with learning difficulties in Bedfordshire and Luton Community NHS Trust. This identified a range of failings including poor clinical governance structures in learning difficulties services, lack of leadership, poor mechanisms for the protection of adults, lack of good systems for the planning of care, and no internal or external auditing of the standard of services provided.
- National Patient Safety Agency<sup>17</sup> report into patient safety issues for people with a learning disability (2004).
- Mencap's *Treat me right!* (2004)<sup>18</sup> report focused on stories from parents and people with learning difficulties, regarding the poor quality of care received in acute and primary care services.
- *The First National Survey of People with Learning Disabilities* (2005)<sup>19</sup> highlighted the disadvantages they faced when compared to the general population. Social isolation, a lack of jobs, poorer health and a lack of money for basic needs, were all cited.
- National Audit of Violence<sup>20</sup> (2005) collected information from 47 learning disability and mental illness inpatient services from 16 trusts in England and Wales. Seventy-nine per cent of staff reported they had been attacked, threatened or made to feel unsafe. Fifty-one per cent of people with learning difficulties reported having experienced violence whilst in inpatient care. Low staffing levels and high levels of unfamiliar agency staff were cited as triggers to violence. Half of patients stated they did not have enough to do during the day and not enough quiet space was available on the wards.
- The Healthcare Commission with CSCI joint investigation in 2006 into Cornwall NHS Partnership Trust found "... services were being provided in totally unacceptable environments, record keeping was so poor that it prevented effective care from being provided...physical restraint being used illegally and excessive use of medication...no treatment plans were evident and senior leaders in the trust lacked strategic vision and an effective operating plan".
- The Healthcare Commission investigation in 2006 into Sutton and Merton NHS Trust found care in this trust to be old fashioned, institutionalised and lacking good care planning and appropriate leadership. Abusive practices were taking place and there was a lack of stimulation and planned activities for people using the service.
- In 2006 the Healthcare Commission took enforcement action against an independent healthcare provider requiring it to close one of its learning difficulty establishments. The main concerns related to inadequate staff training, the lack of Criminal Record

Bureau checks, high levels of Protection of Vulnerable Adults referrals and poor care and treatment of patients.

- The Disability Rights Commission (2006) *Closing the Gap*<sup>21</sup> report highlighted poor access to primary care, lack of health screening, poor treatment in general practice and a lack of user friendly literature to support informed choice.
- Mencap's most recent study *Death by Indifference* (2007)<sup>22</sup> highlighted the pathways of six individual people 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 has prompted an independent inquiry into access to healthcare for people with learning difficulties chaired by Sir Jonathan Michael and reporting in March 2008.
- Mansell's revised study (2007)<sup>23</sup> looked at people with learning difficulties and challenging behaviour or mental health needs. It stated that there is still room for improvement, especially in commissioning relevant services for this group of people, ensuring the skill mix and expertise of the staff is relevant, providing appropriate team based services, longer term specialist services closer to home and monitoring of services.

# Appendix 2

## The audit process

The audit included all NHS trusts and independent healthcare organisations providing adult or specialist adolescent learning difficulty services in England. These were organisations providing:

- acute assessment and treatment
- short break (or respite) services
- individual residential services paid for by the NHS (but not regulated by the Commission for Social Care Inspection)
- low secure services
- medium secure services
- high secure services
- 'old' long stay services
- campus services
- specialist adolescent services

The teams visited individual services rather than all of the healthcare organisations' services. The audit did not address services provided by prisons, day services (health), community learning difficulty teams, challenging behaviour teams, assertive outreach teams, or services for children. Services registered with the Commission

for Social Care Inspection (CSCI) were also outside the scope of the audit. The experience of people with learning difficulties in other forms of specialist care such as mental health services was also not covered.

### Engagement and consultation

In all of its assessment activity, the Healthcare Commission recognises that it must carry out a programme of engagement with a range of experts to ensure it takes the important issues into account. This work was no different. The experts we talked to included a range of people with learning difficulties, family carers, people involved in academic research and teaching, people who work in services including those who advocate on behalf of people with learning difficulties and the voluntary sectors. We established an external reference group of people with learning difficulties and family carer representatives, representatives from the Valuing People support team, Department of Health, NHS, independent healthcare and social care providers, key charitable organisations, specialist academics, and staff from the Healthcare Commission and the CSCI. This reference group has met eight times and continues to meet to ensure appropriate action is taken after publication of these findings.

In 2005, the Healthcare Commission hosted a consultation on health for people with learning difficulties, and their thoughts and concerns informed some of the questions for the data collection.

We held a workshop for independent healthcare providers and a joint workshop hosted by the NHS Confederation, attended by more than 40 representatives from NHS trusts. The events allowed information to be exchanged, and offered these organisations an opportunity to shape the methodology and the scope of the audit by volunteering to be pilot sites.

