CareQuality Commission

National study

Specialist inpatient learning disability services

Follow-up audit of services 2008/09

December 2009

About the Care Quality Commission

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

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

• Driving improvement across health and adult social care.

• Putting people first and championing their rights.

• Acting swiftly to remedy bad practice.

• Gathering and using knowledge and expertise, and working with others.

Contents

Summary

Introduction

In 2007, there was a sense of shock and deep concern following two major investigations into the quality and safety of specialist services for people with learning disabilities in England. This led to the first ever national audit of specialist inpatient healthcare services for people with learning disabilities, which was carried out by the Healthcare Commission. The findings of that audit, and a number of subsequent reports, have done little to provide reassurance for the people themselves and their families. Indeed, there are now even more fundamental concerns: this time about the care of people with learning disabilities in general hospitals and other healthcare settings.

During this period, the consultation paper *Valuing People Now* was published and confirmed the founding principles of the White Paper *Valuing People*. It set these principles within a human rights framework and stressed issues such as access to healthcare, people with very complex needs and full and fair access to services for people from different ethnic groups. In January 2009, the Government published *Valuing People Now: from progress to transformation*, a new three-year strategy on the provision of services for people with learning disabilities. That strategy made clear the need for better commissioning of specialist care for people with learning disabilities and emphasised the need for strong leadership at all levels to make change happen.

Healthcare for All, Sir Jonathan Michael's report into access to healthcare by people with a learning disability, and the subsequent Ombudsman's report *Six lives*, drew together the strands from Mencap's

Death by Indifference work. This drew attention to continued health inequalities experienced by people with learning disabilities and highlighted examples of neglect in general hospital settings that were profoundly disturbing.

In the autumn of 2008, the Healthcare Commission, the Commission for Social Care Inspection and the Mental Health Act Commission reviewed the commissioning of services for people with learning disabilities and complex needs. The report found that current commissioning practice needed to improve by having a better understanding of the needs of the population, being more person-centred, and working in partnership with families and people with learning disabilities.

It has been clear throughout this time that there is still a substantial challenge to ensure the safety and wellbeing of people with learning disabilities in both general and specialist healthcare settings. In recognition of this, it was agreed that a follow-up audit of specialist inpatient services for people with learning disabilities would be appropriate.

The follow-up visits took place from September 2008 to the end of January 2009. Findings from the visits were fed back to the organisations within weeks, with recommendations for action.

While the national picture of specialist inpatient healthcare services for people with a learning disability has progressed since these visits, the national findings contained within this report are important and identify the key areas that every service must pay keen attention to.

Since the follow-up audit, we visited some organisations again to ensure that improvements were being made and that our concerns were being taken seriously. We were pleased to find progress was being made and continue to work with strategic health authorities and Monitor to oversee implementation of action plans.

As the regulator, it is our duty to focus on areas of care that have been historically poor and where people are made particularly vulnerable by low quality. We will continue to scrutinise care for people with a learning disability.

Method used in the follow-up audit

We visited 43 services representing 37 different organisations from both the NHS and independent sector. The services included assessment and treatment services, independent hospital care, and forensic and residential support, catering for people of all age ranges including young people and people with very specific disabilities such as deafness. The size of services ranged from four to 19 places, with the average having six places.

Our visiting teams of reviewers included a clinician, a person with a learning disability or family carer, and an assessor. They asked specific, comprehensive questions to get a full picture of the service. We are very grateful to our reviewers for the time and expertise that they gave to this follow-up audit.

Findings

At the time of the inspections, we found that the quality of specialist healthcare services for people with learning disabilities is at best inconsistent and at worst damaging. This is despite the amount of concern and attention given to services from external bodies since the original 2007 audit. The process by which minimum standards can be established and maintained is surely the first challenge. After this, it falls to everyone involved in these services to work

alongside people with learning disabilities, their families and other supporters to bring about the consistent standards that can meet the needs and expectations of people with learning disabilities.

Our regulatory work since the follow-up visits shows that progress is being made. It is up to all parts of the sector to speed up the pace of improvement and ensure that all care for people with a learning disability is of a high standard.

Detailed findings from inspections between September 2008 to January 2009

My choices: There was some evidence of people making everyday choices such as what to wear, and the use of accessible information to make this possible. However over 53% of services were still not offering the opportunity to choose what to eat.

When it came to bigger decisions, most people did not have a choice about who to live with and who provided their support. This included the gender of people providing personal care. While this might not always be possible in acute settings, 29 of the 43 services visited provided more long-term care.

My day: This included the opportunities for people to engage in positive activities, both within services and in local community facilities. We saw some improvement from 2007, with a wide range of activities within services. There remained some difficulties in accessing community-based activities – often as a result of staffing arrangements.

My rights: This was not a strong area of performance. In terms of external support, advocacy was less available in services than it was in the 2007 audit, with 27 services having no access to advocacy services. There was continued positive evidence of multidisciplinary team involvement in services, and the various meetings were valued by those involved.

Services and staff seemed to remain over-controlling in terms of the restrictions on people's movement. Many services restricted access to various parts of the different buildings on the basis of general rule rather than individual risk assessment.

Despite recommendations going back to *Valuing People* in 2001, very few people were given the opportunity to engage in health action planning or person-centred planning. Similarly, assessment and treatment services showed a lack of use of the care programme approach process with all of its checks, balances and accountability.

Friends and family: This was a welcome area of improvement with the majority of services making positive efforts to support contact and involvement with families. Although often seen as more challenging by services, 10 settings were working to foster friendships away from the service.

Checking quality: The lack of monitoring by commissioners of the quality of specialist services for people with learning disabilities has been a problem in recent years. There was some evidence of improvement, with only 11 services not receiving regular visits from commissioners.

Evidence of internal quality mechanisms such as audit and contact with leaders in the service remained inconsistent.

Staffing: It has been particularly difficult to maintain levels of training, supervision, appraisal and positive morale in this group of services. Again the picture in this audit was mixed, with some evidence of improvement but a significant number of settings struggling to maintain minimum standards.

There was a need for greater awareness of modern ideas and practice in supporting people with learning disabilities. This begins with basic policy documents and continues into modern evidence-based practice.

The cycle of stress for staff – low morale, sickness, absenteeism and inconsistent recruitment was still apparent in some services. It would seem that some more systematic approaches to these issues are needed. There were signs of this beginning, with work to reduce the use of agency staff, and this could be a positive way of breaking into the cycle.

My wellbeing: This theme looked at the fundamental needs of people who use these services. Levels of training and understanding of abuse, including systems for whistle-blowing, were much improved and just a small number of services needed to iron out inconsistencies.

There was some positive evidence of people having control of their own finances, although 13 services still needed to address this issue. There was an inconsistent picture of physical control in the form of physical intervention and the use of PRN (medication given to people as required). The majority of services monitored the use of these approaches but a small number needed to develop robust policies and monitoring arrangements.

Leadership: Developing modern person-centred assessment, support and intervention requires strong and positive leadership. In only four of the 43 services that we visited did staff report that leadership was strong and positive. This could explain the inconsistencies found in other areas of practice.

Services visited previously: We visited 10 services that had also been visited in the previous audit to check their progress. Of these, five had made significant improvement while two had made some improvement but needed further attention. Three services were unable to demonstrate any significant change. The improvements reflected the recommendations made in the first audit, such as access to advocacy, the use of person-centred planning and some health action planning.

Conclusions

It was obvious from the reports on individual services that most of the 10 services that were revisited were of a better standard than the majority of services we visited for the first time. There were, however, notable exceptions both positive and not so positive. We can also say that services that had been monitored by senior managers or commissioning agencies were of better quality than those that had not.

Shared leadership

Good leadership is essential for senior managers and directors of services. It is about having the vision and drive to deliver excellence and refusing to accept poor standards. Good leadership is about inspiring staff at all levels to take account of their own actions and the actions of their colleagues. The governance of these services must be a priority for the board of every NHS trust and senior management team of independent healthcare providers. The chair, directors and non-executives need to take more of an active role to appreciate what poor standards of care in these services mean for individuals.

Responsibility for good leadership lies across senior teams and across agencies. There is a need for joint senior leadership programmes, shared across local areas, for people working in learning disability services. *Valuing People Now* emphasised the need for strong leadership at all levels in health and social care.

Shared values

One of the reasons why recent policy on learning disability services has been set in the context of human rights is because of the need to address a fundamental question: as a society, do we really believe that people with learning disabilities are no different from anyone else and should be afforded the same quality of life as the rest of the population? If this is the case, this should also underpin the moves to transform other forms of care on the basis of citizenship.

By reminding people of this fundamental question and insisting on a response that states that people with learning disabilities have the same human value as anyone else, we are able to encourage everyone involved in services to evaluate them on the basis of their own experience. People who work in services or visit services can ask themselves daily "Would I be happy with this service? Would I live here? Would I be happy with the active treatment that people are receiving here?", and ask what should happen if the answer is "no"?

The Care Quality Commission has its part to play, and an annual visit to services can help to maintain the shared vision and 'keep the pressure on' so that staff feel they have to improve or get a poor report. However, the way we regulate health and adult social care is fundamentally changing. From April 2010 all health and adult social care providers must be registered with us to be legally allowed to operate. Registration requires providers to meet a wide range of new essential common standards which will apply across the care sector.

We will continuously monitor and check how well providers are meeting these standards, which include critical areas such as protecting people from abuse, safeguarding vulnerable people, and respecting and involving people who use services, with specific additional guidance for services provided for people with learning disabilities. If services are no better than the majority that we visited they will struggle to comply with registration requirements. With our new wider enforcement powers, we will identify problems early and take swift action where necessary, including changing the registration status we give providers.

Shared power

For change to truly happen, it must come from the empowerment of the people and families that use services. This is about people having the information about quality of services and a direct role in shaping, maintaining and driving the quality of those services.

It is essential that people in the wider community who do not have experience of learning difficulties are aware of, and involved in, the standards and achievements of local services for people with learning disabilities.

