



Commissioning services and support for people with learning disabilities and complex needs

National report of joint review

March 2009

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Mental Health Act Commission

The Mental Health Act Commission provides a safeguard for people who are detained in hospital under the powers of the Mental Health Act.

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Chapter 1

Executive Summary

In 2008, the Commission for Social Care Inspection, the Healthcare Commission and the Mental Health Act Commission worked together in nine areas of England to see how well people with learning disabilities and complex needs were being supported by local services. This report gives our findings from these nine reviews.

Who do we mean by people with learning disabilities and complex needs?

‘Complex needs’ refers to a range of multiple and additional needs that some people with learning disabilities may have. We also include people with profound and multiple disabilities and people whose behaviour presents a challenge. The group includes people with considerable service and support needs, for whom such services and support can be expensive. Across the country, more than 200,000 people have learning disabilities and complex needs and over the next few years this number is set to increase significantly, and with many more people aged over 60.

The Department of Health’s report *Valuing people now* (2009) reasserts the vision set out in *Valuing people* (2001):

“The vision for people with more complex needs is the same as for everyone: inclusion and participation in all areas of community life, including living independently and having paid work. To assume that some people cannot, and will never, achieve these is to set a ceiling on what progress can be made, both by an individual and by a society.”

People with learning disabilities and complex needs may have a range of multiple and additional needs and behave in a way that presents a challenge, but they are people who can be supported to make decisions and live as empowered citizens. To do so, individuals and their family carers should be fully involved in planning the care and support that they need, and they should have fair access to a range of specialised support.

Our concerns

However, recent reports showed that services for people with learning disabilities have not always been working well, especially for those with complex needs. These reports included:

- The Healthcare Commission and Commission for Social Care Inspection 2006 report, *Joint investigation into the provision of services for people with learning disabilities at Cornwall Partnership NHS Trust*.
- The Mencap 2007 report, *Death by indifference: following up the Treat me right! report*.
- The Healthcare Commission 2007 report, *A life like no other: a national audit of specialist inpatient healthcare services for people with learning difficulties in England*.
- Professor Jim Mansell's 2007 report, *Services for people with learning disabilities and challenging behaviour or mental health needs*.
- Sir Jonathan Michael's 2008 report, *Healthcare for all: report of the independent inquiry into access for people with learning disabilities*.

These reports made us concerned that people, and their family carers, were not being well supported to live full and independent lives. Local councils and primary care trusts have a responsibility to work together to arrange or commission services and support.

Commissioning should be a powerful way of improving the quality of services experienced by people. By commissioning we mean the process of translating aspirations and need into timely and good services for users which meet their needs, promote their independence, provide

choice, are cost-effective, and support the whole community.

There has been much emphasis placed on commissioning and on supporting its development. We wanted to look at it in more depth. We adopted an approach which would 'shine a light' so that those involved in arranging care and support for and with people can learn from our findings and ensure that improvements are made where necessary.

Since we completed our fieldwork, the Government has renewed its 2001 strategy for people with learning disabilities, *Valuing people*, with the publication in January 2009 of *Valuing people now*. This new, three-year government strategy for people with learning disabilities prioritises action for people with more complex needs.

How we carried out the reviews

During 2008, we looked in depth at nine local areas to assess how people with learning disabilities and complex needs were being supported to live their lives fully, through the activities of commissioning. We selected the areas so that we could use information that represents different locations; a mix of services; where 'secure' provision was in place, and so on. As such, we believe that the findings are a fair representation of services across the country and in line with findings of other recent studies. We are grateful to the staff and other people who committed time to work with us on this review, enabling us to draw out some important conclusions relevant to all areas of the country.

In carrying out our review, the starting point was that people and their family carers should be at the centre of commissioning arrangements; that their rights and needs should be the most important factor in deciding what and how services are organised; and that they should be helped to make choices about the support and services they experience.

To help our understanding, we talked to people with learning disabilities, experts by their own experience, and to family members. Our review teams included other such 'experts by experience' and family carers so we could gain a better understanding of what each place was like for people with a learning disability and complex needs.

What we found

Looking at the evidence from the nine reviews as a whole, we found some signs of progress, with staff trying hard to make a difference. Where there was evidence of services being designed with people at the centre, we saw people's lives being transformed. But there was not yet sufficient leadership to claim a substantial, systematic, properly resourced drive to commission services that really met the needs of local populations.

(i) People's rights

People should have person-centred plans which are developed with them and which set out their individual support requirements so that they receive services that meet their expectations. A good quality person-centred plan is fundamental to personalised services and a basic requirement, both in promoting and protecting people's rights and in designing wider service

and support arrangements to enable them to live fulfilled lives. Where good person-centred planning was taking place, it transformed people's lives. But we found too many instances of poor or non-existent plans.

Since 1997, people can receive payments directly to enable them, with their family carers if appropriate, to put together their own arrangements for support and services. More recently, personal budgets have been introduced. While more councils are promoting direct payments and starting to roll out personal budgets, we found few people with learning disabilities and complex needs or their family carers receiving such payments. Although not a choice for everyone, we were told by many people that they would like to be able to get them.

People who find it difficult to understand or communicate require access to independent advocacy. Services existed in almost all areas but we found variable access to such services. Similarly, few people and their families had easy access to information to let them know what services and support were available.

Family carers rarely got the carers' assessments to which they were entitled, arrangements for short-term breaks need improving and too few carers were involved in planning or feeding back about services.

(ii) Strategies for the longer term

In order to put in place good arrangements for people that match their expectations, we expected to see strategies in place locally that took into account people's needs, which looked at the range of services in place to ensure those needs are met and which prioritised

improvements – recognising that not everything can be improved immediately or at the same time. We found:

- Arrangements for the development of strategies were, on the whole, inadequate. We often found that such strategies were in the early stages of development. As such we were able to draw few conclusions about whether plans would lead to better outcomes for people. While staff working in the places we reviewed expected this to happen, we can only report this expectation.
- In particular we found that most joint strategic needs assessments were weak in bringing together information about the needs of people with learning disabilities and complex needs. We do not think that plans can be made without first having a thorough understanding of the needs and expectations of individuals and the combined needs and expectations of people in the local area, whom the plans are intended to benefit.
- People who used services and their family carers often told us that the arrangements in place to receive high quality and consistent feedback from them to inform priorities for the future required much more development. People felt that their views were either not listened to or were not being asked for.
- We found good examples of commissioners putting in place new contracts with providers that require evidence of improved outcomes for people, rather than simply specifying the type of service to be provided. Overall, we saw commissioned services starting to change for the better, with a distinct move away from large-scale care and support to more flexible service patterns where individual expectations are taken into account.

(iii) Services

We found that people were benefiting from more choice in housing – with plans for the last few people in inappropriate NHS campuses to move to accommodation more suited to their needs. Choices for day services and activities had improved.

Employment opportunities – whether supported employment or not – are a distant goal for most people. We saw strategies, plans and attempts to secure jobs for people, but very few people in paid employment. This is likely to become more difficult as the labour market becomes even more challenging.

In common with recent findings in other reports, we found that people experienced particular problems in accessing health services, in ways which others in the population did not:

- Too few people had health action plans or access to a health facilitator.
- Too few people received annual health checks from their doctor.
- People, together with their family carers, had poor experiences of acute hospitals.
- Access to and treatment from mental health services was poor.

More generally, we found that people with learning disabilities and complex needs who are from minority communities need to receive services that are better tailored to meet their specific needs.

Arrangements in place to safeguard people needed improvement, not least because people's situations often placed them in the most vulnerable of circumstances. In some cases they were wholly dependent on health and social care services for their support.

(iv) Making it happen

Bringing about change and improvement requires a combination of an effective set of arrangements between major local organisational partners; structures which function well; commitment on the part of senior staff and other stakeholders; and competent staff. Our review found some but not all of these features were in place.

We met senior managers who told us that they were committed to making services more personalised. We also saw arrangements for the strengthening of NHS commissioning as a result of the World Class Commissioning programme beginning to take shape. Despite this, we saw joint commissioning arrangements to benefit people with learning disabilities taking place unevenly and too slowly.

Many learning disability partnership boards were not playing the roles expected by *Valuing people* – driving change, monitoring developments and ensuring a link to other plans being developed. Few community learning disability teams were fully and effectively integrated, which meant that arrangements for people were piecemeal.

Finally, many staff in contact with people with learning disabilities and complex needs needed to acquire better specific skills and knowledge. But most importantly, there also needs to be a change in mind-sets. Too many people lack ambition and aspirations for what people with the most complex needs can achieve.

The broader view

We saw some grounds for optimism, with the commitment of senior managers to respond positively to the transformation and personalisation agenda set out in *Putting people first* (HM Government, 2007) and to changes to primary care arising from the Michael report. Our nine individual review reports include some good examples of services and support for people and their family carers and commissioning arrangements which are bringing about improvements.

However, we remain concerned at the slow pace of change and priority given to people who typically have high health and social care needs and who are at particular risk or vulnerable.

There is no shortage of guidance or direction. The *Valuing people now* strategy sets out a comprehensive programme of commitments and actions at national, regional and local level – with a range of individuals and organisations working in partnership to secure improvements in the lives of people with learning disabilities. The strategy was published after our fieldwork and during the preparation of this national report: many of the priorities for action we identify are mirrored by *Valuing people now*.

What is now needed is for councils and primary care trusts to demonstrate that the pace of change can be accelerated so that people with learning disabilities and complex needs can fulfil their expectation of enjoying the same basic rights as other people. And personalisation must be central to this.

“Good services for people with multiple and complex needs will by definition be highly personalised and thus central to implementing personalisation policy.” The state of social care in England 2007-08 [Commission for Social Care Inspection, 2009, Page 156.]

Ten challenges

Valuing people now sets out a three-year strategy and a one-year delivery plan for making the changes happen for everyone, including people with complex needs. On the basis of our review, we have identified ten key challenges for councils and primary care trusts (as local strategic partners), learning disability partnership boards and others to address together in their commissioning strategies and practices to improve the quality of life for people with learning disabilities and complex needs. These changes are consistent with the delivery plan in *Valuing people now*.