### Piloting the process

We conducted a successful pilot in the autumn of 2006. The methodology for the audit was piloted in three organisations: one independent healthcare organisation (Care Principles Limited) and two NHS trusts (Hertfordshire Partnership NHS Trust and North Staffordshire Combined NHS Trust). A total of 50 visits to services took place.

Two questionnaires were developed, one for the board/senior management team and one for each individual service manager. These questionnaires were self-assessments and

were completed using a web-based tool. A team of three or four people visited each service that completed a questionnaire. The team included a person with learning difficulties and supporter or family carer, a clinician or manager (from another of the organisations within the pilot) together with an assessment manager from the Healthcare Commission.

Following the half-day visits a written report was sent to the organisation concerned for review and comment.

Each person involved in the visits received one day's training, supported by training materials provided in advance. Following competitive tender, the British Institute of Learning Disabilities ran the training.

The methodology was evaluated through consultation with all those participating and included events for people with learning difficulties and family carers. The pilot was an essential part of the audit, identifying several issues that needed to be changed before the start of the national audit. Changes included:

- revising some questions in both the 'service manager' and 'board' questionnaires

- excluding health day services. This decision was based on the information collected in the pilot, which suggested that these services were less of a risk than others, as people with learning difficulties were not 'living' there
- slimming down the information pack provided before the training and producing a DVD to simplify communication of the process
- modifying the report templates for the visits
- reviewing the use of personal information. It became evident from the reports that when consent was not given to look at care plans or people were considered incapable of giving consent and so files were not examined, the information gathered was much poorer. After careful deliberation, the Healthcare Commission's 'Committee on the use of confidential personal information' gave permission to access people with learning difficulties' files without consent.

## National phase

The Healthcare Commission identified 638 individual learning difficulty services (not including pilot services) that fell within the scope of the audit. They were provided in 72 NHS trusts, and 17 independent healthcare organisations registered with the Healthcare Commission.

| <b>Table 5: Services covered by the audit questionnaire and visited</b>          |   |
|--|---|
|  | <b>Service visited within the audit</b> |
| <b>NHS organisation</b>  |   |
| 5 Boroughs Partnership Trust   | ✓                                       |
| Barnet, Enfield & Haringey Mental Health NHS Trust/North London Forensic Service | ✓                                       |
| Barnsley PCT/Barnsley Social Services  | ✓                                       |
| Bath and North East Somerset PCT   | ✓                                       |
| Bedfordshire and Luton Mental Health and Social Care NHS Trust                   | ✓                                       |
| Berkshire Healthcare Trust   |   |
| Bradford District Care Trust   | ✓                                       |
| Brent Teaching PCT   | ✓                                       |
| Bromley PCT  | ✓                                       |
| Bury PCT   | ✓                                       |
| Calderstones NHS Trust   | ✓                                       |
| Cambridgeshire and Peterborough Mental Health Partnership NHS Trust              | ✓                                       |
| Camden and Islington Mental Health and Social Care Trust                         | ✓                                       |
| Cheshire & Wirral Partnership NHS Trust  | ✓                                       |
| Cornwall Partnership NHS Trust   |   |

| <b>Table 5: Services covered by the audit questionnaire and visited</b> |   |
|---|---|
|   | <b>Service visited within the audit</b> |
| Coventry and Warwickshire Partnership NHS Trust                         | ✓                                       |
| Cumbria PCT   | ✓                                       |
| Derbyshire County PCT/Derbyshire County Council                         | ✓                                       |
| Derbyshire Mental Health Services NHS Trust                             | ✓                                       |
| Devon LD Health & Social Care Partnership                               | ✓                                       |
| Doncaster and South Humber NHS Trust                                    |   |
| Dorset Healthcare NHS Foundation Trust                                  | ✓                                       |
| Dudley PCT – Learning Disability Specialist Health Service              |   |
| East Lancashire PCT   | ✓                                       |
| Eastern & Coastal Kent PCT  | ✓                                       |
| Enfield PCT   |   |
| Gateshead PCT   |   |
| Gloucestershire Partnership NHS Trust                                   | ✓                                       |
| Hampshire Partnership NHS Trust   | ✓                                       |
| Haringey Teaching PCT/Haringey Learning Disabilities Partnership        | ✓                                       |
| Humber Mental Health NHS Trust  | ✓                                       |