All the people who work in these services need to renew their understanding of the law, and their responsibilities for upholding the quality of services provided.

More reports that highlight poor practice can only be part of the solution. Services need to focus on addressing these three fundamental issues and working towards truly person-centred services based on shared leadership, shared values and shared power.
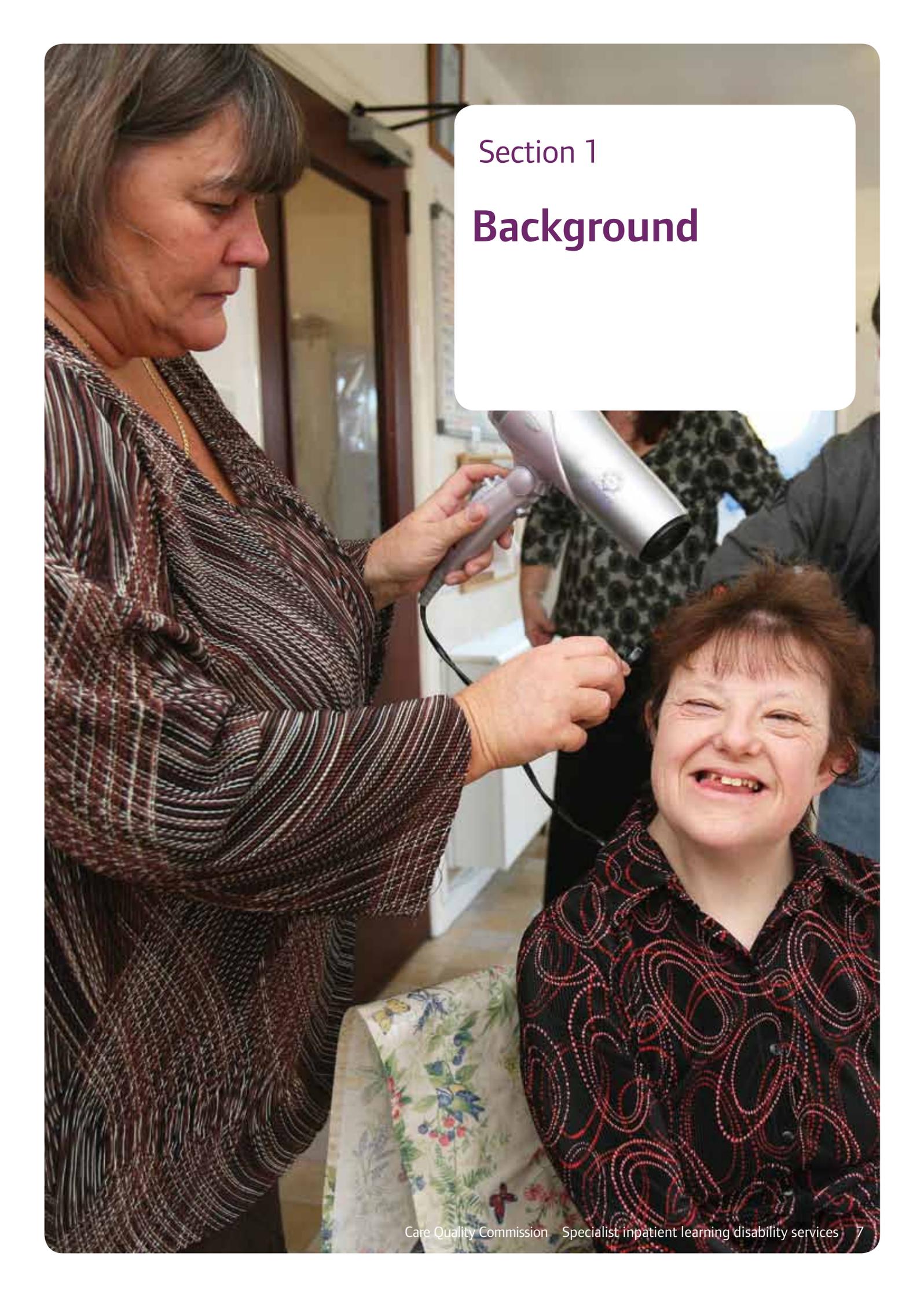
Recommendations

In keeping with current policy and best practice, we make a small number of recommendations to the boards and executive teams of the provider organisations, commissioners of services, strategic health authorities and learning disability partnership boards.

- Boards and senior management teams in NHS and independent healthcare should ensure that they have the evidence and reporting mechanisms to show that their learning disability services are meeting essential common standards. They should be aware that, through our ongoing monitoring of how well services are meeting these standards, we will take more account of the views of people who use services and make sure they are fully involved in decisions about their care.

- Each board should consider nominating a non-executive 'champion' for learning disability, who will take lead responsibility in ensuring that services are being monitored, making use of the skills of people with learning disabilities and family carers. The outcome of these audits should

be fed into the new regional Valuing People Now boards, learning disability partnership boards, and strategic health authorities' assessment of health performance through self-assessment in learning disabilities – this is currently being supported in a few but not all strategic health authorities. The Department of Health is developing a national self-assessment tool to enable partnership boards to benchmark their performance and work programmes.

- Commissioning needs to have a local focus and develop the competence and capacity to deliver high quality services and support for local people. Commissioners should stop buying services that do not adhere to the principles of *Valuing People Now*. Commissioners should develop or revise their commissioning plan for specialist inpatient services as part of this work. Joint strategic needs assessments have local information to support this process – buying appropriate levels of care and support with a suitably qualified workforce – and can demonstrate year-on-year progress.

- Independent healthcare providers and NHS trusts should be able to justify the care, treatment and assessment they provide, ensuring that it meets with national guidance and best practice. Assessment and treatment services must not become campus provision under a different guise. Commissioners across health and social care have a responsibility to work collaboratively with providers to ensure that they do not allow people to remain who are not being treated or assessed.

- Learning disability partnership boards should work with people with learning disabilities and family carers, to empower and support them to speak up and be directly involved in peer audits with health organisations.

Section 1

Background

In 2007, following two large scale investigations into services for people with learning disabilities run by NHS providers[1,2], the Healthcare Commission launched a national audit of specialist inpatient services for people with learning disabilities. The audit aimed to find out whether the abuse and bad practice found during the two investigations was widespread.

The report of the audit *A life like no other*, revealed unacceptably wide variations in the standard of care across England and, in six services providing specialist inpatient healthcare, there were serious concerns about safety.[3]

While there were some good services, many were characterised by some or all of the following features:

- Poor safeguarding procedures.

- Patchy access to advocacy services.

- Poor care planning.

- Lack of internal and external scrutiny and specifically, limited evidence of engagement with commissioners.

- Limited provision of stimulating activities during the day and evening.

- Concerns about the use of physical intervention and PRN (medication given to people as required).

- Institutional regimes.

- Poor leadership and lack of appropriate training for staff.

The audit also raised concerns about the number of people 'stuck' in the NHS or living in NHS campus provision (residential services). On a positive note, the closure of campus provision has now gained momentum and the Department of Health has provided resources to enable people to move on. By 2010, all campus provision should be closed.

Following the audit, each provider organisation was asked to put monitoring arrangements in place to ensure that their management board could ensure that they acted upon their own recommendations arising from their audit.

The Healthcare Commission also outlined measures for other organisations, specifically, primary care trusts (PCTs), strategic health authorities, the Department of Health and local learning disability partnership boards. These included a more active role in commissioning services, increased internal and external scrutiny of services, improvements in the training of health professionals and all processes to ensure the involvement of people who use services and their families.

Full details and copies of the report can be found on our website: www.cqc.org.uk

Policy context

Since the audit of specialist inpatient services, there have been a number of publications and activities relating to the health needs and provision of healthcare to people with learning disabilities.

The Department of Health's consultation paper *Valuing People Now* was published and confirmed the founding principles of its White Paper *Valuing People*.[4,5] These principles were set within a human rights framework and stressed issues such as health, people with very complex needs and full and fair access to services for people from different ethnic groups. In January 2009, the Government published *Valuing People Now: from progress to transformation*, a new three-year strategy on the provision of services for people with learning disabilities. That strategy made clear the need for better commissioning of specialist care for people with learning disabilities and emphasised the need for strong leadership at all levels to make change happen.[6]

The independent inquiry into access to healthcare for people with learning disabilities, led by Sir

Jonathan Michael, published its findings in *Healthcare for all* in July 2008.[7] This, and the subsequent Ombudsman's report *Six lives*,[8] called for an urgent review of primary and non-specialist inpatient healthcare for people with learning disabilities, and drew together the themes from Mencap's *Death by Indifference* report, which told the stories of six people with a learning disability who died while in NHS care.[9] This drew attention to continued health inequalities experienced by people with learning disabilities and highlighted examples of neglect in general hospital settings that were profoundly disturbing.

It is important to deliver services to all those with learning disabilities, but imperative for those with the most complex needs. People who may be more vulnerable due to communication difficulties or additional physical or mental impairments are more likely to need services from specialist and mainstream health services. They therefore find themselves in more vulnerable situations.

During September, October and November 2008, the Healthcare Commission, the Commission for Social Care Inspection and the Mental Health Act Commission jointly reviewed the way in which services for people with learning disabilities and complex needs were commissioned by PCTs and local councils. This work aimed to determine the best practice that is needed to understand the needs of the population, to provide services that are more person-centred, and to work in partnership with families and people with learning disabilities.[10]

All these reports have placed a welcome emphasis on improving the outcomes and experiences of people with learning disabilities who use health services. They also bring into sharp focus the role of specialist learning disability services, including inpatient services and their partnerships with people and families, mainstream health providers, organisations providing social care and other agencies.

Given the large number of published reviews, reports and guidance highlighting good practice, there should be major positive change for people with learning disabilities and their families, but is this the case?

What has the regulator achieved since the last audit?

The Healthcare Commission, and subsequently the Care Quality Commission, initiated a number of actions in response to the national audit.

1. The development of an initial set of five performance indicators specific to learning disabilities for provider trusts:

   • Number of people with a care plan.

   • Delayed transfers of care.