1. Person-centred plans, health action plans and access to good advocacy services are a basic right for every person with a learning disability and complex needs. They are not an optional extra. People without access to good quality independent advocacy are at risk of suffering a breach of their human rights. Special efforts should be made to ensure an inclusive approach. Primary care trusts and councils should ensure they are making sufficient “reasonable adjustments” for people with learning disabilities and complex needs, according to the Disability Discrimination Act 1995 and, for the NHS, in line with the NHS Operating Framework for 2009/10.
2. Agencies responsible for planning and commissioning services should ensure their arrangements for engaging with people with learning disabilities and complex needs and their family carers, as well as with other stakeholders, treat them as equal citizens in planning and providing feedback on the quality of services.
3. Councils should ensure that direct payments and personal budgets are sufficiently taken up by people with learning disabilities and complex needs and their families. Where people choose not to use either of these mechanisms to organise their care, they should still control how others arrange their care through having a say in how resources are spent.
4. Health and social care organisations should ensure they share information so they can assess how their services and support meet the needs of people with learning disabilities and complex needs.
5. Most learning disability partnership boards (local mechanisms with lead responsibility for securing improvements for people) are not fulfilling their intended purpose. Their effectiveness should be ensured and their objectives renewed.
6. Since April 2008, councils and primary care trusts have had the statutory responsibility to prepare joint strategic needs assessments. However, we found that, so far, these do not have sufficient information to ensure clear commissioning strategies for services and support for people with learning disabilities and complex needs. Councils and primary care trusts should make sure that these needs assessments are improved.

7. Community learning disability team arrangements (teams from partner organisations working full time to support people) varied considerably across the reviewed areas, with few achieving a fully integrated and effective style of working. Primary care trusts and councils should ensure the effectiveness of these teams.
8. Almost all areas reported that accessing healthcare, whether primary, hospital or mental health services, was problematic. Primary care trusts should ensure that access to healthcare for people with learning disabilities and complex needs is consistent and fair.
9. Our local reviews identified shortcomings in safeguarding arrangements. Given the greater risks to which people with learning disabilities and complex needs may be exposed, we expect councils and primary care trusts to ensure their safeguarding arrangements are effective.



10. Many staff and, in particular, non-specialist health service staff require development to obtain the specific skills, knowledge and attitudes to work with people with learning disabilities and complex needs. This includes knowledge of relevant legislation. Primary care trusts and councils should ensure that staff attitudes and competences are improved.

Taking our findings forward

It is clear from the three-year strategy and first year delivery plan in *Valuing people now* that transforming the lives of people with learning disabilities is a nationally important activity.

We expect through local action – involving people and family carers; developing strategies; implementing high quality commissioning; improving services; performance management by councils, primary care trusts; strategic health authorities, and other measures – that experiences for people will be improved.

The ten challenges we highlight show significant shortcomings both in the commissioning and provision of services for people.

We believe that if primary care trusts and councils review the ten challenges identified above, such reviews will contribute significantly to the broader programme of work proposed in January's *Valuing people now* delivery plan.

This is one of the final reports published by each of the Commissions before the new Care Quality Commission (CQC) assumes its responsibilities in April 2009.

Our three overall recommendations are to the Care Quality Commission and to health and social care organisations and they reinforce, rather than duplicate, the thrust of *Valuing people now*.

Recommendation 1 – Within the context of *Valuing people now*, NHS and social care commissioning and provider organisations should explicitly address the challenges we identify and as a consequence review the effectiveness of their planning systems to meet the needs of people with learning disabilities and the services and support they provide and/or commission to people with additional and often complex needs, and to make changes to their practices of commissioning and provision.

Recommendation 2 – Councils and NHS bodies should put in place arrangements to develop the personalised services required by people with learning disabilities and complex needs, whether living with their families or in supported living, so that services are actively shaped around needs.

Recommendation 3 – The Care Quality Commission, through its assessment of the performance of local authority and primary care trust commissioners, and its registration system for providers, should put mechanisms in place that give assurance to people with learning disabilities and their families that:

- The recommendations we make above are acted upon.
- Implementation of the *Valuing people now* delivery plan receives proper scrutiny.

Our final task is to thank all those people with learning disabilities and family carers who were at the centre of our reviews. We hope and expect that, as a result of their involvement with these reviews, they will be able to see improvements in services and support for people with learning disabilities and complex needs and their family carers.



Chapter 2

Introduction – Why and how the three commissions carried out a joint review

Introduction

Valuing people stated that “People with learning disabilities have the right to be full members of the society in which they live, to choose where they live and what they do, and to be as independent as they wish to be.”

Despite this assertion and the improvements since *Valuing people* was published, at the start of 2008 the three commissions shared concerns about the quality of services and support for people with learning disabilities, in particular those with complex needs.

Reports had documented how people with learning disabilities received poor services and how their rights were not being safeguarded, despite a wealth of policy and practice guidance about how services should be commissioned and delivered. Because of our joint concerns for people with learning disabilities and complex needs, we agreed to review how local councils and primary care trusts (PCTs) commissioned services and support for people with learning disabilities and complex needs.

Policy and practice guidance for commissioners of services for people with learning disabilities

Since the publication of *Valuing people* in 2001, central and local agencies have aimed to improve services for people with learning disabilities. The Valuing People Support Team assists local health and social care agencies to develop services for people with learning disabilities and to implement policy and practice guidance. More recently, people with learning disabilities have begun to benefit, along with other groups of people, from the Government’s aim to transform adult social care through the creation of a “truly personalised care system” (HM Government, *Putting People First*, 2007, page 2).

Concerns

Despite policy and practice guidance, in recent years several reports have voiced concerns about the quality of services for people with learning disabilities:

- Healthcare Commission and Commission for Social Care Inspection (2006) *Joint investigation into the provision of services for people with learning disabilities at Cornwall Partnership NHS Trust*.

- Healthcare Commission (2007) *Investigation into the service for people with learning disabilities provided by Sutton and Merton Primary Care Trust*.
- Mencap (2007) *Death by indifference: following up the Treat me right! report*.
- Healthcare Commission (2007) *A life like no other: a national audit of specialist inpatient healthcare services for people with learning difficulties in England*.
- Department of Health (2007) *Services for people with learning disabilities and challenging behaviour or mental health needs: report of a project group*. (The 2007 Mansell report.)
- Sir Jonathan Michael (2008) *Healthcare for all: report of the independent inquiry into access for people with learning disabilities*.
- Poor procedures for safeguarding – so that the most vulnerable groups are most exposed to risk.

The reports raised specific concerns relating to people with learning disabilities and complex needs, including:

- The quality of services and support for people with learning disabilities and complex needs.
- The lack of progress for people with learning disabilities with behaviour which may challenge or with mental health needs.
- The acceptance of inappropriate patterns of services for people with learning disabilities and complex needs.
- The transition of young people to adulthood.
- The need for improved and joint measures of local councils' and NHS performance.

Some of the key concerns included:

- The failure of local leadership – allowing services to drift.
- Poor individualised person-centred planning of care and support – people too often expected to fit in with services rather than services being tailored to individual needs.
- The poor quality of commissioning for specialist healthcare services – lacking a strategic approach.
- The continued use of institutionalised services – permitting poor practices to develop and be maintained.
- Diagnostic over-shadowing – where illnesses of people with learning disabilities are viewed as part of the learning disability and so not properly investigated or treated.

Rights

The reports also showed that people with learning disabilities and complex needs were being marginalised and not attaining their full rights to services and support. Both the Disability Rights Commission (DRC) and Mencap showed how care services, particularly health services, discriminate against people with learning disabilities so that they are not fully benefiting from legislation such as the Disability Discrimination Act 2005. This Act requires public sector bodies to produce disability equality plans and to make “reasonable adjustments” so that people with disabilities are not excluded from services.

The DRC 2007 report recommended that “urgent and positive action is needed to ensure that people with learning disabilities and/or mental health problems and their carers ... know their

rights in relation to physical health and the services to support this” (page 27). In 2008, the House of Commons/House of Lords Joint Committee on Human Rights urged government departments to make it clear that the Human Rights Act and the Disability Equality Duty arising from the Disability Discrimination Act 2005 mean that people with learning disabilities have the same rights to services as other people.

The three Commissions’ joint review

Given these concerns, the three Commissions agreed that action should be taken to respond to the needs of people who had so far not benefited sufficiently from *Valuing people* “starting with people with the most complex support needs” (page 10). We decided that, as a priority, we should work together to improve the quality of life for people with learning disabilities and complex needs.



We wanted to place people with learning disabilities and complex needs and their family carers at the heart of this joint commissioning review and to understand the impact of commissioning processes from their perspective.

To prepare for the review, we looked at a wide range of references and commissioning guidance and worked with a national expert advisory group, which included people with learning disabilities and family carers, to develop an eight-point assessment framework of outcomes for people with learning disabilities and complex needs. The framework drew on the Department of Health’s *Commissioning framework for health and well-being* (2007), incorporating *Valuing people* priorities. Copies of this assessment framework were sent in July 2008 to PCTs and local councils as part of the Commissions’ aim of promoting awareness of the needs of people with learning disabilities and complex needs, so that PCTs and local councils could use the framework to carry out their own self-assessments. Our assessment framework is at appendix one.

Reviews were carried out in nine areas by teams of six people, made up of a member of staff from each of the Commissions,¹ an expert by experience – someone with a learning disability who had experience of services; a family carer of someone with learning disabilities and complex needs; and a ‘peer commissioner’ – someone with experience of commissioning learning disability services. These nine areas were broadly representative of all English areas, taking into account geography, socio-economic characteristics and patterns of service provision, and ensuring that the areas included an In

¹ In the case of the Mental Health Act Commission, the team member was either a staff member of the Commission or a member of the Commission itself.

Control pilot area; an area with NHS campus provision; an area commissioning or providing a hospital with secure accommodation; and an area with a national learning disability indicator within its local area agreement.