| <b>Table 5: Services covered by the audit questionnaire and visited</b> |   |
|---|---|
|   | <b>Service visited within the audit</b> |
| Isle of Wight NHS PCT   |   |
| Kent and Medway NHS and Social Care Partnership Trust                   | ✓                                       |
| Kingston Primary Care Trust   | ✓                                       |
| Knowsley PCT/Knowsley Metropolitan Borough Council                      |   |
| Leeds Mental Health and Teaching NHS Trust                              | ✓                                       |
| Leicestershire Partnership NHS Trust                                    | ✓                                       |
| Lincolnshire Partnership NHS Trust                                      |   |
| North Lincolnshire PCT  | ✓                                       |
| Mersey Care NHS Trust   | ✓                                       |
| Milton Keynes PCT   |   |
| Norfolk PCT   | ✓                                       |
| North Cumbria Mental Health & Learning Disabilities NHS Trust           | ✓                                       |
| North East Essex PCT  | ✓                                       |
| North East London Mental Health NHS Trust                               |   |
| North Yorkshire and York PCT  | ✓                                       |
| Northamptonshire Healthcare Trust                                       | ✓                                       |

| <b>Table 5: Services covered by the audit questionnaire and visited</b> |   |
|---|---|
|   | <b>Service visited within the audit</b> |
| Northumberland, Tyne and Wear NHS Trust                                 | ✓                                       |
| Nottinghamshire Healthcare NHS Trust                                    | ✓                                       |
| Oxleas NHS Foundation Trust   |   |
| Plymouth Teaching PCT   |   |
| Portsmouth City Teaching PCT  | ✓                                       |
| Rotherham PCT/Rotherham Learning Disability Service                     | ✓                                       |
| Sandwell Mental Health & Social Care Trust                              | ✓                                       |
| Sheffield Care Trust  | ✓                                       |
| Solihull Care Trust   | ✓                                       |
| South Birmingham PCT  | ✓                                       |
| South Essex Partnership NHS Foundation Trust                            | ✓                                       |
| South London & Maudsley NHS Foundation Trust                            |   |
| South Staffordshire Healthcare NHS Foundation Trust                     | ✓                                       |
| South West London and St George's Mental Health NHS Trust               | ✓                                       |
| South West Yorkshire Mental Health Trust                                | ✓                                       |
| Stockport PCT   |   |

| <b>Table 5: Services covered by the audit questionnaire and visited</b>          |   |
|--|---|
|  | <b>Service visited within the audit</b> |
| Suffolk Mental Health Partnership NHS Trust                                      | ✓                                       |
| Surrey and Borders Partnership NHS Trust   | ✓                                       |
| Sussex Partnership NHS Trust   | ✓                                       |
| Swindon PCT  | ✓                                       |
| Tees, Esk and Wear Valleys NHS Trust   | ✓                                       |
| The Ridgeway NHS Partnership   | ✓                                       |
| Walsall Teaching PCT/Walsall Integrated Learning Disability Service              | ✓                                       |
| Wolverhampton City PCT   |   |
| Worcestershire Mental Health Partnership NHS Trust/Worcestershire County Council |   |
| <b>Independent healthcare provider organisations</b>                             |   |
| Acorn Care Ltd   | ✓                                       |
| Alpha Hospitals  |   |
| Brookdale Healthcare Ltd   |   |
| Care Aspirations   | ✓                                       |
| Care Principles Ltd  | ✓                                       |
| Castlebeck Care (Teesdale) Ltd   | ✓                                       |

| <b>Table 5: Services covered by the audit questionnaire and visited</b> |   |
|---|---|
|   | <b>Service visited within the audit</b> |
| Fairhome Care Group   | ✓                                       |
| Glencare Group  |   |
| HealthLinc Individual Care  |   |
| Innova Care Ltd   | ✓                                       |
| Modus Care Ltd  |   |
| Partnerships in Care Ltd  | ✓                                       |
| Richmond Fellowship   | ✓                                       |
| St Luke's Hospital Group (MILD Group)                                   | ✓                                       |
| St Andrew's Group of Hospitals  | ✓                                       |
| The David Lewis National Epilepsy Centre                                | ✓                                       |
| The National Autistic Society   | ✓                                       |

| <b>Table 6: Number of services included in the audit by Healthcare Commission area and sector</b> |                    |            |                               |
|---|--------------------|------------|-------------------------------|
| <b>Region</b>   | <b>Area</b>        | <b>NHS</b> | <b>Independent healthcare</b> |
| Central   | East Midlands      | 68         | 9                             |
|   | West Midlands      | 92         | 2                             |
|   | East of England    | 74         | 28                            |
| London and South East   | London             | 34         | 2                             |
|   | South East         | 78         | 1                             |
| North   | North East         | 61         | 10                            |
|   | North West         | 43         | 2                             |
|   | Yorkshire & Humber | 50         | 0                             |
| South West  | South Central      | 35         | 6                             |
|   | South West         | 39         | 4                             |
| <b>Total</b>  |                    | <b>574</b> | <b>64</b>                     |