   • Best practice in mental health services for people with a learning disability (Green Light Toolkit).

   • Campus provision.

   • Data quality on ethnic group.

   Data on the performance against these indicators was collected in 2008/09. This was the first time that information about performance relating to specific learning disability issues had been collected. This is currently being analysed.

2. A follow-up audit to ensure that change was taking place and that we had visited at least one service from every provider in England (this report highlights the findings of that follow-up audit).

3. Involving learning disability partnership boards as a third party to the annual health check declarations, to ensure that people with learning disabilities, family carers and professionals have a say in trusts' declarations. We will publish a short paper about the findings.

4. Developing and piloting face-to-face interviews for people with learning disabilities as part of the

patient survey programme, to ensure that their voices are heard and issues acted upon.

On 1 April 2009, the Care Quality Commission became the new regulator for health and adult social care, and is currently working on a review of physical healthcare for people with learning disabilities and mental health needs; developing a learning disability strategy to highlight what the Care Quality Commission as the regulator will do over the next five years (due to be published in the autumn of 2009); and recruiting a person with learning disabilities as an employee to support direction and policy within the Commission.

We have also made significant progress in developing a new performance indicator for the 2009/10 assessment year, titled 'Access to healthcare for people with a learning disability', which includes a suite of measures that are a direct response to Sir Jonathan Michael's enquiry. These are aimed at acute trusts, mental health and learning disability trusts. The details of the indicators have recently been published on our website (www.cqc.org.uk). Data on the indicator will be collected directly from trusts in 2010, and includes trusts' performance on:

- Understanding the local population of people with learning disabilities.

- Having accessible information.

- Providing support for family carers.

- Providing regular training for staff around the needs of people with learning disabilities.

- Having representation from people with learning disabilities and family carers on trust boards or local groups.

- Having systems to regularly audit practices for people with learning disabilities.

Methodology for the follow-up audit

Selection of sites
This audit (as with the previous audit in 2007) included healthcare providers in the NHS and independent sector, that provide adult or specialist adolescent services in England. For this audit, we visited an additional 43 individual services (see Appendix A).

We did not ask organisations to update the long self-assessment questionnaire that was used in the national audit, as this would have been too burdensome. Although this data was now 18 months old, our audit teams were still allowed to use it, but only as a starting point of where the services were at that point in time. Appendix B lists the organisations and units visited.

The audit teams
As in the previous audit, the teams of auditors each had a clinician, a family carer or person with learning disabilities, and an assessor. We used the same peer reviewers and provided specific training on the changes to the methodology.

The visits
Each service was given 24 hours' notice of the visit. The teams met beforehand to focus on the issues, and to allocate roles and tasks to each member of the team.

The previous audit had a set of 12 routine questions, devised by an expert reference group, which each team were required to ask. This was to look for potential trends, both good and poor, across the services. The team were also allowed to ask any other questions that arose from the self-assessment questionnaire. In the first national audit, most teams asked more than the 12 routine questions.

The follow-up audit used the results of the first national audit as a baseline. Trends showing a need

for improvement were used to formulate the new 12 routine questions, some of which were the same as the previous audit. As well as the routine questions in the report template, assessors had prompts of what teams 'should' expect to see in each area. These prompts were developed from the national report (see Appendix C for the list of routine questions).

In this audit, very few teams asked questions other than the 12 routine questions, as they thought that these questions were appropriate and comprehensive.

After the visit, the assessor collected the evidence from other team members and wrote the draft report. The other team members were able to read and comment on the report to ensure that they were all happy with the draft. After being internally quality assured, the report was sent to the provider organisation to check for factual accuracy. This process was the same as the previous national audit.

The individual report for each service is published on our website (**www.cqc.org.uk.ldaudit**). We also provided an easy read version of these reports for people living in the services.
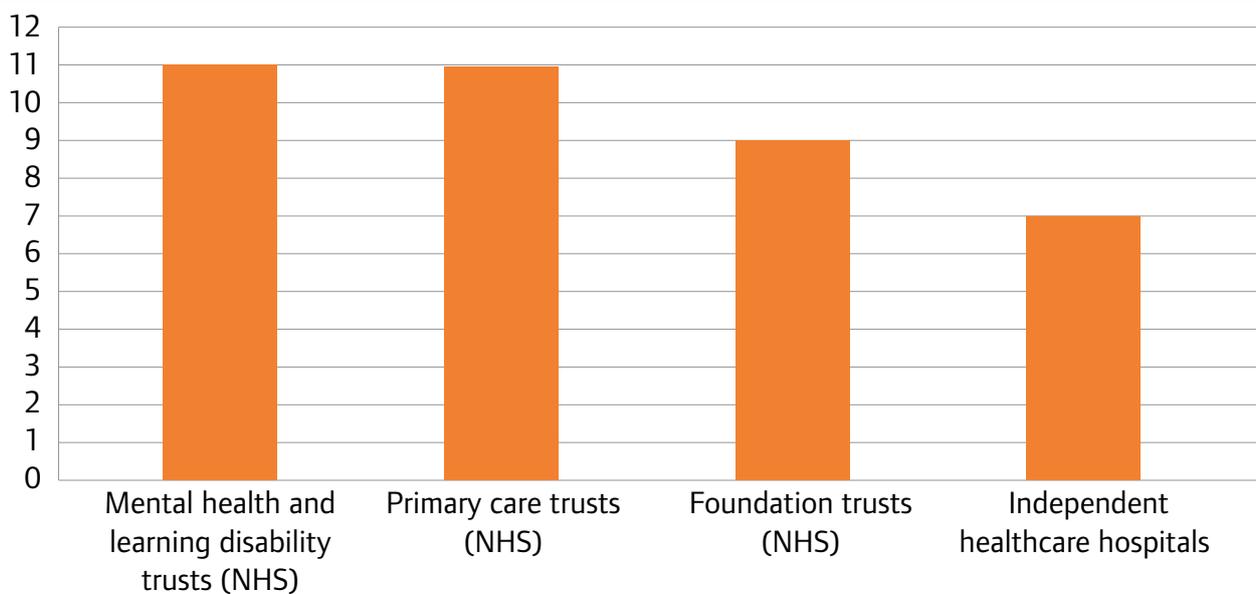
Section 2

Our findings

The services

We visited 43 individual services from 37 different provider organisations.

The organisations that provided more than one service included: Coventry and Warwickshire Partnership NHS Trust, Hampshire Partnership NHS Trust, Shropshire County PCT, Surrey and Borders Partnership NHS Foundation Trust, and Sussex Partnership NHS Trust.

Figure 1: Type of organisation visited

Type of organisation	Number visited
Mental health and learning disability trusts (NHS)	11
Primary care trusts (NHS)	11
Foundation trusts (NHS)	9
Independent healthcare hospitals	7

These organisations provided a range of services including:

• Acute assessment and treatment.

• Secure services.

• Specialist adolescent services.

• NHS campus provision (residential units).
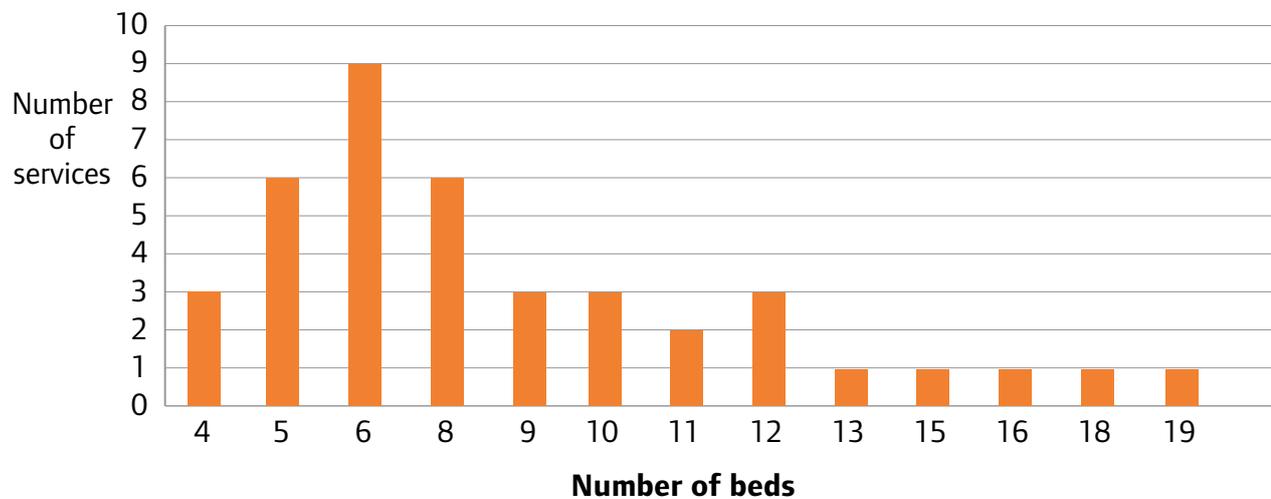
• Independent hospital provision.