Fieldwork took place from September to November 2008, usually spread over a two-week period. Councils and PCTs received headline feedback shortly after the reviews and later a final report. These local reports are available on the Commissions' websites. Appendix two describes in more detail how the methodology for the joint review was developed, how the fieldwork was carried out and how the review teams reported their findings. The Office for Public Management has evaluated the process and methodology of the reviews, including how they were experienced by the teams themselves and by the PCTs and councils, with the findings reported at the end of March 2009.

The next four chapters summarise the main findings of the nine reviews. Chapter 3 looks at commissioning from the perspectives of people with learning disabilities and complex needs and their family carers. Chapter 4 takes a broader view of commissioning, while Chapter 5 looks at the services that people receive. Chapter 6 reviews the arrangements for making things happen.



Chapter 3

Findings – Putting people at the centre

“A person-centred approach to planning means that planning should start with the individual (not with services), and take account of their wishes and aspirations. Person-centred planning is a mechanism for reflecting the needs and preferences of a person with a learning disability and covers such issues as housing, education, employment and leisure.” (Valuing people, 2001, page 49.)

Conclusions

From the perspectives of people with learning disabilities and complex needs and their family carers, the joint reviews clearly identified a number of commissioning issues requiring urgent attention:

- Few people with learning disabilities and complex needs were benefiting from person-centred planning, with many lacking services and support to meet their own individual needs.
- Strategic commissioning was poorly informed by information from person-centred plans, direct payments or personal budgets – commissioning was too often still concerned

with arranging for blocks of services for groups of people.

- Too few people with learning disabilities and complex needs and their family carers benefited from the flexibility of direct payments or personal budgets to tailor services to meet individual needs.
- The voices of people with learning disabilities and complex needs were not being fully heard, with access to advocacy limited by shortfalls in funding and the insufficient skills and experience of advocates.
- People with learning disabilities and complex needs and their family carers wanted better information about services in order to make informed choices.
- Transition planning for young people as they become adults needed improvement and to be firmly embedded in person-centred approaches so that transitions become as smooth as possible.
- Too few family carers had received carers’ assessments – they lost out on potential benefits which can improve the quality of their own lives while they continue to support their family members.

But the reviews also showed that where person-centred planning took place to support people in facilitating their self-directed care, the lives of people with learning disabilities and complex needs could be transformed.

Introduction

Person-centred, self-directed planning should provide the basis for the services and support received by individuals and, when grouped with other people's plans, should inform the development of strategic and operational commissioning plans.

Person-centred planning was a recurrent weakness in all nine review areas. Senior health and social care managers acknowledged the need to develop more and better planning, with some councils having person-centred planning co-ordinators, but in practice, most people did not have person-centred plans. There were exceptions: in Doncaster some 50 per cent of people with learning disabilities had person-centred plans.

Encouraging person-centred planning

In one area, commissioners supported people, their relatives and their circle of support in training for person-centred planning. This led to a range of imaginative solutions, including one where Jill, who had learning disabilities and complex needs, joined a community time-bank. Jill was able to exchange the time-bank's credits she earned by dog-walking for massages which she enjoyed receiving.

Given the significance of person-centred plans in providing information about the needs of people and as the basis for engaging with all the individuals and agencies who can contribute to plan development, this is disappointing. The reports identified how, for many councils, person-centred planning had significant resource implications, for example because of the use of specialist assessment and care planning staff, the additional requirement for staff training and the extra time to prepare a person-centred plan, compared with less intensive forms of care planning. With person-centred planning still not in the mainstream of care planning for most people with learning disabilities, it was not surprising that many people with learning disabilities and complex needs and their family carers, as well as some staff, had not heard of or were vague about the role and function of person-centred plans – and how these differed from previous styles of care planning.

Even where person-centred plans were found, the review teams expressed concerns about the quality of many of the plans, for example how well they were implemented; the extent to which they were shared with staff; inconsistencies across health and social care approaches to person-centred plans; how contracts were allocated and monitored from a person-centred perspective; the lack of involvement of family carers and even of people who used services themselves; and whether the intended outcomes of person-centred planning were being achieved.

Pilot work for person-centred planning was under way in some areas. Councils intended to roll out person-centred planning to more people, but so far not all people with learning disabilities and complex needs had such plans. As a result, many joint reviews recommended that people with learning disabilities and complex needs should

be given priority as person-centred planning is phased in. A further frequent recommendation of the reports was that person-centred plans and reviews should inform strategic commissioning intentions, as there was little evidence that this was happening. Other recommendations stressed the need for councils and PCTs to work together in developing person-centred planning and for a person-centred plan approach to be used with younger people with learning disabilities and complex needs to facilitate transition planning.

While only a minority of people with learning disabilities and complex needs were receiving person-centred planning, most had some form of care planning arrangements; that is, assessment, the development and implementation of a care plan and a subsequent review. Care plans should include a description of the immediate and long-term goals of the person, with a clear indication of the treatments and/or interventions proposed and, as far as possible, should be drawn up with the involvement of the person and his or her family or carers. Progress and possible changes to the plan should be reviewed regularly. In the case of people detained under the Mental Health Act and others with relatively complex mental health needs, the care plan should have been part of a coherent care programme approach recorded in clinical notes.²

However, the quality of many care plans was poor and they were frequently not tailored to the individual needs of and objectives for the person whose plan it was. Many recording systems were also poor, lacked supervisory monitoring or were

² For people with learning disabilities who were detained under the Mental Health Act whom we met during the reviews, the relevant guidance was the *Mental Health Code of Practice* (1999), paragraphs 15.5 – 15.7. The revised *Mental Health Act Code of Practice* (2008) continues to provide such guidance at paragraphs 23.42 – 23.44.

not available in accessible formats. Care plan reviews were often found to be intermittent and rarely led to changes in the plans' objectives.

Direct payments and personal budgets

One way of improving people's lives is through the use of self-directed schemes, such as direct payments. One of our review sites, Gateshead, had been included in the 13 sites for piloting the individual budgets scheme, the forerunner of what are now being rolled out as personal budgets. Across the nine councils, the proportions of people with learning disabilities receiving direct payments varied significantly, with some councils assessed as lagging in their promotion and in the take-up of direct payments. Other councils were noted for their efforts in actively promoting direct payments. For example, Hillingdon Council had a scheme where adult social care teams were given incentives to increase the take-up of direct payments for people with learning disabilities.

Overall, most councils needed to increase the take-up of direct payments, particularly for people with learning disabilities and complex needs and their carers.



Advocacy

Advocacy can be crucial in supporting disabled people in making their voices heard. For this reason, when *Valuing people* policies were introduced, funds were made available for three years to develop advocacy services for people with learning disabilities in partnership with the voluntary sector. People who used advocacy services and family carers valued and benefited from advocacy services. Many representatives on learning disability partnership boards who were users of services were supported by advocates or were self-advocates. Dudley PCT had involved the local advocacy services in auditing the PCT's learning disability service.

But reports also cited waiting lists for advocates and made recommendations that councils and PCTs should review the resources allocated to advocacy services, particularly for people with learning disabilities and complex needs. In some areas, such reviews were already under way. Some reports noted the difficulties which generic advocacy schemes could have in working with people with learning disabilities and complex needs, commenting on the lack of specialist staff skills and experience, especially when working with people with little verbal communication.

Information for the general public, people using services and family carers

Making informed choices about services requires information on local services and their quality. The joint review assessment framework included two specific items on how commissioners provided information about services and their quality. The reviews found a mixed picture. Some areas had helpful and informative services, for example at a Lancashire tourist information centre, but

overall the reviews found limitations both in the content, quality and formats of the information available about services. Nevertheless, some good examples of information were found: for example, the accessible and easy-read information provided in Dorset to people moving from NHS campus units and Stoke-on-Trent's range of accessible information available on day opportunities for people using services and family carers. Doncaster health staff had developed an impressive primary care support pack for people with learning disabilities and complex needs to help them understand and access primary care services and to raise the profile of their health needs in primary care.

But for the most part, there were deficiencies in the quality and accessibility of information about services for people with learning disabilities and complex needs. As one family carer said *"You've got to find out for yourself, haven't you?"* Eight of the nine reports included recommendations to councils and PCTs for improving the availability and accessibility of information about services for people with learning disabilities and complex needs.

Complaints

Complaints provide feedback about the quality of services and can form an important part of quality assurance processes. Most people who used services, carers and staff were aware of the complaints procedure, although reported complaints were few. Some carers felt that making complaints could be detrimental to the service experienced by the complainant, although no evidence was provided to justify this fear. Periodic reports about complaints were usually made to senior management groups or to councils' overview and scrutiny committees. Lancashire had produced a DVD for people who lacked literacy

skills, targeted at people new to services to enable them both to express their views and, if appropriate, to complain. Some PCTs and councils had arrangements for dealing with complaints that related to both health and social care issues.

Family carers

Family carers play significant roles both as advocates and as providers of direct care and support. The recent publication *Carers at the heart of 21st century families and communities* (HM Government, 2008) recognises the importance that family carers play in the lives of those they care for and sets out a range of actions and proposals to improve the support that is available for carers. Joint review teams met with carers. These sessions were valuable in gaining carers' perspectives on commissioning and on the services which they experienced.

Across the reviews, commissioners and planners were described as failing to engage and benefit sufficiently from the views of family carers. A frequent recommendation to PCTs and councils in the reports was that more should be done to engage carers in the commissioning process, including contributing to the joint strategic needs assessment.

More positively, most carers felt that they knew how to complain, although in practice they made few formal complaints.

Just as assessments are the starting point for determining the needs of people with learning disabilities and complex needs, so, under successive Carers Acts, carers are entitled to assessments. During the fieldwork, review teams heard from many carers that they had not been assessed nor informed of their right to an assessment. In some cases, carers' assessments had taken place and been

recorded on the family member's file, without the knowledge of the carer. Where assessments had taken place, carers reported that these assessments had led to significant differences to their lives. One family carer who had had an assessment told a review team:

“The assessment has made the world of difference. Without the carer's assessment, I would not have been able to continue in full time employment.”