**Table 7: Number of services included in the audit by type of service and sector**

| Type of service                          | NHS        | Independent healthcare |
|--|------------|------------------------|
| Acute assessment and treatment           | 117        | 13                     |
| Campus                                   | 88         | 4                      |
| 'Old' long stay provision                | 19         | 0                      |
| Residential services paid for by the NHS | 191        | 0                      |
| Short break (or respite)                 | 67         | 0                      |
| Low secure service                       | 52         | 30                     |
| Medium secure service                    | 17         | 10                     |
| High secure service                      | 1          | 0                      |
| Specialist adolescent services           | 6          | 2                      |
| Other                                    | 16         | 5                      |
| <b>Total</b>                             | <b>574</b> | <b>64</b>              |

## Method

The audit was launched in January 2007. There were two parts to the audit data collection: firstly a self-assessment questionnaire and then a one-day visit to selected services undertaken by 'peer reviewers.'

### Part one: collection of data

We designed two questionnaires: One questionnaire to be completed by the senior management team/board and a further questionnaire for the manager responsible for the day-to-day running of each individual service. This allowed us to take a broader view, exploring strategic intentions and communication mechanisms at the same time as viewing services provided directly to people with learning difficulties.

For the purposes of this audit, the definition of an individual service was a building-based service for people with learning difficulties provided by the organisation. Some organisations have multiple individual services on the same site. This means that if there were, for example, two services next door to each other with the same manager, that manager should have completed two separate questionnaires.

We sent out 638 service manager questionnaires and 89 board questionnaires. Most respondents completed the questionnaire using a web-based system, but around 75 service managers (without an e-mail address) completed a paper copy.

We received 590 service manager questionnaires (response rate = 92.5%) and 84 board questionnaires (response rate = 97%). Where a service did not return a questionnaire, we automatically selected it for a visit.

### Questionnaire design

The Healthcare Commission developed the two questionnaires with support from the external reference group. By looking at current measures and benchmarks such as *Essence of Care*<sup>24</sup>, *Better Metrics*<sup>25</sup> and standards such as the *Independent Healthcare National Minimum Standards*<sup>26</sup> and Valuing People. We developed 65 questions for service managers and 10 for the board/senior managers.

We asked for the same core information from adolescent services as we did from adult services, but added questions around safeguarding arrangements, and how many young people had looked after child status. Boards were additionally asked how they addressed the standards set out in the *National Service Framework for Children, Young People and Maternity Services*.

Each member of the external reference group was then asked to individually score each question in relation to highlighting good and poor performance. We chose the questions with the highest overall agreement, which identified 12 questions (ten from the service managers and two from the board) to be followed up routinely by the peer review teams in every visit made.

We did not look at how services were commissioned as part of the audit, as the audit focused on those things that are closer to the experiences of people who use these services, such as the quality of services. However, the questionnaire for managers of individual services did ask about the way services were commissioned.

## Part two: the visits

### *Review teams*

An important part of the audit was the involvement of a wide range of people experienced in the provision of services for people with learning difficulties. We received applications from 86 people with learning difficulties, 120 family carers and 175 professionals to take part as 'peer reviewers' in the audit visits. For the adolescent services we ensured people had specialist knowledge of young people's needs.

### *Training*

To take part in the audit visits, the peer reviewers had to undertake training. The British Institute of Learning Disabilities (BILD) ran the training programme. It included communicating with people with learning difficulties, contextual information about learning difficulties' services, *Valuing People* principles, the audit process and a training pack to read before the one-day session. We held eight regional training sessions.

**Table 8: Number of people who attended the BILD training sessions**

| Role                              | Number of people who attended training |
|-----------------------------------|--|
| Family carer                      | 111                                    |
| Person with learning difficulties | 77                                     |
| Clinician or manager              | 83                                     |
| Healthcare Commission staff       | 43                                     |
| <b>Total</b>                      | <b>314</b>                             |

### *Selection of sites for visits*

The Healthcare Commission collated and analysed all of the 677 questionnaire responses (590 service questionnaires, of which 483 were provided by NHS organisations and 107 from independent healthcare organisations and 84 board questionnaires with 70 NHS and 14 independent healthcare providers). We subsequently visited 154 services:

- 20% were selected randomly
- 60% were selected because our analysis suggested that there might be unacceptable levels of risk

- 20% of services were selected that appeared to be performing well, so the peer review team could gather examples of good practice

We analysed written information collected from the site visit reports. These reports produced around 6,500 pieces of information. This data was mapped according to the following themes:

- good practice or positive practice identified by our assessment teams
- relationships between the person using the services and other people
- everyday choices and control over own life
- person-centred care
- physical intervention, seclusion and use of PRN medication to manage behaviour
- staffing, staff management and training
- money
- environment
- arrangements for monitoring of the service
- arrangements policy, practice for safeguarding

Within each theme, key findings were identified and summarised.