Figure 2: Types of different learning disability services visited

Number of services (y-axis, 0–16)

Type of service (x-axis):
- Residential unit: 16
- Assessment and treatment unit: 14
- Independent hospital: 4
- Rehabilitation unit: 3
- Low secure forensic unit: 2
- Assessment, treatment and respite unit: 1
- Continuing care and treatment: 1
- Specialist service*: 1
- Young person's service: 1
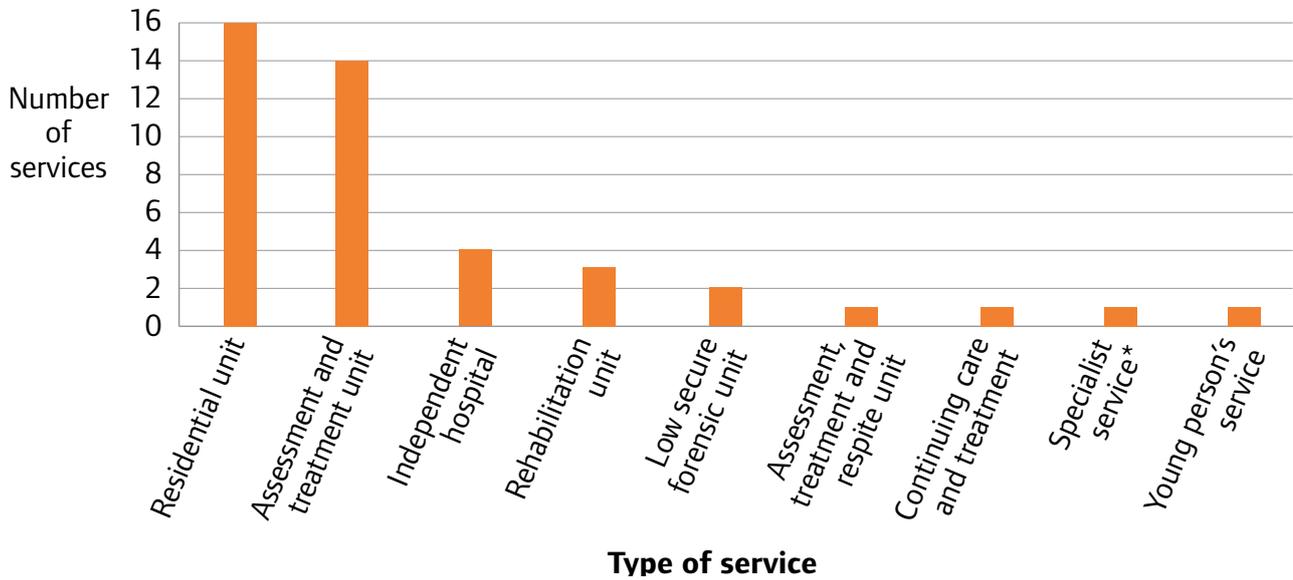
*For deaf male patients with a learning disability detained under the Mental Health Act.

The number of beds in each unit varied, with the average service having six beds. The largest service was an NHS provider, with 19 beds and the three smallest services each had four beds.

Figure 3: Number of beds at 40 of the services visited

Number of services (y-axis, 0–10)

Number of beds (x-axis):
- 4: 3
- 5: 6
- 6: 9
- 8: 6
- 9: 3
- 10: 3
- 11: 2
- 12: 3
- 13: 1
- 15: 1
- 16: 1
- 18: 1
- 19: 1

Note: the chart only shows 40 services, as three review teams did not record how many beds they offered.

In the last audit, we arranged our findings under five themes that are consider important to people with learning disabilities and family carers. These were:

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

We used most of these headings again in this follow-up audit to help to compare progress and to see where there are still problems. However, we have changed "me and others" to "family and friends", and have added separate headings "checking quality" and "staffing". This was to give extra attention to these areas and to bring out any issues that may be hidden in a larger grouping.

The following summarises our findings under each of the seven themes, with quotes from our review teams.

My choices

We wanted to understand how services support people to make everyday choices and also to be involved in bigger decisions, such as where to live or who to live with.

In the last audit, we found limited evidence that people were supported in ways that promoted their independence. In some services, people had little or no choices in everyday things, including what to eat.

We also found that training for staff to support communication and understanding was lacking, and that the availability of accessible information to help service users make choices was limited. In the first audit, we recommended that services, particularly those in campus provision, improved opportunities for people to make choices, improve communication and increase the availability of accessible materials and techniques.

In the follow-up audit, "my choices" was the largest coded section, which means that the assessors wrote more about this than any other section. We looked at issues regarding choice in what people ate, what clothes they wore, who they lived with, who supported them and what choices they had during the day.

The picture our peer review teams found was mixed, with over 53% of services still not offering basic choices to people, such as what they ate:

> **"We observed that menus were written a week in advance and that patients appeared to have limited input into developing the menu. The menu was fixed."**

The times at which people were allowed to eat were also generally restricted. Many service users had a limited choice of when they could eat by having restricted access to the kitchen and having set meal times regardless of their activity plans. This created a much more institutional service than should have been the case.

> **"Service users are not allowed to access the only kitchen independently and have to ask staff if they want a drink."**

However, there was a much more positive picture with people being able to choose their own clothes, and only one service stated that they did not routinely allow this.

Choices about who people live with and who supports them was more complex. The majority of people did not have the choice of who they lived with or which staff supported them, but this would not be possible due to the nature of some of the services. For example, an acute assessment and treatment service where people are admitted short term would not be able to offer this choice, as it would be governed around bed capacity and specialist support. However, 67% of services (29 out of 43) were not acute assessment and treatment services, and people had lived there for many months, if not years.

To be able to choose who you spend the majority of your time with must be one of the most fundamental things most people take for granted. For this group of people, it is not a choice they are 'allowed' to make. Even gender issues were not taken into account in many services:

> **"There was no choice by service users about which staff, of which gender supported them."**

Communication

We saw more of a mixed picture of performance relating to accessible communication that supports people to make informed choices. Although many services were still not providing this, the follow-up audit showed that more services were trying to than in the previous audit.

> **"We saw staff interacting well with one service user who was able to verbalise needs. For another, pictorial symbols were being used very successfully to support communication and choices about everything, including activities."**

Out of 43 services visited, we made a total of 123 recommendations on improving choices for people in everyday areas.

My day

We wanted to understand what activities people did and how they lived their day-to-day lives. We were interested in how engaged people were with their local communities and what opportunities they had to go out and make use of local facilities including the cinema, leisure centres, and the theatre.

When we visited services in 2007, we found that some, particularly those providing services for young people and adolescents, did have a range of positive experiences and activities. However, many services had very little evidence that they had offered activities, and if people had actually left the site it

was only to go on shopping trips. We recommended to a range of services that they make activities more meaningful and frequent.

In the follow-up audit, we found more positive daily activities. The range of opportunities available on-site had increased from only gardening, to gym facilities, arts and crafts and domestic chores. Off-site activities, as in the previous audit, were more limited in choice, from shopping and hairdressing appointments, to visiting a safari park or going for walks.

> **"One service provided a unique therapy called 'eco-therapy', which involved service users contributing to making wooden sculptures which are then displayed in the gardens of the hospital."**

> **"The review team were informed that each individual has a daily activity plan which is updated every week. We saw a good range of activities within the care plans and throughout the day of the visit. The unit provides variety and a balance of activities including exercise, leisure, daily living skills and supported work."**

This was a positive development, but unfortunately there were still many services whose day, evening and weekend activities were limited mainly due to staff shortages or lack of drivers:

> **"There was a large variation in activities; some patients seemed very busy, while other patients had large gaps in their timetables."**

> **"Again, a major factor on the number of activities being scheduled and planned activities going ahead was the availability of staff, this was even more of a factor during evenings and weekends."**

> *"Pressures arising from sickness or annual leave can reduce staffing levels to four support workers. This is not unsafe, but impacts on the activities and outings for the day, as the considerable physical care needs of the residents tend to take precedence."*

Many of the on-site activities were sedentary in nature and, when questioned, many staff did not seem to know why people were doing certain activities or how they fitted into their active treatment plan.

> *"We rarely saw evidence of active treatment plans across the services and with many activities it was unclear as to how they were being used to help service users live more independently."*

> *"Clients are engaged in activities, it was not clear how these related to an assessment and treatment programme."*

We made 100 recommendations across the 43 services that related to day services.

My rights

We wanted to explore whether people were placed at the 'centre' of their care and how the services treated them, including their plans for discharge. In particular, we wanted to know if they were treated with dignity and respect and if their human rights were upheld. We looked at whether people could access advocacy services and what kinds of complaints systems were in place.

Advocacy
In 2007, we found that just over a quarter of all services did not provide independent advocacy and in some places advocacy services were not available.

In the follow-up audit, we found that 27 services out of the 43 did not provide regular access to advocacy

services, and half had negative issues raised about advocacy, including lack of a choice of advocate, or no advocate available:

> *"In one case, a family carer said that she had not had access to advocacy despite requests."*

> *"There is not sufficient advocacy into the unit; this had been recognised by the senior staff and negotiations were underway with the PCT to fund an increase."*

However, we found that services that did have access to independent advocates had more positive issues raised:

> *"There is an effective independent advocacy service in place to support residents and families."*

> *"Staff told us that service users and their family carers are told about the independent advocacy service on admission and encouraged to use it. An automatic referral is made at admission."*

Of the services where independent advocacy was used, there was some evidence that change had taken place as a result of advocacy intervention:

> *"As a result of advocate intervention, residents are now supported to participate in the written weekly summaries prepared for the multidisciplinary ward round instead of giving verbal feedback."*

Overall, advocacy services seemed to be in a poorer position than they were in the previous audit.

Restriction of movement
In the previous audit, we found significant evidence of inappropriate restrictions on freedom and a lack of risk assessments in many of the services we visited. Unfortunately in the follow-up visit, this situation was not much better. Seventeen out of

the 43 services had no risk assessments in place regarding locking doors. Many services locked bedrooms, toilets, bathrooms and kitchens, and individual risk assessments on the whole did not support this practice.

"Staff stated that none of the service users were safe to leave the premises without direct supervision. It was reported and observed that there were no up-to-date risk assessments in place for any of the service users and no behavioural guidelines. There was no locked door policy in place."

"The unit has a locked front door that is opened with a swipe card. None of the residents currently placed at the unit are detained and none had control of a swipe card to enable them free access to and from the building."

"A cold water dispenser was available, but cups were locked in the kitchen so service users had to ask staff when they wanted some water."

Some services had clear up-to-date policies in place that were adhered to and we saw that service users were able to move around as and when they liked.

"The unit has an open plan kitchen available which is unlocked and accessible at any time for patients… The activities room is unlocked and accessible at any time as well as a quiet room."

"For some people, where it was not appropriate to have free movement around the building, some had policies that supported the locking of doors."

"Risk assessments for locked doors were in place and we saw evidence that these had been reviewed, such as staff signatures and dates."

"We observed detailed and personalised risk assessments within the individual care plans."