Similarly, family carers can also benefit from direct payments. Just as the take-up of direct payments has been slow for people with disabilities, so too has it for family carers, although one council, Dudley, had slightly more carers getting direct payments than people with learning disabilities. Many carers to whom the review teams spoke said that they had never been told about direct payments, although the few carers we met receiving direct payments praised their value and flexibility.

Some carers also told review teams that they were unaware of the existence of active carers' groups in their areas and this reflected a common view of carers that they lacked information for themselves and for those they cared for. This may be a consequence of the move away from grouped services, so personalisation can present a challenge to ensure that both people with learning disabilities and complex needs and family carers have the potential benefit of meeting with others to share experiences and support. Where review teams heard about carers' organisations, these were said to be very helpful in acting as information signposts. In Stoke-on-Trent, GP surgeries had developed helpful carers' information packs.

Young people becoming adults

Almost all review reports included findings about how young people with learning disabilities and complex needs were supported as they became adults. For most areas, transition planning for these younger people's needs raised concerns that remained to be fully resolved. For example, person-centred planning was not fully embedded in children's disability services so that plans to prepare young people for adulthood needed improvement and to inform strategic commissioning.

Easing the transition from children's and young people's services to adult services

In one area, families received direct payments during the Easter and summer holidays so that they could choose for themselves what sort of breaks and activities most benefited them and their teenage sons and daughters with learning disabilities and complex needs.

This meant that the families and young people could move away from the more traditional children's holiday placements as they began the transition from services for children and young people to adult services. It was proving an excellent way for families to try direct payments out before deciding if they wanted them when they reached adult services.

Relationships with health services were still developing but improving, for example, over issues such as continuing healthcare needs. In some places, policies had yet to become front-line practices and there needed to be better links between adult social care and children's and education services. On the other hand, the Lancashire review team heard how person-centred review training had been successfully introduced to schools to develop action plans for young people in preparation for their transition to adult services. By contrast, one family elsewhere experienced a period of five months without any respite support following transition from children's to adults' services. This caused extreme pressure on the family as their entitlement to respite, on moving to adults' services, dropped from 80 to 42 nights per year.



Chapter 4

Findings – Strategic commissioning

*“Commissioning is the process of translating aspirations and need into timely and quality services for users which meet their needs, promote their independence, provide choice, are cost-effective, and support the whole community.” From CSCI (2006) *Relentless optimism: creative commissioning for personalised care**

Conclusions

Findings from the joint reviews presented a mixed picture of strategic commissioning with areas for development outweighing strengths.

The strengths included:

- Patterns of services are changing for the better and thus providing increased choice and there are plans for further changes.
- Contracting with service providers is increasingly outcomes-based.

Areas for development were:

- Joint strategic needs assessments require information about the needs of people with learning disabilities and complex needs, including information aggregated from person-centred plans and from family carers.

- Joint strategic needs assessments lack information about the needs of their areas' diverse communities.
- Sharing of information across health and social care needs improvement.
- Systematic arrangements for reviewing existing services and for deciding priorities need further development.
- PCTs and councils need to be more proactive in developing and managing provider markets.
- Tendering arrangements need to be more flexible and faster and service level agreements should be universal.
- PCT and council commissioners need to improve the arrangements for gaining feedback from people with learning disabilities and complex needs who use services, and from their family carers, about the quality of the services and support received.

Valuing people now (2007) stated that “*Planning and commissioning decisions should be based on what people have said they want and need in their lives through their own person-centred plans*” (page 23). Our evidence is that this has yet to happen fully for people with learning disabilities and complex needs. However, these

reviews also suggest some cautious optimism that the pressure of recent policy and practice guidance and the thrust towards personalisation (*Putting People First*, HM Government, 2007) may at last be beginning to effect improvements in both NHS and local councils' joint commissioning. But these potential improvements have yet to be fully realised.

This chapter looks at the processes of strategic commissioning and the tasks undertaken by specialist staff in PCTs and councils who have the day-to-day responsibilities and tasks of commissioning. For the NHS, considerable direction and guidance derive from the current World Class Commissioning programme. For councils, the Department of Health, with the Care Services Improvement Partnership, has issued guidance, such as *Commissioning for personalisation* (2008), to assist councils in their commissioning tasks, both generally and



in respect of people with learning disabilities and complex needs.

Drawing on a range of commissioning models, this chapter follows the three broad phases of the commissioning cycle: (1) strategic planning, (2) procuring services and (3) monitoring, evaluation and feedback. These three phases form the three principal headings of this chapter.

Strategic planning

Strategic planning includes three components: assessing needs, reviewing service provision and deciding priorities.

Assessing needs

Assessment of need forms the starting point in the commissioning cycle. Since 1 April 2008, PCTs and councils have had to prepare a joint strategic needs assessment (JSNA) of the health and well-being of their local community. JSNAs are intended to inform both local area agreements and the sustainable communities strategy. At the time of the joint review fieldwork (September to November 2008), PCTs and councils were still preparing their JSNAs so that where these documents existed they were for the most part in draft only. Some PCTs and councils had maintained registers of people with learning disabilities but where the review reports referred to them, it was to note that they were out of date or not used for planning purposes. By contrast, Gateshead and Stoke-on-Trent PCTs were beginning to collect information about the population of people with learning disabilities from GPs, using the new Enhanced Service for Learning Disabilities Scheme to support GPs in this process.

Overall, the reviews found that local JSNAs were so far weak in their coverage of the needs of people with learning disabilities and complex needs. Local reports thus recommended that PCTs and councils include information about the needs of this group. Department of Health guidance (2007) on preparing JSNAs calls for the engagement of people with learning disabilities in the preparation of JSNAs, but the review teams judged that this had yet to take place.

For the most part, information from individuals' assessments and plans failed to influence in any systematic way the development of commissioning strategies and plans. The Dorset report, however, cited a pilot exercise which had collated information from 20 person-centred plans to identify themes that could inform commissioners.

In relation to learning disabilities, a significant gap existed in information about the differing needs of areas' diverse communities and in the engagement with people from minority communities in the preparation of JSNAs and strategic plans. As a result, many plans failed to take into account the full range of communities in their areas.

A common report theme was that all three components of the commissioning cycle would benefit from improving existing arrangements for sharing information across health and social care. Some reports referred to the benefits that were expected from the appointment of a joint director of public health who would lead on assessing population needs.

Reviewing service provision

Most areas lacked systematic reviews of existing service provision. Dorset was an exception in, for example, having recently reviewed its services for people with learning disabilities and challenging behaviour in the light of the Mansell report.³ Nevertheless, all local commissioners were generally aware that both day and housing/residential services needed to be modernised to respond to the current drive for personalisation, even if they had not carried out a systematic review. Lancashire, for example, planned to give priority to undertaking a learning disability service gap analysis in 2009. Similarly, in Harrow there was an awareness of the dearth of single-sex services in day and respite care for people from the Asian community.

Deciding priorities

In the absence of some form of joint strategic needs analysis which includes people with learning disabilities and complex needs, learning disability commissioners lacked safe foundations on which to base decisions on priorities for development. Many review reports included recommendations for councils and PCTs to develop learning disability commissioning strategies. Consultation and engagement arrangements were, for the most part, weak, so that reviews recommended improving engagement and consultation with people who used services, potential users, family carers, existing and prospective providers and other stakeholders.

³ Department of Health (2007) *Services for people with learning disabilities and challenging behaviour or mental health needs: report of a project group*. (The 2007 Mansell report.)

Despite these deficiencies, all the areas visited were beginning to respond to the current thrust of health and social care national policies, in particular the personalisation agenda, and intended to work in an increasingly joint way in developing their strategic plans.

Procuring services

Once decisions have been made on the joint strategic commissioning strategy, commissioning models identify three elements to ensure the changes in service patterns: designing services; shaping the structure of supply; and planning capacity and managing demand. Given the lack of sound JSNAs and learning disability strategies that successfully include people with learning disabilities and complex needs, it was not surprising that our reviews gained relatively little information about these separate components of the commissioning cycle.

Nevertheless, some reports documented how local health and social care commissioners were beginning to take a more proactive approach. Redbridge, for example, had prioritised funding to support smaller providers, social enterprise schemes and innovative services that stimulated the market, as well as meeting needs. The council had also promoted the sub-contracting of service provision between larger and smaller providers, ensuring flexibility in service provision and support for smaller providers. Gateshead Council had moved from being a principal provider to specialising in key areas, opening up the market to some 15 new providers in the area. Doncaster Council belonged to a procurement concordat aiming to support small and medium sized enterprises, with preferred provider status being awarded to providers that demonstrate that they meet

certain outcomes. On the other hand, some areas had still to roll out service level agreements to all providers – particularly in-house providers. Some providers, particularly smaller providers, found tendering processes slow and inflexible.

Innovative market development

Dudley Council provided an innovation grant to independent sector providers that required additional funding to set up independent day care provision or supported housing provision. At the time of our fieldwork, one independent residential care home had been successful in securing funding to develop day services for people with learning disabilities, including those who have complex needs. Dudley will again be offering the innovation grant in 2009/10.



Active and responsive commissioning

A year ago, Elspeth and Annie lived with seven other people in a large housing association property and were due to move into more personalised services. A commissioner worked with the housing association while staff trained in person-centred planning developed individual plans for each of the nine residents, working with the residents, family carers and specialists, such as occupational therapists, to ensure that the residents were at the heart of the planning process.

As the plans were developed staff became aware that although Elspeth and Annie had lived together for many years, and would be happy to be near each other, they wanted even more independence. The outcome was that they moved from their previous large and shared property into individual flats, but next door to each other, and are now doing really well. The flats have two bedrooms so that Elspeth can invite her relatives to stay over with her sometimes – an important part of her plan.

Family carers of both Elspeth and Annie were concerned to ensure sufficient hands-on support. The use of telecare ensures the two residents' safety without the need for a constant staff presence, therefore increasing their independence. They now lead a much more active life – going to the gym, shopping, cooking, and helping out in the local shop. Just what life should be like!

Marketplace event

Gateshead arranged a marketplace event which enabled people who were using services that were to be re-provided to meet potential providers. The majority of the people with a learning disability who were having their services re-provided came to the day's event as well as some 25 providers.