### Visits

Before each visit (usually the day before the visit was due to take place) the peer review team met to look at the completed questionnaires and decided which questions they needed to follow-up during the visit, in addition to the 12 pre-selected routine questions.

The peer review teams visited 154 services in April and May 2007. Services visited included seven specialist adolescent services (four NHS and two independent sector) and 21 independent healthcare services. The geographical split of the services by Healthcare Commission region is shown in the table below.

| <b>Table 9: Location of visits by geographical region</b> |                                   |
|---|-----------------------------------|
| <b>Region</b>   | <b>Number of services visited</b> |
| North   | 40                                |
| Central   | 65                                |
| London & South East                                       | 26                                |
| South West  | 23                                |
| <b>Total</b>  | <b>154</b>                        |

The visits lasted for a full day and the chief executive of each organisation was given 24 hours notice of the visit.

During the visits, the peer review teams asked questions and listened to people with learning difficulties who lived there, and to the staff working there.

They also observed the environment in which people were living, how they were being cared for and how they were interacting with other people. The peer review teams made notes and forwarded the information they had collected to the Healthcare Commission's assessment manager at the end of the visit.

#### *Reporting findings to healthcare organisations*

An escalation process was developed to ensure peer review teams knew what to do if they found evidence of unsafe services, abusive treatment or serious failings. Such action was immediately invoked.

The process was developed jointly with the CSCI so that any services the review teams felt to be social in nature, rather than healthcare, could be referred to the CSCI for registration.

Following the visit, the Healthcare Commission produced a 'table of results' from information collected during the visit and from the self-assessment questionnaires. One of the Healthcare Commission's quality assurance national panels ensured consistency between

the reports and recommendations made. The table of results was sent to the service to confirm the information was factually accurate.

We included recommendations to promote change. We asked the service to share our findings with the people who use the service in the most appropriate way.

The purpose behind the tables was to provide information to services to promote analysis and change, to provide consistent information we could analyse for this national report and to aid development in assessing services for people with learning difficulties in the future.

We carefully considered whether the Healthcare Commission should publish individual tables of results, concluding that we should not as the information was often personal and people who lived there could be too easily identified.

A summary of our recommendations for each organisation at the visit stage is available on the Healthcare Commission's website [www.healthcarecommission.org.uk](http://www.healthcarecommission.org.uk)

A detailed report outlining the findings in specialist adolescent services will be published on our website in early 2008.

# Appendix 3

## Membership of the external reference group

| Name                  | Organisation                            | Role  |
|-----------------------|---|---|
| Annie Norman          | Royal College of Nursing representative | Lead Learning Disability Nurse                                      |
| Ayesha Janjua         | Turning Point                           | Policy Lead   |
| Bernadette Oxley      | Commission for Social Care Inspection   | Methodology Manager<br>Quality, Performance and Methods Directorate |
| Bob Tindall           | United Response                         | Managing Director   |
| Brian Innes           | Care Principles Ltd                     | Corporate Compliance Manager  |
| Chris Hatton          | Lancaster University                    | Head of Department  |
| Christine Braithwaite | Healthcare Commission                   | Development Manager – Investigations                                |
| Clive Bugg            | Care Principles Ltd                     | Corporate Compliance Manager  |
| Colin Hedges          | Healthcare Inspectorate Wales           | Inspections Officer   |
| David Cooper          | National Forum                          | Person with learning difficulties                                   |
| Debra Moore           | Care Services Improvement Partnership   | Joint National Programme Lead Learning Disabilities                 |
| Donovan Bell          | Sense                                   | Policy and Quality Team   |
| Emma Doyle            | Healthcare Commission                   | Team Leader, Informatics  |
| Fiona Ritchie         | Healthcare Commission                   | Lead for Learning Disabilities                                      |
| Helen Dorr            | National Family Carer Network           | Coordinator   |