Considering all the implications of the Bournewood judgement* and issues surrounding the deprivation of liberty, it is surprising that more services have not become more sensitive to these issues. This raises concerns from a human rights perspective.

Care planning

In the previous audit, poor discharge planning and delayed discharges were not uncommon. Some people were 'stuck' in the system with no indication of when they could expect to leave the service. *Valuing People*[5] in 2001 stated that people should have person-centred plans and that everyone should have an individual health action plan. People are also entitled to a community care assessment and to have their care planned under the Care Programme Approach (CPA) if they have complex mental health needs. This was also reinforced by *Valuing People Now*[4] in 2009. In the follow-up audit (eight years after *Valuing People*), the majority of services still did not have person-centred plans or health action plans in place. We found very little evidence of people having a community care assessment and, surprisingly for the people with mental health needs who were in assessment and treatment services, we found little evidence of CPAs for this group.

"The staff we spoke to were not aware of any person-centred plans or health action plans being used in the service, and this was confirmed by the service users' records."

"No service user currently had a person-centred plan or health action plan in place."

* The judgement of the European Court of Human Rights, published on 5 October 2004, in the case of H.L. v. the United Kingdom. It is so called because H.L's care and treatment took place in Bournewood Hospital.

"There were no community care assessments within the records."

"Despite their complex needs, no residents were on a CPA. The writing of personalised care plans (PCPs) had not commenced."

A few services did have person-centred plans that showed real involvement and ownership by the individuals:

"The patients are encouraged to write in their own person-centred plans and documentary evidence is available to support this which includes clients' drawings and own words used in the plans."

However in some instances, when people were admitted into services and they had either health action plans or person-centred plans, these did not seem to be used.

"Some people who have been admitted from community living have a health action plan or a person-centred plan, but these are not used by the unit."

A minority of services implemented CPA, and when these were instigated they tended to be well supported:

"Some units were now implementing six-monthly CPA review meetings as part of the care pathway. These meetings involve unit staff, the PCT commissioning manager, social workers, patient advocate, family and friends."

In the previous audit, on a more positive note, we found evidence which suggested that people had good access to healthcare professionals. Again, in the follow-up audit, this was seen as positive, with many comments being written about good multidisciplinary team meetings and multidisciplinary team involvement in the care planning that they implement.

"There were several examples of appropriate multidisciplinary discussion and access to health services for investigations and treatment."

"The ward round is multidisciplinary and attended by the service user, any appropriate carer or family member, the inpatient nursing team, community mental health team and other professionals involved in the delivery of care, in order to review progress, make changes to treatment programmes and plan for discharge."

But with the lack of person-centred plans, it is little surprise that many services needed to embed the idea of involving people in their care planning and treatment. Unfortunately the majority of services did not show evidence that they were involving people in this way.

"No evidence of service user involvement in formulating care plans and they were not routinely offered a copy in an accessible format."

"Some of the care plans had been signed by service users, but there was limited evidence that they were actively involved in the development of the plans."

"The care plans that were reviewed were all in written format and were not in an accessible format for the people who use the services."

However, we did see evidence of some good care and treatment planning in a minority of services.

"Care plans for four of the seven current residents were reviewed and were found to be comprehensive, containing a great deal of information about the individual's circumstances, behaviours and other person-centred content."

> "The treatment plans examined were outcome-focused and clearly identified the actions required to meet the specific needs of the individual as well as monitoring and reviewing the results of these interventions."

Of the 43 services visited, we made 264 recommendations that related to ensuring that people were at the centre of their care.

Family and friends

Under this theme, we looked to see if families were encouraged to visit their relatives, how this was supported and how friendships were developed and maintained. Unfortunately in the original audit, we found the majority of services had very few people with friends inside the service – most of their friends were employees of the service, and friends outside of the service were even rarer. Families often found it difficult to visit their relatives when they were placed far from their original placement, and many people did not have any contact with their family.

In the follow-up audit, this seemed to improve with the majority of services trying to maintain family contact.

> "The nursing team encourage contact with carers and family and actively seek to involve carers and family during a person's stay where appropriate."

> "The family carer was complementary about the staff and the service and said that things had improved further over the last 18 months."

Some families were present during the follow-up visits and gave positive feedback about their involvement with the services.

> "Relatives and carers who were interviewed provided positive feedback on the engagement and involvement they had with the service and confirmed that they know the staff and feel able to discuss their relatives' care with staff and ask for advice."

Maintaining or encouraging friendships seemed to be more difficult for staff to achieve. It was reported that 13 services did not actively support service users to make friends outside the unit.

> "By being confined to the home, residents were not supported and encouraged to make friends outside of the service."

> "We saw no evidence of friendships being made or sustained within or outside of the service."

However, 10 services reported that staff were actively supporting service users to make friends outside the unit by supporting them to attend community activities and by giving access to telephone communications.

> "Friendships outside of the unit were facilitated and supported and service users also had access to payphones, a cordless phone for more privacy and had their own mobile phones."

Checking quality

Previously we found that too often managers and commissioners were not monitoring the services that they either bought or were responsible for. Many had never visited the services to check that people were happy and receiving the care and treatment they needed. However, in the follow-up audit, we found a better response to commissioners. Only 11 services reported that they did not have regular visits from their commissioners.

> "No engagement from commissioners of the service – there are no stated outcomes for individuals and no expectation to provide reports."

Although 11 services is too many, this is an improvement from the previous audit. Managers are also becoming more engaged with the services and we saw that more audits were happening in this follow-up. However, many services still had no contact with senior managers or had any evidence of carrying out any audits.

"There was no local and limited trust-wide systematic audit arrangement in place to assess the quality of service planning or delivery, and no evidence of timely actions planned or implemented upon findings to drive up quality improvements."

The services that tended to carry out audits also tended to have visits from more senior managers.

Staffing

Staffing was one of the greatest issues in the first audit. Many staff had not attended basic mandatory training, the majority had no supervision or appraisal and morale was low.

We see a mixed picture in the follow-up audit, as some services ensured that all staff had received their mandatory training, appraisals and supervision, while many others had not.

"None of the staff of the unit had completed all of their annual mandatory training due to insufficient training opportunities provided by the trust, insufficient staffing in post and a lack of robust arrangements to backfill staff to facilitate their attendance."

"None of the seven staff interviewed had completed all of their annual mandatory training but all had completed some elements."

"Appropriate training, both mandatory and developmental, has been undertaken with supervision and appraisal systems established and embedded into the unit culture to support staff."

"Staff receive extensive mandatory and update training on a rolling schedule. Staff felt supported by the trust for training opportunities."

This is a positive change in the right direction, but many more organisations have to do significant work to catch up.

The disappointing element to training is that the majority of staff questioned did not know what *Valuing People* was. Since this has been a major part of learning disability culture, it is difficult to see how staff can work to up-to-date methods if they do not even know of the existence of the most significant policy document to be published.

"The introductory corporate brochure provided during the visit makes reference to Valuing People, however this has not been evidenced within staff training nor had the Disability Discrimination Act, the disability equality duty and diversity awareness."

"There had been no training on communications, valuing people, person-centred awareness, dignity, challenging behaviour, autistic spectrum disorder, medication or on epilepsy. None of the staff had undertaken training on disability discrimination/disability equality duty, or on the Mental Health Act or Mental Capacity Act, and most had not been provided with safeguarding training."

A shortage of staff was more of a common factor in this audit than previously across all the services. It was reported that inadequate staffing levels due to vacancies and sickness impacted greatly on the

quality of services. For example, a shortage of staff meant that some planned activities for service users did not go ahead.

> **"Current staffing levels are operating at 2.25 below the full establishment complement, which was reported by the team manager as set to provide minimum staffing levels. Concern is expressed that levels do not accommodate annual leave, training leave or sickness situations."**

> **"Levels of staffing were adequate to maintain a safe environment but very restrictive during holidays, training and sickness. This ultimately resulted in a reduction in activities for clients which on frequent occasions staff felt was unacceptable."**

> **"Substantive staffing currently is around half complement and the unit has almost 11 whole time equivalent vacancies."**

Very few services were fully staffed using permanent members of staff.

Most organisations however were monitoring their usage of agency staff and actively working to decrease this, mostly by having bank staff.

> **"The manager of the campus has developed a bank of staff who can be called upon to fill in shifts. External staffing agencies are not used."**

> **"The trust has made a conscious effort to reduce the use of agency staff, preferring to have regular bank staff that tend to work on the same units."**

There did not appear to be an active recruitment drive to fill vacant posts in many services.

Absenteeism due to sickness is still an area of concern within the services. Nine services reported

that they have issues with absenteeism due to sickness, which in turn, means a reliance on bank and agency staff.

> **"Sickness has been a problem on the unit with two members of staff on long term sick and one member of staff on maternity leave."**

A few trusts were actively trying to reduce sickness rates by putting policies into place to support staff, monitoring sickness rates and implementing return to work interviews.

> **"Staff sickness is monitored and reviewed on an ongoing basis. The trust has policies to support staff on long term sickness and when returning to work."**

We made 222 recommendations across 43 services regarding friends and family, supporting staff, sickness and monitoring services.

My wellbeing

Under this theme, we looked at how safe people were and if they were free from abuse. We looked at the environment they lived in and if their privacy, dignity and cultural needs were met. This included looking at health and safety policies and procedures relating to the protection of vulnerable adults.

Safeguarding
In our first audit, we made six referrals highlighting safeguarding concerns to the relevant local authorities. We also found low levels of reporting under 'whistle-blowing' procedures and had concerns about the ability of staff to make child or adult protection referrals.

In the follow-up audit, we escalated eight causes for concern to the chief executive or director of the services on the same day. All causes for concern were either managed through safeguarding

procedures from the local authority or reviewed by multidisciplinary teams. Each assessor followed up all causes for concern and we will continue to monitor these services in the future. One service has since been closed, and two services from the same organisation were of such poor quality that our investigations team carried out an initial consideration into the trust's learning disability service.

This is 16% more than the previous audit (19% of services compared to 3% in the 2007 audit).