Many of the carers attending this event were reassured that the needs of their family member could be managed in alternatives to the traditional services they were currently receiving.

More positively, most councils were moving away from block contracts to more flexible options for people and to developing preferred provider schemes. Some councils were using contracts which were increasingly outcomes-based. For example, Dorset's proposed contract for people moving from NHS campus units was outcomes-based and would serve as a model for all future contracts used by the council and NHS Dorset.

Monitoring and evaluation

Monitoring and evaluation covers three elements: supporting choice; managing performance; and seeking the views of those who use services and, where appropriate, family carers. Of the three phases of the strategic planning cycle, the joint reviews suggest that monitoring and evaluation is the most under-developed.

Supporting choice

People with learning disabilities and complex needs can be severely restricted in their choices by the limited availability, for example, of day opportunities. Our reviews found that options are slowly beginning to expand as services move away from older and more limited styles of provision. At the same time, some people are beginning to exercise choice through direct payments and personal budgets. The reports indicate that the *Supporting People* housing programme is creating more options for people with learning disabilities and complex needs, as for other groups of people in housing need. By contrast, the review teams reported that opportunities for employment were severely limited.

Managing performance

Many areas were still developing mechanisms for reviewing service quality, adopting quality assurance frameworks and setting up performance management arrangements for learning disability services. Some reports recommended that contracts include clauses to ensure that providers address matters such as safeguarding, privacy and dignity and that these matters should be monitored and reported on. The review teams found that where poorly performing providers were identified, these were being handled appropriately by councils and PCTs.

Seeking the views of people who use services

The previous chapter described how information from person-centred plans considered together was having little impact on commissioning strategies. In the same way, the joint reviews observed that the views of people who used services and their family carers had too little influence on commissioners to inform monitoring and evaluation. One positive exception was Stoke-on-Trent's REACH parliament of people with learning disabilities, which monitored the implementation of the learning disabilities and complex needs strategy against *Valuing people* aims and fed back its views to the council and the PCT.



Chapter 5

Findings – Services and support for people with learning disabilities and complex needs

Conclusions

Between them, the nine areas presented a mixed but improving picture of the services available to people with learning disabilities and complex needs.

The strengths were:

- Choice in housing is increasing and benefiting from developments in the *Supporting People* programme.
- The relocation of people remaining in inappropriate NHS campus accommodation had been planned.
- Choices for day activities and services are improving – although transport for getting out and about remains a problem in some areas, limiting people's access to mainstream community activities.

Areas for improvement:

- There were significant numbers of people living outside their home areas, so that they could lose touch with their local communities.
- Employment prospects for people with learning disabilities and complex needs remained poor.

- Few people with learning disabilities and complex needs had a health action plan, calling into question whether their health needs were being fully and appropriately met.
- Across all the areas, there were reports of poor experiences of primary and hospital care and poor access to mental health services, indicating that people with learning disabilities and complex needs were failing to receive the same level of services as other people – which is their right.
- Services for people with learning disabilities and complex needs from minority ethnic communities were mixed, so that many people were effectively experiencing discrimination in their rights of access to services.
- The short-break services for family carers in many areas needed improvement.
- Safeguarding arrangements were improving but in almost all areas they needed to get better, to decrease the risk of abuse or exploitation of some of the most vulnerable of citizens.

Patterns of services for people with learning disabilities are changing. Councils and the NHS are increasingly moving from providing and commissioning institutional and segregated

forms of services as they respond to the drive for personalisation. The joint reviews found evidence of these changing service patterns but at the same time they documented the need for further improvements.

Housing

Where people live is probably the most important feature of their daily lives and this is as true for people with learning disabilities and complex needs. From the publication of the Jay Report [1979], which provided an influential boost to the closure of long-stay hospitals, it will have taken over 30 years to see the last people who do not need specialist, in-patient hospital care moving away from hospital sites into the community. For a few of the review areas, there were still some people in NHS campus provision but with definite plans to move in the near future.

The reviews found significant variations in the numbers of people living out of area: one borough had some 160 people living out of area, while another had fewer than five. The former had yet to develop detailed plans for returning people from out-of-area placements or strategies for reducing future numbers placed out of borough.

People with learning disabilities and complex needs, like other people in need of social housing, were benefiting from the *Supporting People* housing programme. Redbridge, for example, was using *Supporting People* funds to employ a resettlement officer who had established good links with a range of housing options. Both the Harrow and Hillingdon reports commented on the strength and value of the *Supporting People* programme in developing greater housing options for all people with learning disabilities. Doncaster had carried out an analysis of housing need for people with

complex needs and employed a placements officer to review housing needs and sought to match these with potential placements. Dudley's good partnership working with housing services supported a housing initiative for people with learning disabilities and complex needs.

Employment

Very few people with learning disabilities and complex needs in the sampled areas were in any form of employment, despite strategies, plans and attempts to secure jobs for people with learning disabilities. Few people with learning disabilities were employed directly by PCTs or councils for the benefit of such employees and employers and to serve as examples to other local employers. Some councils were making major efforts to find jobs for people with learning disabilities and complex needs. Dudley Council employed a job coach to assist people with learning disabilities into paid employment and had recently been awarded lottery funds to employ a 'work mate' whose responsibility would be to find work in the statutory sector for people with learning disabilities, including those with complex needs. Both Dudley and Stoke-on-Trent had set targets of supporting a small number of people with complex needs to secure paid employment. By contrast, in another area, some people had been in supported employment preparation training for up to five years.

Overall, few people with learning disabilities and complex needs had been able to secure any form of employment.

Day opportunities

Across the country, day services for people with learning disabilities are changing for the better and this was true for the nine sampled areas. Nevertheless, many people still experienced the block groupings of traditional day centres, as at one centre where all the residents went to the same day centre at the same time and joined in the same group outings to accommodate staff shift patterns. This did not allow for any flexibility in daily routine or support any individual goals and aspirations. *“I would like to try using public transport but have to use the minibus”*, one person told the review team. One family carer told us about her son: *“He was going to be awarded a medal at a presentation but staff took him home early because it was the end of their shift. He was very upset.”*

Elsewhere, choices about day activities were increasing as large day centres were closing, with smaller bases opening and being reformulated, for example, as neighbourhood resource centres. Lancashire had used its learning disability development fund to commission a leisure co-ordinator officer whose leadership had achieved increased numbers of people accessing Lancashire College; the reforming of a multi-sports group; the provision of adapted bicycles for people with complex needs; and, through improved changing facilities and an inclusive fitness programme, had boosted numbers of people with learning disabilities using a local leisure centre. Lancashire also had a day service just for women with learning disabilities, including those with complex needs, which benefited the Asian community.

Overall, it was perhaps a measure of the way in which day services were getting better that only one review team made a recommendation aimed at seeking further improvements to day services.

Transport

One aspect of day services that continued to present problems was transport. Seven of the nine areas reported problems with arrangements for transport for people with learning disabilities and complex needs, particularly with the flexibility for accessing their day services. Two reports made specific recommendations aimed at improving transport services.

Health

A few months before the reviews took place, Sir Jonathan Michael published *Healthcare for all*, and strategic health authorities had asked PCTs across the country to assess their health services for people with learning disabilities in the light of the report. Although some of our review teams heard that this work was in hand, it was too early to see any improvements specifically arising from the Michael report.

Our findings endorse the critical conclusions made by Sir Jonathan: although there are some examples of good health service practices, the general picture found in the nine reviews was again that health services needed to improve significantly to meet the needs of people with learning disabilities, especially those with complex needs. Additionally our review showed that improvements were also needed for the few people with learning disabilities and complex needs we met who were detained under the Mental Health Act.

Health action plans

Valuing people viewed an individual's health action plan as the basis for assessing and planning to meet the health needs of someone with learning disabilities and called for all people with learning disabilities to have these plans by June 2005. None of the nine areas had achieved this goal.

The reports suggest that the health resources needed to achieve this objective had never been sufficiently provided. One review report stated that work on health action plans had begun in 2006 but had not been sustained. Another review described the very recent appointment of a health action plan facilitator. A third had found poor co-ordination and implementation of the plans, commenting that *“Professionals, family carers and people with learning disabilities were left unaware or confused as to how to use the plans”*. Other areas presented a mixed picture: one review found some good health action plans but other plans were out of date, could not be found on case files or had not been prepared at all. In one area, no one with learning disabilities and complex needs had a health action plan. Not surprisingly, five reviews made recommendations for improvement in the provision of health action plans.



Primary and secondary health services

Although there were exceptions, both primary and secondary healthcare services generally lacked understanding of the needs of people with learning disabilities. Access to and treatment by health services were frequent concerns of family carers. As one report stated:

“This resulted in a lack of confidence in health services, deteriorating health needs and the perception that people with learning disabilities were not viewed as equal citizens.”

The reviews reported that some of these difficulties had been identified and that staff training sessions had been arranged, but the review teams also heard that take-up was sometimes disappointingly low from the very staff groups who had been identified as most needing training.

To respond to people going into hospital, some areas had liaison nurses. Carers reported that such nurses were highly valued for facilitating patients' hospital admission and treatment. But such posts were rare. By contrast, many family carers said that they were required by hospital staff to provide care support when their disabled family member was in hospital, and thus had to sleep in armchairs on the wards for several days. Other carers explained how they were expected to lift, bathe and provide the direct care to family members but were not allowed to eat or use the toilet on the ward.

GP services

One review drew attention to an important issue arising as young people with learning disabilities and complex needs move into adult services. While young, they may have received health services from paediatricians based in a secondary care setting which could otherwise have been accessed from primary care as a GP patient. However, as the young person becomes an adult, their healthcare responsibilities transfer to GPs, who can lack knowledge of or an established relationship with their new patient.

Drawing on the results of pilot schemes and the Welsh experience of a statutory scheme, people with learning disabilities and their English GPs have been encouraged respectively to receive and provide annual health checks. The introduction in 2008 of the Direct Enhanced Service, by which English GPs will receive reimbursement for every annual health check of people with learning disabilities, was too new to have effected changes identifiable during the review fieldwork. However, one area, Gateshead, was already promoting such checks through the recent recruitment of three people with learning disabilities to part-time posts to work with GP surgeries in support of the annual health check process.