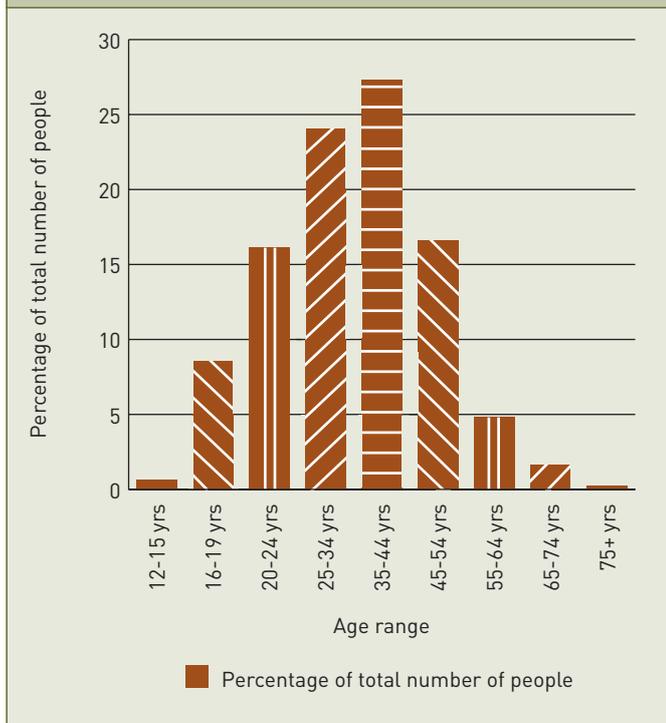
| <b>Name</b>        | <b>Organisation</b>                                  | <b>Role</b>                                |
|--------------------|--|--|
| Jan Norman         | Healthcare Commission                                | Area Manager East, Central Region          |
| Jane Willett       | National Patient Safety Agency                       | Safer Practice Lead/Learning Disabilities  |
| Dr Jean Collins    | Values into Action                                   | Former Chief Executive                     |
| Jim Blair          | Royal College of Nursing                             | Senior Lecturer Learning Disabilities      |
| John Greensill     | Walsall Council (Adult Services)                     | Head of Learning Disability                |
| Julie Ross         | N/A  | Supporter for David Cooper                 |
| Karen Flood        | National Forum for People with Learning Disabilities | Co-Chair National Forum                    |
| Kate Lawrence      | Healthcare Commission                                | Development Manager, Methods Team          |
| Keith Smith        | British Institute of Learning Disabilities           | Chief Executive                            |
| Kiran Dattani Pitt | Values into Action                                   | Chief Executive                            |
| Lesley Simpson     | Healthcare Inspectorate Wales                        | Inspections Manager                        |
| Lisa Bateman       | Gateshead Council, Involvement Worker                | Supporter for Paul Regan                   |
| Mandy Collins      | Healthcare Inspectorate Wales                        | Director of Development and Investigations |
| Mary Mulvey        | Department of Health                                 | Policy Lead                                |
| Nick Jones         | Healthcare Commission                                | Deputy Head of Strategy                    |

| <b>Name</b>    | <b>Organisation</b>  | <b>Role</b>   |
|----------------|--|---|
| Paul Regan     | National Forum for People with Learning Disabilities       | National Forum Representative   |
| Peter Oakes    | Hull University  | Clinical Lecturer   |
| Rebecca Cooper | National Forum for People with Learning Disabilities       | National Forum Representative   |
| Rob Greig      | Department of Health                                       | National Director for Learning Disabilities   |
| Simon Hewson   | Tizard Centre, University of Kent Honorary Senior Lecturer |   |
| Stephanie Long | Commission for Social Care Inspection                      | Provider Relationship Manager   |
| Sue Carmichael | Department of Health                                       | Joint Programme Lead- Learning Disabilities   |
| Dr Tom Tait    | Growing Older with Learning Disabilities (GOLD) Ltd        | Director<br>Dr Tait was involved in half of the meetings until Mr Jim Blair took over |
| Yvonne Cox     | The Ridgeway Partnership NHS Trust                         | Chief Executive   |