Areas of concern ranged from institutional care, poor environment, lack of day activities, poor staffing levels, lack of care planning and people's basic human rights not being addressed.

Safeguarding training

At 14 services in the follow-up audit, not all staff had attended appropriate training, such as safeguarding and the protection of vulnerable adults (POVA). This ranged from having no members of staff attending the training to a few staff not being up-to-date with training.

> **"The staff interviewed by the team had not completed safeguarding training this year and did not feel confident to raise safeguarding concerns outside of the unit using the established interagency policy and protocol."**

> **"According to the training matrix, no staff had attended the basic safeguarding adults training within the required three-year timeframe and some staff had not attended for a considerable length of time. Such was the concern that we checked individual staff records, which confirmed the database was correct."**

The remainder of the services provided appropriate training that was refreshed regularly. This is a marked improvement from the previous audit.

> **"Staff interviewed confirmed that they had received training in adult protection and child protection, this was evidenced on the office training schedule."**

Staff at most services demonstrated an understanding of abuse and how to report it. However, at four services staff did not assure our audit teams that they had an understanding of abuse. It was also reported that these services had not undertaken appropriate training.

On the whole, staff at the services we visited understood whistle-blowing and felt that they were supported to use this policy if necessary. Again a marked improvement from the previous audit.

All but nine services had evidence that staff in post had been appropriately Criminal Records Bureau (CRB) checked and that these checks were mainly carried out by HR departments before staff could take up their positions. The HR departments had systems in place to monitor that these checks were kept up-to-date.

> **"A robust system of monitoring CRB checks is in place and includes processes to follow up on any disclosures, whether declared or not and action is subsequently taken on an individual basis."**

Finance

The majority of services demonstrated that they support people to have financial independence and control, for example by people having their own bank accounts and choosing when and on what they spend their money.

> **"Patients have the option to open their own bank account or to store their money in the hospital account."**

> **"When the service user arrives, a bank account is opened if they do not already have one."**

Thirteen services reported that people did not have financial freedom. In seven services, people's financial capabilities had not been assessed.

> "No evidence was presented to demonstrate how the process of managing residents' finances is transparent or consistent. It was quite evident that residents have not been empowered and supported to manage their own finances."

> "Only two patients deal entirely with their own money, despite all but one patient having the capacity to manage their own finances."

> "There was no evidence in healthcare records reviewed that financial capacity assessments were being completed and the outcome documented."

These services were long-stay residential services, independent hospitals and one assessment and treatment unit.

Restraint

In the previous audit, there were concerns about the levels of medication used to manage behaviour, especially PRN (pro re nata) which is administered as required – to sedate people as a form of restraint, for example. There was also a concern raised about the amount of physical intervention that some units used. Because of this, we concentrated on a routine question concerning medication.

We found the documentation of PRN medication was inadequate at 16 services (37%).

At seven services, the policy for the administration of PRN medication was absent, and some lacked details or had not been recently reviewed. However, policies and procedures at other services were reported to be sufficient.

> "There was evidence of an over-reliance on the use of PRN rather than alternative interventions, seen by interviews with staff and observing prescription charts."

> "There was no evidence provided of a PRN medication policy or accurate up-to-date guidelines for staff to follow for individual service users."

The assessments and monitoring of service users' need for PRN medication was also mixed. Some services reported that records and care plans were completed and informative, whereas at nine services, the records were absent or incomplete regarding PRN usage for the service user.

> "There were no specific risk assessments in place for physical interventions and no health monitoring form available following physical restraint."

> "The peer review team felt strongly that there is heavy reliance on managing clients through medication rather than alternative therapies for dealing with challenging behaviour, for example, psychology input."

The use of seclusion was reported at only two services.

We made 201 recommendations in 43 services regarding people's wellbeing.

Leadership

In the last audit, the conclusions and resulting recommendations made in the report stated that good leadership was the key to having empowered staff that, in turn, could empower people who use services. We found leadership to be lacking in many of the services we visited previously. In the follow-up audit, only four services stated that they had good leaders in the service, which directly influenced the quality of service provided.

"(The service)…has highly motivated staff with good ideas and enthusiasm for improving and developing services. The service appears to be well run, with an innovative and motivated ward manager and staff."

"The staff … who met the audit team were well motivated with good ideas for the continued improvement of the service. The unit has recently gone through a service redesign. This included a major environmental upgrade and staffing reallocation. The unit has refocused its aims and objectives, to providing an assessment and treatment service. The changes have been overseen by a new leadership team and with major capital investment."

"The greatest strength of this unit was the commitment and respect for young people demonstrated by the manager of the Young Persons Service. Her leadership and drive encouraged positive relationships between young people and her team of staff, who interacted warmly and with confidence during the audit."

Services previously visited

Of the 10 services we visited previously, we found most had improved. Five services have made significant improvements, two services have made improvements but need more attention, and three have seen surprisingly little change since the last audit.

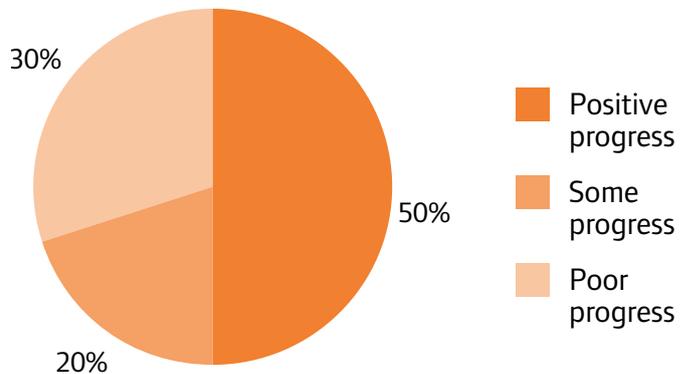**Figure 4:**
Improvements in 10 previously visited services

30%
20%
50%

- Positive progress
- Some progress
- Poor progress

Table 1: Areas where significant improvement is needed	
Areas of significant improvement	**Number of services applicable**
Better communication environments	4
Better environment	5
Better choices for people	4
More external monitoring	5
All staff CRB checked	5
Better training for staff	7
Access to advocates	8
Health action plans/person-centred plans	3
Ensuring that cultural needs are identified and acted upon	2
Staffing supervision up-to-date	6

Areas where improvement needs to be made in many of these 10 services are shown in Table 1.

It is good to see that after the first audit, the majority of services did improve their services, including five in a way that has significantly changed the lives of people living in these services.

Of the five services that have significantly improved, the improvement has not just been on external issues such as improving the environment and making sure that staff are trained (which should be easy to change) but also on more challenging issues. These included having good independent advocacy, ensuring that people's needs are at the centre of their care, looking at person-centred planning and health action plans and, the most welcome for people with communication difficulties, making sure that different ways of communicating everyday choices and more complex life events are a high priority, with total communication systems being developed. People who use services were starting to make informed choices about what they wanted to do in their life.

Improvement in areas to support staff in their job has been significant in the majority of the 10 services, such as staff supervision, training and ensuring that there are enough staff to be able to offer choices in daytime activities.

> **"The trust has taken significant steps to address shortfalls in staff training, with supervision to support staff."**

> **"The redecoration programme, together with the upgrading of facilities, has made a great difference to the living conditions."**

It is notable that the areas that have improved the most are ones that have had most monitoring from either senior managers or commissioners.

However, the teams in three services felt that progress was too slow and needed to gain momentum. There were other issues in the services that had areas of ongoing concern.

Table 2: Areas of ongoing concern	
Areas of ongoing concern	**Number of services applicable**
Poor care planning	3
Poor staffing levels	2
Lack of activities	2
Lack of health action plans	5
Progress on safeguarding but still more needed	3
Lack of risk assessments and locked door policies/ individual assessments	2

"Overall, while there has been some progress in the past year, it is disappointing that there had been little change to the daily lives or environments for all residents…especially with regard to increased independence…and choice… Because of increasing problems with maintaining adequate staffing levels and with recruiting to the increasing number of vacant substantive posts, the improvements for the residents would not have been achieved had it not been for the professionalism and commitment of staff."

We made a total of 910 recommendations in 43 services.
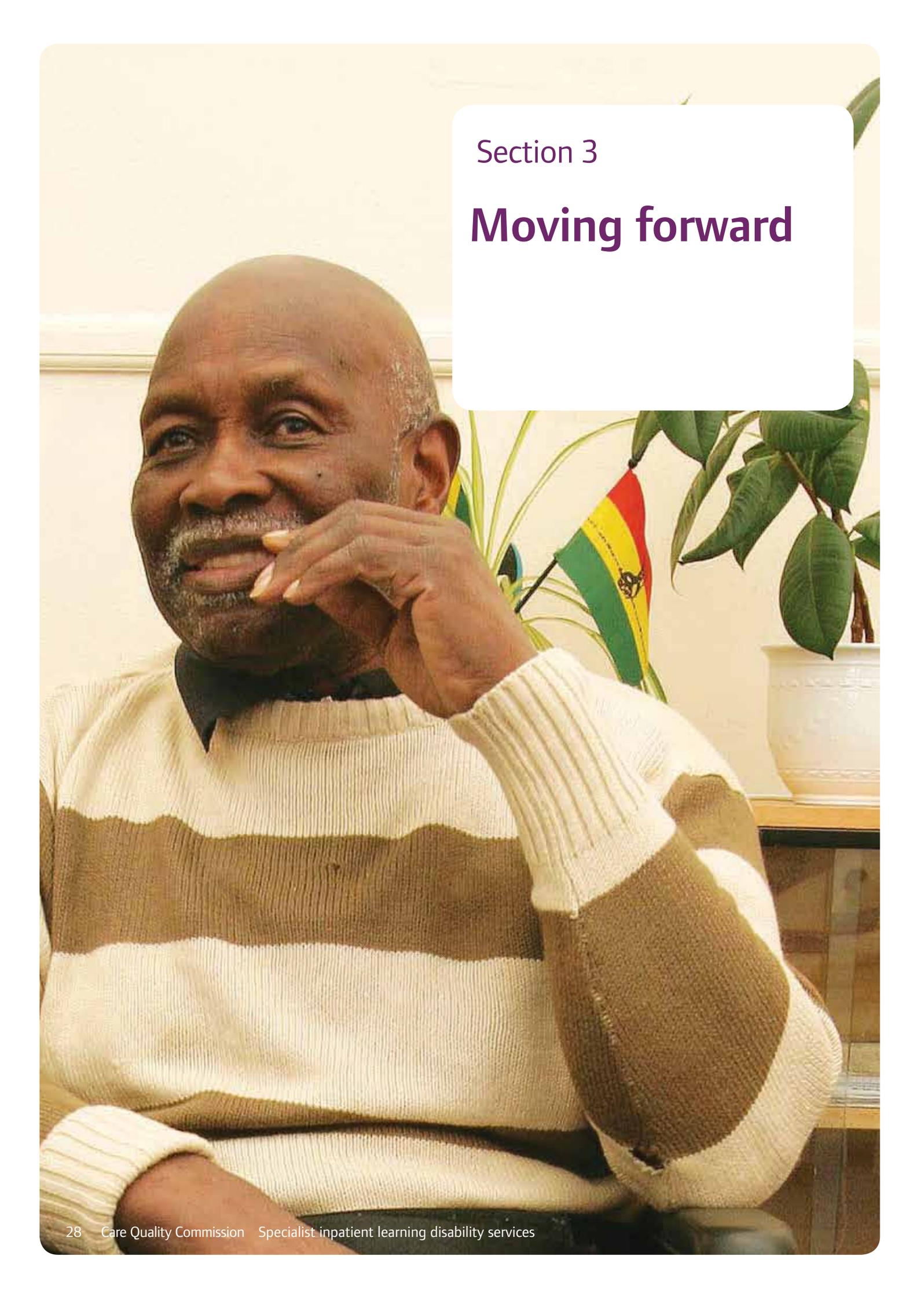
Section 3