Mental health services

Two areas reported that they had used the Valuing People Support Team's 2004 *Green light toolkit*, to help NHS mental health trusts judge progress in providing services for people with learning disabilities. In one area, work had only recently started. By contrast, in another area the toolkit had led to the successful development of a joint learning disabilities and mental health protocol.

However, all nine areas reported problems with access to and/or the treatment provided by local mental health services:

- staff lacked awareness of the mental health needs of people with learning disabilities
- a joint mental health/learning disabilities protocol had not been shared, for example, with primary care staff
- staff lacked knowledge of mental health legislation
- joint learning disability/mental health working was not formally integrated
- specialist mental health services were not available
- the mental health needs of people with learning disabilities and complex needs were not being adequately met
- communications between learning disabilities and mental health teams were not robust
- there was poor access to mainstream mental health services.

The review teams found some positive mental health examples. In Redbridge, the local mental health trust was setting up a single specialist unit for patients with dual diagnosis on the mental health trust site. The trust was also involving people with learning disabilities who used services in developing quality standards for its learning disability service. And in Gateshead an intensive support team worked effectively with individuals using in-patient mental health services to co-ordinate and oversee discharge.

One report described how difficulties in recruiting and retaining psychiatrists to consultant posts had been overcome by recruiting a psychiatrist to work part-time with mental health services

and part-time with learning disability services: the psychiatrist's links with mental health services positively supported better access for people with learning disability. This model was likely to be extended elsewhere in the area.

However, apart from this example, the reviews found little evidence of the involvement of psychiatrists in the care of people with learning disabilities and complex needs. One report pointed to the lack of evidence in patients' medical records of any review of the use of psychiatric medicines, even when such a review had been identified and documented as a need. In another area, the review team was concerned that a care home had not identified a person's deteriorating mental health needs, resulting in a delay in referring to psychiatric services.

Services and support for people from minority communities

Some reviewed services were effective in engaging with and responding to the needs of people from minority communities. Dudley's Equal Access and Support Team was successfully meeting the needs of people with learning disabilities and complex needs, including those from black, Asian and minority ethnic communities. Hillingdon's Upward group of people with learning disabilities actively worked with some communities to raise awareness of disability and to promote diversity, contributing positively to the equalities and diversity agendas.

Encouraging independence

Adita is a woman from an Asian community who has learning disabilities and mental health issues. She lived with her two brothers but, as Adita reached the age of 40, they realised that their mother was increasingly unable to cope with Adita's behaviours in response to the pressures of family living. Adita and her family worked with her care manager to develop a person-centred care plan which identified her need for accommodation where she would be comfortable but could maintain her independence. After visiting different housing options, Adita and her family agreed that it would be a good choice to live with two other people in a house which encouraged independent living.

Adita is now doing things that she was never able to do before and is becoming much more independent. Her brothers stated that this has had a major effect on their sister who is now building up her own life and is planning to go to Pakistan to visit relatives which in the past she felt unable to do.

The care manager was praised for his continued support. Adita, her mother and her brothers are assured that they can still contact him if there are any problems.

Other areas had more to do to address equality and diversity issues, for example gender-specific services or specialist advocacy, or to overcome the view of some staff who justified the lack of targeted services for people from minority ethnic communities with the statement "Well, they look

after their own". By contrast, Dorset PCT was allocating significant resources in appointing three community development posts to improve the engagement of black and minority ethnic communities.

Services for family carers

There was a mixed picture for services and support for family carers. Chapter 3 described how few family carers had received an assessment, but those who had, and were aware that they had, generally reported that they had gained real benefits in the subsequent services and support they received.

Innovative support for a family carer

Jean's son, Adam, has severe learning disabilities. Jean spends much of her time acting as his main carer.

After a carer's assessment, she and her care manager came up with an innovative way of using direct payments: the council gave Jean money to pay for her to attend a course in nail care. This was seen as a good way to encourage her to relax.

However, the use of direct payments in this way has had more far-reaching consequences as Jean now provides nail care for people with learning disabilities and for the staff supporting them. She has also secured a part-time paid job using these new skills. An excellent way of supporting family carers in getting their own life back.

For most family carers, the principal service was that of respite care/short-term breaks: five reviews reported criticism of the availability or the quality of these services, although commissioners were usually aware of the deficiencies. A few reviews referred to carers' emergency respite schemes although these appeared not to be known to all family carers. The carers' strategy within the NHS Operating Framework for 2009/10 may lead to improvements in carers' services – although not necessarily specifically for carers of people with learning disabilities – since one of the key requirements is that PCTs work with councils and publish joint plans on how their combined funding will support breaks for carers in a personalised way.

Safeguarding

The Cornwall and the Sutton & Merton investigations, as well as *Healthcare for all*, identified concerns about safeguarding so that the joint review assessment framework included coverage of safeguarding issues. During the joint review fieldwork phase, the Commission for Social Care Inspection published its own report, *Safeguarding adults* (2008), describing uneven progress amongst councils in developing effective safeguarding arrangements and variability in the support given to individuals who experience abuse. Also during fieldwork the



Department of Health published briefing sheets and newsletters relating to the new deprivation of liberty safeguards. Safeguarding was thus a very live policy and practice issue for councils and PCTs.

Like previous reports, our review found significant differences between the areas in their safeguarding arrangements for people with learning disabilities and complex needs. In most places, councils and PCTs were taking steps to improve these arrangements and to learn from the experiences of safeguarding referrals and investigations. Contracts with the independent sector included specific safeguarding requirements and in most places these processes were appropriately checked by contract monitoring staff. Review teams reported that councils and PCTs made training available on safeguarding, although it was not always fully taken up.

Despite this awareness and work under way, the joint reviews found that existing safeguarding arrangements remained of concern. For example:

- staff lacked knowledge of safeguarding reporting processes
- reporting arrangements were not secure and did not enable effective learning from inquiries

- provider staff lacked awareness of safeguarding issues, for example in respect of rights under the Mental Health Act
- monitoring of providers' safeguarding practices was poor
- audit trails of safeguarding decision-making were poor
- safeguarding leadership responsibilities were unclear
- awareness of safeguarding issues across key stakeholder groups needed improvement
- contract specifications did not address safeguarding issues sufficiently
- there were concerns about financial safeguards.

All but one review report included at least one recommendation aimed at improving safeguarding performance, for example, by increasing staff knowledge and awareness of safeguarding legislation and procedures; having better information for people with learning disabilities and complex needs; and learning from improved performance management.



Chapter 6

Findings – Making it happen

Conclusions

To bring about change and improvements requires commitment on the part of senior staff and other stakeholders, well functioning organisational structures and competent staff.

The joint review found that some but not all of these elements were in place.

Organisational commitment

- Senior NHS and council social care managers expressed commitment to and acceptance of the drive to increase personalisation of services for people with learning disabilities, including those with complex needs – but such commitment was still to be turned fully into effective operational arrangements.
- Organisational commitment was indicated, for example, by the development of joint commissioning and pooled budgets – but these were not fully implemented across all nine areas.

Leadership from learning disability partnership boards

- Most learning disability partnership boards were not fulfilling effectively the roles intended for them by *Valuing people*; that is, being the local drivers for change, in monitoring service development and providing links to the wider local strategic planning agendas.

Effective joint commissioning structures

- Despite stated commitment to joint commissioning, few places had effective and stable structures to carry such commitment into operation and to bring about the strategic commissioning required to achieve the personalisation of services and support for people with learning disabilities and complex needs.

Effective community learning disability teams

- All areas had some form of community learning disability team in place. While some teams were reported as effective, few operated in a soundly integrated fashion so that the overall position seems much as when *Valuing people* was published in 2001.
- Across the nine areas, the variety of other teams which worked with people with learning disabilities and complex needs indicated the lack of a common organisational model for specialist teams working with people with learning disabilities and complex needs.

Engagement of providers

- Engagement with provider stakeholders was variable, limiting their potential to contribute to the development of strategy and to respond readily to changes in service needs.

Competent staff

- Most areas had plans to develop staff competencies to meet the demands of increased personalisation of services but there were reports that non-specialist health staff were less likely to take up training offered.

Overall, the joint reviews show that systems and structures are beginning to be set up to 'make it happen,' taking on board the personalisation agenda and the implications for people with learning disabilities and complex needs. However, the reviews also raise doubts about whether the level of commitment and the current pace of change are sufficient within the foreseeable future to bring about the

improvements in services and support for people with learning disabilities and complex needs which national policies set out to achieve.

At a local level, making it happen requires a successful combination of a number of elements:

- organisational commitment
- leadership from learning disability partnership boards
- effective joint commissioning structures
- effective community learning disability teams
- engagement of providers
- competent staff.

Organisational commitment

Government's broad objective in health and social care is to achieve greater personalisation in the way that services are commissioned and delivered. This objective has recently been reinforced for people with learning disabilities through the publication of *Valuing people now: making it happen for everyone* (2009), setting out a three-year strategy and a one-year delivery plan to improve services for people with learning disabilities.

Across all the reviewed areas, the personalisation model was being accepted and adopted – but this was happening at different speeds in different areas, and reflected different ways of translating formal commitment into both commissioning and face-to-face delivery of services and support to people with learning disabilities and complex needs and their family carers. Senior managers acknowledged that they and their organisations needed to respond to the pressures for change in adult social

care services but local implementation often still needed to recognise fully that people with learning disabilities and complex needs are as much part of the personalisation agenda as any other group.

The reviews found that senior officers and members in NHS and council organisations stated that they were committed to working in partnership, both at the strategic and the operational level. Joint commissioning boards, joint commissioners and joint directors of public health were all seen as evidence of such commitment. In some areas, these evidenced commitments were new. In one area, the first meeting of the generic joint commissioning board took place during the fieldwork period. In another, the joint director of public health was yet to be appointed. The reviews found that for the most part there is a considerable way to go before these aspects of joint working are successfully operating in practice.