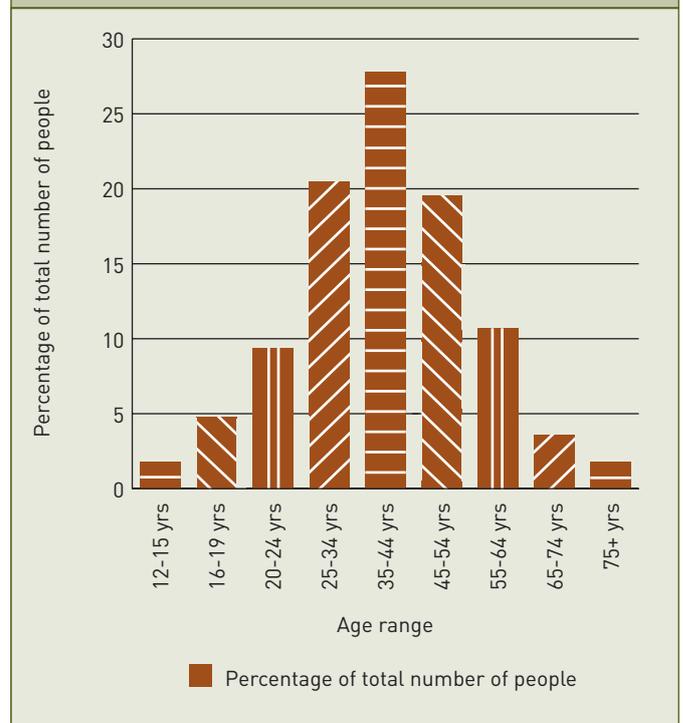
# Appendix 4

## Tables of population and service profiles

**Figure 3: Proportion of people in learning difficulty services by age range in the independent sector**

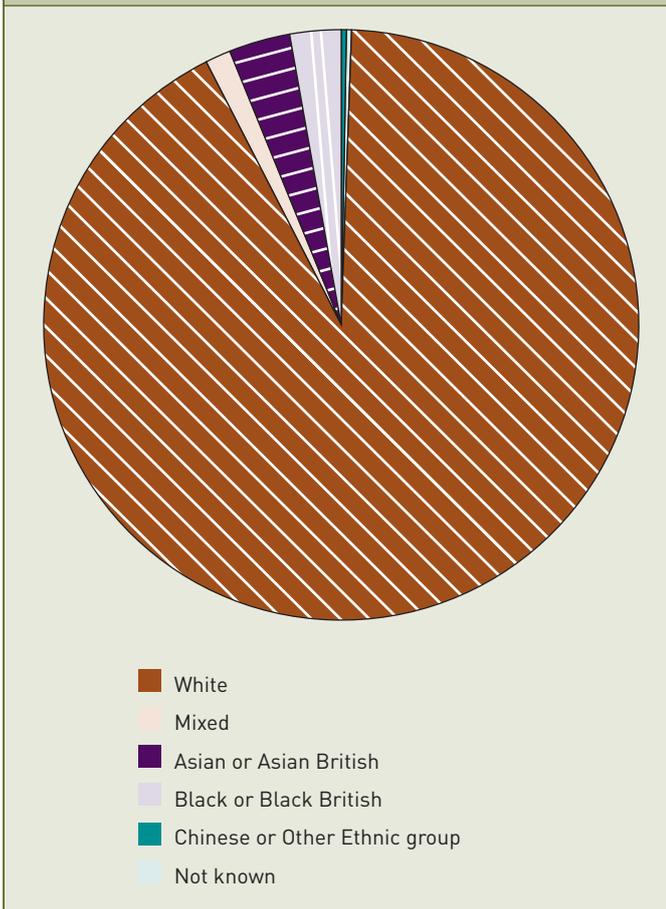


**Figure 4: Proportion of people in learning difficulty services by age range in the NHS**

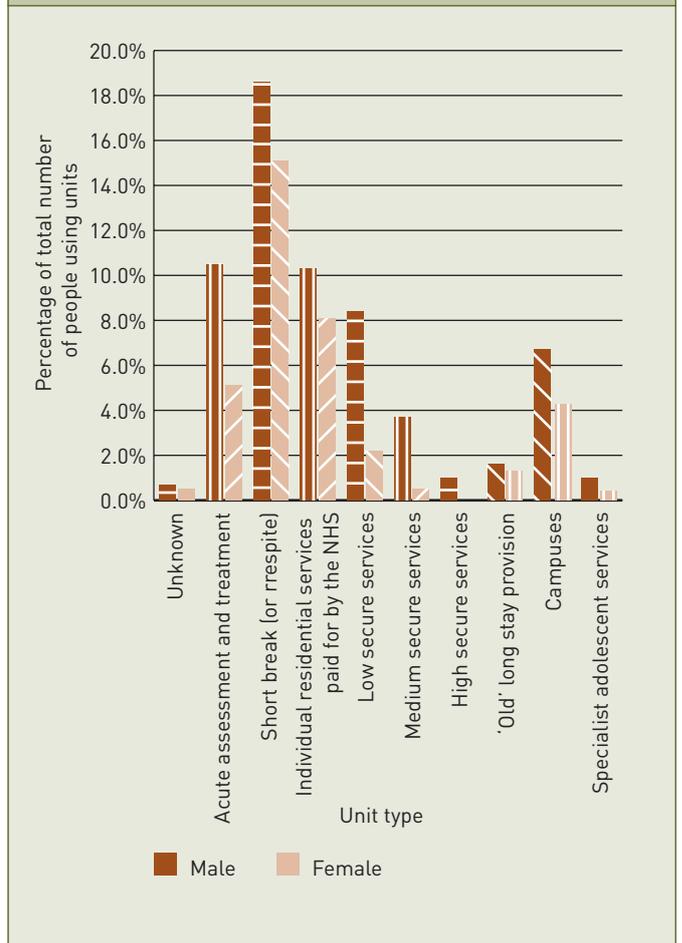


| <b>Table 10: Breakdown of ethnic groups using learning disability services and in England as a whole</b>   |   |  |
|--|---|--|
| <b>Level 1 Ethnic Group</b>  | <b>Percentage of people using services in ethnic group*</b> | <b>Percentage of people in England in ethnic group</b> |
| White  | 91.9%   | 91.3%  |
| Mixed  | 1.5%  | 1.4%   |
| Asian or Asian British   | 3.2%  | 4.4%   |
| Black or Black British   | 2.8%  | 2.2%   |
| Chinese or Other Ethnic Group  | 0.3%  | 0.8%   |
| Not Known  | 0.4%  | 0  |
| <p>Source of data for National breakdown of ethnic groups: Office of National Statistics from the compendium (Extracts may only be reproduced by permission. This can be found on <a href="http://www.statistics.gov.uk/cci/nugget.asp?id=455">http://www.statistics.gov.uk/cci/nugget.asp?id=455</a>)</p> <p>* For graphical representation see figure 5.</p> |   |  |

**Figure 5: Proportion of people using learning difficulty services by ethnic group**



**Figure 6: Proportion of people using learning difficulty services by gender**



| <b>Table 11: Number of people with learning difficulties who were detained under the Mental Health Act</b> |                         |
|--|-------------------------|
| <b>Unit type</b>   | <b>Number of people</b> |
| Unknown  | 51                      |
| Acute assessment and treatment   | 237                     |
| Short break (or respite)   | 0                       |
| Individual residential services paid for by the NHS  | 18                      |
| Low secure services  | 483                     |
| Medium secure services   | 245                     |
| High secure services   | 46                      |
| 'Old' long stay provision  | 17                      |
| Campuses   | 85                      |
| Specialist adolescent services   | 41                      |
| <b>Total</b>   | <b>1223</b>             |

# Glossary

## **Acute assessment and treatment services**

Services that care for people with learning difficulties, as inpatients, on a short-term basis. People are admitted because of a breakdown in their mental health or their challenging behaviour. Their health needs are assessed by a multi disciplinary team that produces a time limited treatment plan. Patients then go back to their original placement.

## **Adolescent services**

Health services in the NHS and independent sector, which focus on young people between the ages of 12 and 19.

## **Campus provision**

Long-term care commissioned and provided by the NHS, where people live in 24 hour care. It is not registered by the Healthcare Commission or the Commission for Social Care Inspection.

## **Commission for Social Care Inspection**

Registers, inspects and reports on adult social care services and councils who arrange these services in England. Its role is to improve social care and stamp out bad practice.