Moving forward

Conclusions

It was obvious from the reports for individual services that most of the 10 services we revisited were of a better standard than the majority of those that we visited for the first time. There were, however, notable exceptions both positive and not so positive. We can also say that the services that had been monitored by senior managers or commissioning agencies were of better quality than those that had not. While the national picture of specialist inpatient healthcare services for people with learning disabilities has progressed since these visits, the national findings contained within this report are important and identify the key areas that every service must pay keen attention to.

Shared leadership

Good leadership is essential for senior managers and directors of services. It is about having the vision and drive to deliver excellence and refusing to accept poor standards. Good leadership is about inspiring staff at all levels to take account of their own actions and the actions of their colleagues. The governance of these services must be a priority for the board of every trust and for the senior management team of independent healthcare providers. For the chair, directors and non-executives to appreciate what poor standards of care in these services mean for individuals, they need to take more of an active role.

Responsibility for good leadership lies across senior teams and across agencies. There is a need for joint senior leadership programmes, shared across local areas, for people working in learning disability services. *Valuing People Now*[6] emphasised the need for strong leadership at all levels in health and social care.

Shared values

One of the reasons why recent policy on learning disability services has been set in the context of human rights is because of the need to address a fundamental question: as a society, do we really believe that people with learning disabilities are no different from anyone else and should be afforded the same quality of life as the rest of the population? If this is the case, this should also underpin the moves to transform other forms of care on the basis of citizenship.

By reminding people of this fundamental question and insisting on a response that states that people with learning disabilities have the same human value as anyone else, we are able to encourage everyone involved in services to evaluate them on the basis of their own experience. People who work in services or visit services can ask themselves daily "would I be happy with this service? Would I live here? Would I be happy with the active treatment that people are receiving here?", and ask what should happen if the answer is "no"?

The Care Quality Commission has its part to play, and an annual visit to services can help to maintain the shared vision and 'keep the pressure on' so that staff feel they have to improve or they will get a poor report. However, the way we regulate health and adult social care is fundamentally changing. From April 2010 all health and adult social care providers must be registered with us to be legally allowed to operate. Registration requires providers to meet a wide range of new essential common standards which will apply across the care sector.

We will continuously monitor and check how well providers are meeting these standards, which include critical areas such as protecting people from abuse, safeguarding vulnerable people, and respecting and involving people who use services, with specific additional guidance for services provided for people with learning disabilities. If services are no better than the majority that we visited they will struggle to comply with the legal registration standards. With our new wider enforcement powers, we will identify problems early and take swift action where necessary, including changing the registration status we give providers.

Shared power

For change to truly happen, it must come from the empowerment of the people and families that use services. This is about people having the information about quality of services and a direct role in shaping, maintaining and driving the quality of those services.

It is essential that people in the wider community who do not have experience of learning disabilities are aware of, and involved in, the standards and achievements of local services for people with learning disabilities.

All the people who work in these services need to renew their understanding of the law, and their responsibilities for upholding the quality of services provided.

More reports that highlight poor practice can only be part of the solution. Perhaps services need to focus on addressing these three fundamental issues and working towards truly person-centred services based on shared leadership, shared values and shared power.

Recommendations

Rather than having many recommendations that can be a challenge to deliver, we have decided to make only a few recommendations. However, we will make sure that these recommendations are monitored through strategic health authorities, Monitor and future reviews and studies that we will develop.

- Boards and senior management teams in NHS and independent healthcare should ensure that they have the evidence and reporting mechanisms to show that their learning disability services are meeting the registration standards. They should be aware that, through our ongoing monitoring of how well services are meeting essential common standards, we will take more account of the views of people who use services and make sure they are fully involved in decisions about their care.

- Each board should consider nominating a non-executive 'champion' for learning disability, who will take lead responsibility in ensuring that services are being monitored, making use of the skills of people with learning disabilities and family carers. The outcome of these audits should be fed into the new regional Valuing People Now boards, learning disability partnership boards, and strategic health authorities' assessment of health performance through self-assessment in learning disabilities – this is currently being supported in a few but not all strategic health authorities. The Department of Health is developing a national self-assessment tool to enable partnership boards to benchmark their performance and work programmes.

- Commissioning needs to have a local focus and develop the competence and capacity to deliver high quality services and support for local people. Commissioners should stop buying services that do not adhere to the principles of *Valuing People Now*. Commissioners should develop or revise their commissioning plan for specialist inpatient services as part of this work. Joint strategic needs assessments have local information to support this process – buying appropriate levels of care and support with a suitably qualified workforce – and can demonstrate year-on-year progress.

- Independent healthcare providers and NHS trusts should be able to justify the care, treatment and assessment they provide, ensuring that it meets with national guidance and best practice. Assessment and treatment services must not become campus provision under a different guise. Commissioners across health and social care have a responsibility to work collaboratively with providers to ensure that they do not allow people to remain who are not being treated or assessed.

- Learning disability partnership boards should work with people with learning disabilities and family carers, to empower and support them to speak up and be directly involved in peer audits with health organisations.

Appendix A: Shortlisting of services

The following section describes how the 43 services were shortlisted to take part in the follow-up audit.

Of the 43 services, 19 organisations were not visited in the previous audit; some of these organisations had more than one service.

This provided 21 individual sites from the 19 organisations. All 21 were due to be visited, but four services were found to have closed (two campus and two acute assessment and treatment units). This left 17 individual services to visit. From their previous self-assessments, we would have deemed these services to be acceptable, therefore their scores did not show a high enough risk to be visited the first time round.

We chose 10 services that had been visited previously and were found to have the highest number of recommendations overall. We visited these to ascertain whether they had made progress since the last national audit.

Many organisations were visited previously, but had more individual sites that had not been visited. We chose nine of these by looking at the previous self-assessment questionnaire and taking the nine next highest scoring services (a high score being potentially poor) and we visited all nine.

In the previous audit, 90 services indicated through their self-assessment questionnaire that they were operating residential services that were not registered by the Commission for Social Care Inspection (CSCI) and did not have qualified nursing staff on duty. None of these were seen as having any particular issues or risk factors, but we visited some to see if they had made progress to register the services and to look at the quality of the service. As these were potentially low risk, we only chose to visit two.

We were aware that nine new independent healthcare providers had registered after the last audit, and we decided to randomly select three for a visit.

Lastly, we had received intelligence about two services which suggested that including them in the follow-up audit would be beneficial, and we visited both.

We visited a total of 43 individual units.

Appendix B: Organisations visited

We visited the following 37 organisations:

2 Gether NHS Foundation Trust

Alpha Hospitals

Berkshire Healthcare NHS Foundation Trust

Bradford District Care Trust

Brookdale Healthcare Ltd

Cheswold Park Hospital

Coventry and Warwickshire Partnership Trust

Dorset Healthcare NHS Foundation Trust

Dudley PCT

Enfield PCT

Glencare Group

Hampshire Partnership NHS Trust

HealthLinc Individual Care

Isle of Wight NHS PCT

Leeds Partnership NHS Foundation Trust

Leicestershire Partnership NHS Trust

Lincolnshire Partnership NHS Trust

Milton Keynes PCT

Norfolk PCT

North East Essex PCT

North East London NHS Foundation Trust (formerly known as North East London Mental Health NHS Trust)

Northamptonshire Healthcare NHS Foundation Trust

Oxleas NHS Foundation Trust

Plymouth Teaching PCT

Portsmouth City Teaching PCT

Priory Grange Potters Bar

Rose Lodge

Rotherham, Doncaster and South Humber Mental Health NHS Foundation Trust (formerly known as Doncaster and South Humber NHS Trust)

Shropshire County PCT

South Birmingham PCT

South Staffordshire Healthcare NHS Foundation Trust

Suffolk Mental Health Partnership NHS Trust

Surrey and Borders Partnership NHS Foundation Trust

Sussex Partnership NHS Trust

Tees, Esk and Wear Valleys NHS Trust

Wolverhampton City PCT

Worcestershire Mental Health Partnership NHS Trust

Appendix C: Routine questions asked by the review team

R1: Independence and choice

"How do you ensure that people with learning difficulties are offered informed choices, to improve their independence as much as possible?"