Pooled budgets can be an indicator of successful partnerships. In two areas, pooled budget arrangements worked well. In another two areas, pooled budgets were planned for 2009, while, for one area, the stimulus of joining the In Control scheme had led to pooling of funds. Although review teams were told about budgets under pressure, the availability or otherwise of funds to develop services for people with learning disabilities and complex needs was not, at this stage, reported as a significant barrier to further improvements in services. One reason for this was that many councils and PCTs did not know what proportions of their budgets were being spent on people with learning disabilities and complex needs.

Foreshadowed by *Valuing people* in 2001, but more clearly spelled out in *Putting people first*, HM Government policy papers have made clear

the intent to achieve a radical transformation of previous policies and practice in the learning disability field. The present review confirms that PCTs and councils have already begun to change but messages still need to cascade from senior managers to all their staff, as well as to service providers and their staff. People with learning disabilities and complex needs and their family carers will also need to take on board the personalisation drive – but the reports agree with other findings that where personalisation has been successfully introduced, the new approach has been welcomed.

Within the NHS, World Class Commissioning had raised the general profile of commissioning amongst, for example, professional executive committees and clinical advisory groups to PCT boards, as well as gaining a higher profile for people with learning disabilities and complex needs within primary care. A non-executive director of one PCT board was the learning disabilities champion. Elsewhere, an indication of the PCT's commitment to joint working with the council was its continuation of funding for learning disability services, despite significant financial challenges. However, it was generally too early to see the impact of such commitment or of World Class Commissioning on people's lives.



Leadership from learning disability partnership boards

Valuing people (page 9) stated “At a local level, learning disability partnership boards will have lead responsibility for ensuring implementation” of the improvements in learning disabilities. The most recent statement from *Valuing people now: the delivery plan* (2009) re-iterates the importance of these boards:

“Effective partnership boards are central to the strategic planning, commissioning, delivery and performance management of services for people with learning disabilities and their families” (page 28).

Most of the nine review reports found that partnership boards did not act as strategic drivers for the development of learning disability services. Typically, people thought that they lacked operational and strategic focus and had no real influence on strategic decision making. Or as one person with learning disabilities who served on a partnership board said, “It needs to get better at action”.

Valuing people aimed to set learning disability partnership boards firmly within the broader local strategic partnership (LSP) planning frameworks: “Close links between Learning Disability Partnership Boards and LSPs will ensure a common direction and help to address wider issues, such as access to other local services, including transport” (page 108). The joint review reports provided no evidence that any such links were close or effective in providing significant input from the learning disability partnership boards to broader planning arenas.

Some areas had recognised this deficiency and had recently restructured in an attempt to promote partnership boards’ role and to strengthen how they sat within other local partnerships, for example, the LSP. One geographically large area was preparing to reduce the number of its partnership boards to match those of new PCT boundaries and was also hoping thereby to increase the consistency of the partnership boards’ strategic directions.

There were concerns about the representative nature of many learning disability partnership boards; for example, under-representation of people from minority communities, people with learning disabilities and complex needs, family carers and providers. Often, despite publicity and the availability of accessible, easy-read minutes and papers, partnership boards and their functions were not known to potential stakeholders or those with interests in learning disability services.

By contrast, Dudley’s Partnership Board was described as well established, with good stakeholder involvement, producing good quality work and with well-identified and appropriate work-streams and targets for the future, including reviewing the needs of people with learning disabilities and complex needs. Dudley’s Partnership Board had adopted a Bill of Rights which had been incorporated into the joint commissioning structure. One positive and common practice was for partnership boards to be co-chaired by people with learning disabilities.

Effective joint commissioning structures

Across the nine review areas, while there was broad commitment to some form of joint commissioning between health and social care, the forms of this commitment were varied and often in a state of change. Because of financial pressures, in one area the joint commissioner post had been cut. In another, a previous joint commissioning group was considered dysfunctional and had been disbanded. Following a study by an external consultant, a restyled unit was being set up, but at the time of fieldwork, staff were not in post. In another, the first meeting of a joint commissioning board, covering all services, took place during the joint review fieldwork. By contrast, Doncaster was said to have effective monthly joint commissioning meetings, with both learning disabilities and mental health as standard agenda items. And in Lancashire, joint commissioners were represented on the learning disability partnership board.

Community learning disability teams

In 2001, *Valuing people* commented that “Community learning disability teams were forerunners in partnership working, but they have not consolidated their position” (page 107). This was still true for most of the review areas. Most teams lacked full integration; that is, sharing allocation and referral arrangements and the same recording systems, files and IT systems. Often, teams in the same area operated in different ways. Some parts of one area had no community learning disability teams (CLDTs). Another area had three teams, each hosted in different NHS trusts and not integrated with the council.

However, there were also positive reports of CLDTs: one team member was the designated champion in self-directed support who mentored other colleagues. Another CLDT was noted by the review team as having become increasingly person-centred, with the PCT having recently addressed its under-resourcing of healthcare professionals and with all team staff now using a single database.

Community learning disability teams – working together

In Lancashire, although only one team was fully integrated, it was using both the single assessment process and the integrated social services information system, with positive feedback from team members about this way of working. Council staff were the main users of the single assessment process and the information system, but full health participation in both of these systems was planned to take place alongside the programme to integrate fully the remaining community learning disability teams.

In addition to CLDTs, the reviewed areas had a wide range of other specialist teams which worked with people with learning disabilities and complex needs. These included teams for working to treat challenging behaviour; to assist with transitions; to facilitate links with health services; to support people with autism; to develop self-directed support to adults; to promote equal access and support; to provide and support staff with therapy; to help people manage challenging behaviours; to improve healthcare for vulnerable adults in acute hospitals; and to review and monitor people living in residential care.

The variety of such teams across the different areas shows that there is no consensus on a single organisational model by which to construct service patterns to meet the needs of people with learning disabilities and complex needs. Team structures reflect local patterns and the effectiveness of other services complementing specialist learning disability services.

Engagement of providers

A major factor in achieving change and improvements in services for people with learning disabilities and complex needs is the quality of service providers. While commissioners and contract managers can secure monitoring of contracted services against service specifications, providers need to be engaged in the direction of travel as services modernise. Across the reviewed areas, the patterns of engagement were variable: in some places, providers were well engaged, for example, via provider forums and involvement with learning disability partnership boards. Elsewhere, such links were lacking.

Competent staff

For people with learning disabilities and complex needs and their family carers, the success of policies, strategies and plans is measured not by the quality of such documents but by the way in which people who work for them, and how the wider community, respond to them as individuals and to their individual needs. Whether people with learning disabilities and complex needs employ their own staff or use staff provided by other organisations, staff commitment and competence are essential.

Information about staff competence and training was broadly positive, with most review reports referring to PCT and council recognition of the need to provide training to prepare and improve the skills and knowledge relevant to the personalisation agenda, with training to be open to independent providers. However, some areas reported delays in developing workforce planning and in ensuring that staff were ready to take on board the implications of the increasing personalisation of services.

Staff working with people with learning disabilities and complex needs required additional training and skills. For example, one report identified the need to skill people specifically for working with this group, including training for care managers in best practice for commissioning. Another report noted the availability of good quality multi-agency training but also commented that despite the priority for primary care staff to have training, there was often a poor take-up by generic health staff. A similar finding was made in another area, where some staff had not received specific training to support approaches to person-centred planning, health action planning and working with people with complex needs, although such training was readily available. The review findings mirror those of Sir Jonathan Michael's report that generalist health staff often have limited knowledge about learning disability affecting people's access to, and the quality of, healthcare.



Chapter 7

Summary and recommendations

What is now needed is for councils and primary care trusts to demonstrate that the pace of change can be accelerated so that people with learning disabilities and complex needs can fulfil their expectation of enjoying the same basic rights as other people. And personalisation must be central to this.

Ten challenges

Valuing people now sets out a three-year strategy and a one-year delivery plan for making the changes happen for everyone, including people with complex needs. On the basis of our review, we have identified ten key challenges for councils and primary care trusts (as local strategic partners), learning disability partnership boards and others to address together in their commissioning strategies and practices to improve the quality of life for people with learning disabilities and complex needs. These changes are consistent with the delivery plan in *Valuing People Now*.

1. Person-centred plans, health action plans and access to good advocacy services are a basic right for every person with a learning disability and complex needs. They are not an optional extra. People without access to good quality independent advocacy are

at risk of suffering a breach of their human rights. Special efforts should be made to ensure an inclusive approach. Primary care trusts and councils should ensure they are making sufficient 'reasonable adjustments' for people with learning disabilities and complex needs, according to the Disability Discrimination Act 1995 and, for the NHS, in line with the NHS Operating Framework for 2009/10.

2. Agencies responsible for planning and commissioning services should ensure their arrangements for engaging with people with learning disabilities and complex needs and their family carers, as well as with other stakeholders, treat them as equal citizens in planning and providing feedback on the quality of services.
3. Councils should ensure that direct payments and personal budgets are sufficiently taken up by people with learning disabilities and complex needs and their families. Where people choose not to use either of these mechanisms to organise their care, they should still control how others arrange their care through having a say in how resources are spent.

4. Health and social care organisations should ensure they share information so they can assess how their services and support meet the needs of people with learning disabilities and complex needs.
5. Most learning disability partnership boards (local mechanisms with lead responsibility for securing improvements for people) are not fulfilling their intended purpose. Their effectiveness should be ensured and their objectives renewed.
6. Since April 2008, councils and primary care trusts have had the statutory responsibility to prepare joint strategic needs assessments. However, we found that, so far, these do not have sufficient information to ensure clear commissioning strategies for services and support for people with learning disabilities and complex needs. Councils and primary care trusts should make sure that these needs assessments are improved.
7. Community learning disability team arrangements (teams from partner organisations working full time to support people) varied considerably across the reviewed areas, with few achieving a fully integrated and effective style of working. Primary care trusts and councils should ensure the effectiveness of these teams.
8. Almost all areas reported that accessing healthcare, whether primary, hospital or mental health services, was problematic. Primary care trusts should ensure that access to healthcare for people with learning disabilities and complex needs is consistent and fair.
9. Our local reviews identified shortcomings in safeguarding arrangements. Given the greater risks to which people with learning disabilities and complex needs may be exposed, we expect councils and primary care trusts to ensure their safeguarding arrangements to demonstrate that they are effective.
10. Many staff and, in particular, health service staff, require development to obtain the specific skills, knowledge and attitudes to work with people with learning disabilities and complex needs. This includes knowledge of relevant legislation. Primary care trusts and councils should ensure that staff attitudes and competences are improved.