## **Community learning disability teams**

Normally multi disciplinary in nature, these teams specialise in learning difficulties and predominantly support people to live in their local community. Professionals such as social workers, community learning disability nurses, consultants, psychiatrists, physiotherapists, speech and language

therapists, and occupational therapists can all be part of these teams.

## **Forensic services**

Services offered to people who are likely to become a danger to themselves or others and as a result have been or are likely to be in contact with the law.

## **Healthcare Commission**

The Healthcare Commission is the independent health watchdog for England. It checks that healthcare services meet the required standards in safety, cleanliness, waiting times and many other areas.

## **Independent healthcare**

Services classed as specialist hospital provision registered with the Healthcare Commission. Independent healthcare establishments are run by an organisation or individual, other than the NHS.

## **Looked after children status**

Refers to children who have been provided with accommodation, for a continuous period of more than 24 hours in circumstances set out in part of the Children Act 1989. It can also refer to a child who is placed in the care of a local authority by virtue of an order under part IV of the Act (that is, under a care order).

## **Makaton**

A form of sign language that has been simplified and is used to communicate with, and by, people with learning difficulties.

**Old long-stay provision**

Provision of residential 24 hour care in what was old hospital style accommodation run by the NHS.

**POVA (protection of vulnerable adults)**

Launched by the Department of Health on 26 July 2004, the Protection of Vulnerable Adults scheme acts as a workforce ban on those professionals who have harmed vulnerable adults in their care. It adds an extra layer to the pre-employment processes, including Criminal Records Bureau checks, which already take place and stop known abusers from entering the care workforce.

**PRN (Pro re nata)**

Medication that can be given as and when required rather than at specific times.

**Short break**

Where an offer of care is given (normally via family carers) to the person with learning difficulties. This allows their family to take a break.

**Specialist teams**

Teams of highly trained staff who work with specific people with learning difficulties (for instance, people who challenge services), in their homes, or services where they are currently living. The teams support them to lead a fulfilled life. The majority of this work tends to be within the person's local community.

**Strategic health authorities**

Created by the Government in 2002 to manage the local NHS on behalf of the secretary of state, there were originally 28 strategic health authorities (SHAs). On 1 July 2006 this was reduced to ten. They are responsible for development, performance, increase of capacity and integration of programmes into local health service plans. The SHAs manage the NHS locally and are a key link between the Department of Health and the NHS.

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