The national findings recommended that methods of communication should be more accessible for people using the services to support day-to-day choices in:

- What and when they eat.
- What they wear.
- Who they live with.
- Who supports them.
- What they do during the day.
- Accessible communication available to support choice.

R2: Day-to-day lives and activities

"What activities do people with learning difficulties participate in each day and evenings to support them in their treatment and to live more independently?"

The national findings recommended that people using the services should:

- Be given more choice of activities.
- Have active treatment plans.
- Be offered activities to live more independently.
- Have more frequent activity.

- Have a range of activities.
- Be offered activities that are more culturally sensitive.
- Be able to go off site more (if appropriate).
- (For adolescents) be engaged in meaningful education and age appropriate activities.

R3: Independent advocacy

"What access and take up of independent advocacy services is there within the service?"

The national findings recommended that services should have:

- Advocates who are independent of the services.
- Appropriately trained advocates.
- A choice of advocates.
- Evidence of take up.
- Evidence of change taking place as a result of advocacy intervention.
- Cultural awareness around appropriate advocates.

R4: Locking of doors

"Which doors in your service are usually locked and are ones that service users do not have their own keys for?"

The national findings recommended that services should:

- Have appropriate up-to-date risk assessments.

- Have evidence of policies and procedures being updated.

- Ensure that people's care plans specify level of risk.

- Give people as much independence as possible.

- Reduce restrictive practices.

- Ensure people's dignity is respected.

R5: Planning care with and around the person receiving care – treatment plans

"Please tell us how many people using the services have an up-to-date accessible copy of each of these documents:

- Person-centred plan

- Community Care Assessment

- Health Action Plan

- Care Programme Approach

- Transition plan (for young people)

- Care plan/treatment plan."

The national findings recommended that services should:

- Involve individuals in all their care plans.

- Produce better treatment plans with robust outcomes.

- Have up-to-date health action plans.

- Have evidence of multidisciplinary support in care planning.

- Produce plans that are accessible for the individual.

- Have evidence of regular reviews and updates.

- Have evidence of dignity issues specified.

- Have evidence of cultural needs and preferences.

R6: Supporting staff

"Have staff had all appropriate training to be able to do the job competently?"

The national findings recommended that all staff should have appropriate mandatory training in:

- Valuing People.

- Disability Discrimination Act/ Disability Equality Duty.

- Diversity awareness.

- Communication.

- Understand behaviours and how to support them.

- Person-centred awareness.

- Vulnerable adults/children.

- Dignity.

- Working with people that challenge.

R7: Staffing and sickness

"How many agency or bank staff have worked in your unit in the last month? (Please tell us the number of different people, not the number of shifts or roles covered by them.)"

The national findings recommended that services should:

- Have sufficient levels of staff.

- Reduce the use of agency or bank staff.

- Actively reduce sickness rates.

R8: Monitoring services

"Who, external to the unit, monitors the quality of service?"

The national findings recommended that services should:

- Have regular reviews by commissioners.

- Have evidence of audit activity.

- Have evidence of senior management scrutiny.

- Have recorded monitoring of visits.

R9: Friends and family

"How are friendships supported within the unit and family involvement maintained?"

The national findings recommended that people using the services should be actively supported:

- To make friends outside of the service.

- To maintain involvement with their families.

- With flexible and imaginative thinking around circle of friends.

R10: Safeguarding

"Do all staff know how to make a child protection or adult protection referral?"

The national findings recommended that services should:

- Provide appropriate training to staff.

- Ensure that all staff understand abuse.

- Ensure that all staff understand whistle-blowing.

- Have evidence of Criminal Records Bureau checks.

- Make referrals swiftly.

- Positively support staff regarding whistle-blowing.

- Ensure that all staff encourage complaints and understand why they are important.

R11: Finance

"Please tell us how many people in your unit are being supported to have financial independence and control?"

The national findings recommended that people using the services should be actively supported:

- To have more financial freedom.

- To have individual bank accounts.

- To understand financial matters better.

R12: PRN medication

"How many of the people that use the services in your unit have been chemically restrained (administered PRN medication for challenging behaviour) in the last six months?"

The national findings recommended that services should have:

- Reduced its use of PRN (behaviour).

- Reviewed the appropriateness of PRN.

- Evidence that alternative strategies have been tried before PRN.

Appendix D: Recommendations for each service made by theme

Name of service unit	Name of organisation	My choices	My day	My rights	Me and others	My wellbeing	Total number of recommendations per service
Hollybrook Unit	2 Gether NHS Foundation Trust	2	3	8	5	5	23
Lower West Side	Alpha Hospitals	0	2	2	7	6	17
Campion Unit	Berkshire Healthcare NHS Foundation Trust	1	2	3	4	3	13
The Highfield Unit	Bradford District Care Trust	3	1	2	2	1	9
Cooper 1	Brookdale Healthcare Ltd	3	2	8	7	9	29
Cheswold Lane	Cheswold Park Hospital	3	6	11	7	7	34
9 Sycamore Crescent	Coventry And Warwickshire Partnership NHS Trust	0	2	9	1	6	18
1 Kinver Mews	Coventry and Warwickshire Partnership NHS Trust	3	2	7	6	6	24
11 Sycamore Crescent	Coventry and Warwickshire Partnership Trust	1	1	5	2	1	10
Sapphire Lodge Assessment and Treatment Unit	Rotherham, Doncaster and South Humber Mental Health NHS Foundation Trust	3	2	11	15	13	44

Name of service unit	Name of organisation	My choices	My day	My rights	Me and others	My wellbeing	Total number of recommendations per service
Delphwood Avenue	Dorset Healthcare NHS Foundation Trust	7	5	6	10	1	29
The Ridge Hill Centre	Dudley PCT	4	1	0	0	8	13
Seacole Centre	Enfield PCT	5	1	0	0	12	18
Ashwood Centre (The outram Lodge)	Glencare Group	4	2	9	7	4	26
Brook Lane	Hampshire Partnership NHS Trust	5	2	5	6	3	21
Coldeast Way	Hampshire Partnership NHS Trust	4	1	5	5	2	17
Bradley woodlands Independent Hospital	HealthLinc Individual Care	4	4	5	8	7	28
White Lodge	Isle of Wight NHS PCT	4	2	10	6	4	26
Frith Hospital	Leicestershire Partnership NHS Trust	1	0	5	1	0	7
Long Leys Court Assessment and Treatment Unit	Lincolnshire Partnership NHS Trust	5	3	8	4	6	26
Oakwood House	Milton Keynes PCT	6	5	9	6	5	31
3 Mill Close	Norfolk PCT	3	2	8	4	5	22
Magpie Rise	North East Essex PCT	2	1	0	0	2	5

Name of service	Name of organisation	My choices	My day	My rights	Me and others	My wellbeing	Total number of recommendations per service
Victor Hugo – Assessment & Treatment Unit	North East London NHS Foundation Trust (formerly known as North East London Mental Health NHS Trust)	6	0	10	6	10	32
39 Camelot Way	Northamptonshire Healthcare NHS Foundation Trust	2	2	3	2	0	9
Atlas House	Oxleas NHS Foundation Trust	4	4	10	10	5	33
The Willows	Plymouth Teaching PCT	4	4	6	4	4	22
Avenue House	Portsmouth City Teaching PCT 1	1	3	4	4	3	15
190 Barnet Road	Priory Grange Potters Bar	3	1	4	6	4	18
Underhill Street	Rose Lodge	2	4	5	6	1	18
Haughmond Ward	Shropshire County PCT	1	1	4	1	1	8
85 Church Parade	Shropshire County PCT	1	1	5	4	1	12
Oakswood Road	South Birmingham PCT	2	5	10	11	5	33
New Burton House (Broadoaks & Pippins)	South Staffordshire Healthcare NHS Foundation Trust	2	3	4	6	6	21
Kedington	Suffolk Mental Health Partnership NHS Trust	0	0	4	3	3	10
8 Ethel Bailey Close	Surrey and Borders Partnership NHS Foundation Trust	4	3	9	11	7	34
Derby House	Surrey and Borders Partnership NHS Foundation Trust	4	3	6	12	7	32

Name of service	Name of organisation	My choices	My day	My rights	Me and others	My wellbeing	Total number of recommendations per service
36 Alinora Crescent	Sussex Partnership NHS Trust	1	3	10	2	6	22
Birch House	Sussex Partnership NHS Trust	2	5	13	5	9	34
FARNE	Tees, Esk and Wear Valleys NHS Trust	2	1	1	2	1	7
44 Pond Lane	Wolverhampton City PCT	1	1	6	4	2	14
Groves Bungalow	Worcestershire Mental Health Partnership NHS Trust	5	2	8	8	8	31
3 Woodland Square	Leeds Partnership NHS Foundation Trust	3	2	6	2	2	15
	Number of recommendations	123	100	264	222	201	910

References

1. Healthcare Commission, *Joint investigation into the provision of services for people with learning disabilities at Cornwall Partnership NHS Trust*, 2006.

2. Healthcare Commission, *Investigation into the services for people with learning disabilities provided by Sutton and Merton Primary Care Trust*, 2007.

3. Healthcare Commission, *A life like no other: a national audit of specialist inpatient health services for people with learning difficulties in England*, 2007.

4. Department of Health, *Valuing People Now: a new three-year strategy for people with learning disabilities*, 2009.

5. Department of Health, *Valuing People, a new strategy for learning disability for the 21st century: a white paper*, 2001.

6. Department of Health, *Valuing People Now: from progress to transformation,* 2009.

7. Sir Jonathan Michael, *Healthcare for all: report of the Independent Inquiry into access to healthcare for people with learning disabilities*, 2008.

8. Local Government Ombudsman, Parliamentary and Health Services Ombudsman, *Six lives: the provision of public services to people with learning disabilities*, 2009.

9. Mencap, *Death by indifference*, 2007.

10. Commission for Social Care Inspection, Healthcare Commission, Mental Health Act Commission, *Commissioning services and support for people with learning disabilities and complex needs*, 2009.