Taking our findings forward

It is clear from *Valuing people now's* three-year strategy and its first-year delivery plan that transforming the lives of people with learning disabilities is a nationally important priority.

We expect through local action – involving people and family carers; developing strategies; implementing high quality commissioning; improving services; performance management by councils, primary care trusts; strategic health authorities, and other measures – that experiences for people will be improved.

The ten challenges we highlight show significant shortcomings both in the commissioning and provision of services for people.

We believe that if primary care trusts and councils review the ten challenges identified above, such reviews will contribute significantly to the broader programme of work proposed in January's *Valuing people now* delivery plan.

This is one of the final reports published by each of the Commissions before the new Care Quality Commission (CQC) assumes its responsibilities in April 2009.

Our three overall recommendations are to the Care Quality Commission and to health and social care organisations and they reinforce, rather than duplicate, the thrust of *Valuing people now*.

Recommendation 1 – Within the context of *Valuing People Now*, NHS and social care commissioner and provider organisations should explicitly address the challenges we identify and as a consequence review the effectiveness of their planning systems to meet the needs of people with learning disabilities and the services and support they provide and/or commission to additional and often complex needs, and to make changes to their practices of commissioning and provision.

Recommendation 2 – Councils and NHS bodies should put in place arrangements to develop the personalised services required by people with learning disabilities and complex needs, whether living with their families or in supported living – so that services are actively shaped around needs.

Recommendation 3 – The Care Quality Commission, through its assessment of the performance of local authority and primary care trust commissioners, and its registration system for providers, should put mechanisms in place that give assurance to people with learning disabilities and their families that:

- The recommendations we make above are acted upon.
- Implementation of the *Valuing people now* delivery plan receives proper scrutiny.



Appendix One

Framework used to assess commissioning

Background

The decision to undertake a joint review of the commissioning of services for people with learning disabilities and complex needs by CSCI, the Healthcare Commission and the Mental Health Act Commission derives from concerns about the quality of care commissioned across health and social care.

In 2006, the Healthcare Commission and CSCI joint investigation into Cornwall NHS Partnership Trust found that *“services were being provided in totally unacceptable environments, record keeping was so poor that it prevented effective care from being provided, and senior leaders in the trust lacked strategic vision and an effective operating plan”*.

The Healthcare Commission investigation in 2006 found care in Sutton and Merton NHS Trust to be old fashioned, institutionalised and lacking good care planning and appropriate leadership. In both Cornwall and Sutton and Merton, safeguarding practices were also deemed to be unacceptable. In 2007, following these concerns, the Healthcare Commission undertook a national audit of specialist inpatient healthcare services for people with learning difficulties in England. CSCI worked with the Healthcare Commission on the design of the audit questionnaire with both organisations committed to ensuring that an item on commissioning was included. The report that followed the audit, *A life like no other*, concluded that there was:

- a poor set of procedures for safeguarding vulnerable people
- poor planning of care for people
- lack of internal and external scrutiny
- lack of stimulating activities and opportunities
- poor physical intervention practices
- lack of leadership
- residential care provided by health services in institutionalised settings.

These findings, combined with a number of reports and policy documents raising concerns about the quality of care, support and provision for people with learning disabilities, and particularly those with complex and challenging needs, resulted in the three Commissions working together to develop an assessment framework for the review of commissioning practices.

We have undertaken a literature and policy review of current commissioning guidance and have worked with an expert reference group to develop a definition of commissioning that will be used for this review.

Commissioning

Good commissioners understand people's needs now and how to plan for the future. They are able to shape services that are fair, of good quality and change in accordance with people's needs and wishes. Commissioners use the resources they have in the most effective ways to ensure that localities have the capacity to meet people's needs and wishes.

Commissioning includes a range of activities, such as:

- knowing what services people need to live a good life
- using this knowledge to plan changes for the whole local area
- taking action to change services where they are not good enough
- paying for services to meet individual needs
- checking that outcomes from services are of a good quality and changing services and plans if needed.

Commissioning is a cyclical process, which ensures that the needs and wishes of people from the local area are well understood and the market managed so there are a range of local supports and provision available at a reasonable price. In a mixed market that takes account of individual budgets and the role of people purchasing their own services, commissioners ask providers to offer and deliver services specified in the joint strategic needs assessments that is based on information about current and future need gleaned from person-centred plans. This demonstrates that commissioners have listened to what people are asking for now as well as planning for their future needs and wishes. Commissioners have detailed knowledge of the resources available and use them to the best effect. They ensure that contracts are in place which meet people's needs and that information on how they are doing this is gathered regularly to assess their effectiveness. This covers whether services are fit for purpose and, crucially, whether they are providing the diversity of provision people want. When this is not the case, commissioners take action to procure and contract with new services or support existing providers to change.

Policy context for the commissioning of services

Joint strategic needs assessment and partnership working

The Local Government and Public Involvement in Health Act 2007 places a duty on local authorities and their partner PCTs to produce a joint strategic needs assessment. This will lead to stronger partnerships between communities, local government and the NHS and improved commissioning practices based on better information.

This vision of stronger local partnerships is reinforced in the cross sector concordat *Putting people first: a shared vision and commitment to the transformation of adult social care*.

Joint strategic needs assessments will identify priorities for action through local area agreements. This will help commissioners, and particularly practice-based commissioners, to specify outcomes that encourage local innovation and help providers to develop services that respond to local need.

Commissioning framework for health and well-being

Additionally, the Department of Health *Commissioning framework for health and well-being* aims for a:

- shift towards services that are personal, sensitive to individual need and that maintain independence and dignity
- strategic reorientation towards promoting health and wellbeing, investing now to reduce future ill-health costs
- stronger focus on commissioning the services and interventions that will achieve better health across health services and local government with everyone working together to promote inclusion and tackle health inequalities.

This is particularly important for people with learning disabilities for whom access to good quality health care is problematic.

The assessment framework we have developed is based on the eight steps to effective commissioning outlined in this document, and a policy and literature review comprising over 50 documents.

Implicit in the development of the standards is the application of the *Valuing people* priorities:

1. Putting people at the centre of commissioning

Outcome: People with learning disabilities, their families and their carers are routinely involved in the planning, design, development and evaluation of services, resulting in a far more personalised approach to service delivery.

1.1 Commissioners involve a range of people with learning disabilities and complex needs, and their family carers, in identifying commissioning priorities, service planning, service developments and service evaluation.

1.2 Commissioners make sure that a person-centred approach is applied to the development and design of services, and results in provision that can be tailored to an individual's specific need.

1.3 Commissioners are able to demonstrate that people who use services are actively involved in the planning of their own support, are making decisions, and that their views and wishes have been acted upon.

1.4 Commissioners apply person-centred approaches and active case planning to people in NHS campus provision (or who are in hospital settings but not receiving treatment) with the result that numbers decrease and alternative, personalised services and support increase.

1.5 Independent advocacy services are promoted and supported and are easily available to assist people with learning disabilities with complex needs and their family carers. Commissioners are able to demonstrate that improvements to access and the quality of services for people have been achieved and that these services remain effective.

1.6 Interpreting services are promoted and supported, and are easily available to assist people with learning disabilities and complex needs and their family carers. Commissioners are able to demonstrate that improvements to access and the quality of services for people have been achieved and that these services remain effective.

1.7 Commissioners provide information about locally available services, supports and resources for people with learning disabilities and complex needs in a range of accessible formats. They ensure that people are well informed and signposted toward services such as health, social care, community support, etc available to them and know how to access them.

1.8 Commissioners provide evidence-based information to people with learning disabilities and complex needs, and their family carers, about the quality of the services, supports and resources in the area.

1.9 People with learning disabilities and complex needs receiving support from a council or through a range of funding streams have a named care manager/health facilitator/navigator whom they have met, who actively monitors how their needs are being fulfilled and offers support should they wish to raise concerns.

1.10 Complaints procedures are easy to access and follow and are sensitive to the needs of people using them. Commissioners can demonstrate that complaints have been acted on.

2. Understanding the needs of populations and individuals

Outcome: Local authorities and PCTs have an improved understanding of the current and emerging health and social care needs of their learning disability population, particularly those with complex needs, and their family carers, and have secured the resources and investment to meet their requirements.

2.1 Commissioners have a clear understanding of the numbers and of the current and future social care and health needs of the learning disability population – both short term, to inform local area agreements (three to five years), and long term, to inform strategic planning (five to ten years).

2.2 In addition, commissioners have a detailed understanding of the specific social care and health needs of adults within that population who have complex needs and whose behaviour presents a challenge to services. This includes the detail of how many people are:

- approaching transition from childhood to adulthood
- approaching transition from adulthood to older age
- placed in the area and funded by other commissioning organisations
- placed out of area by the commissioner
- in hospital or living on NHS campuses or in other NHS provided settings
- living at home on their own and not receiving services
- living at home with family carers and not receiving services
- supported by housing agencies with Supporting People funding
- from black, Asian and ethnic minorities
- expressing the need to support their lifestyle, including that of, for example, religion and sexual orientation
- using self-directed support (direct payments and individual budgets)
- experiencing complex health needs
- experiencing or have experienced forensic intervention.

2.3 Commissioners can demonstrate that people with learning disabilities and complex needs who use services, their carers and family are actively and routinely involved in contributing to the joint strategic needs assessment.

2.4 Commissioners have undertaken a gap analysis with partner agencies as part of the joint strategic needs assessment. This analysis identifies, for example, the numbers of people excluded from services and support because of their challenging behaviour. It will identify strategies, actions, resources and timescales needed to address gaps in services – including workforce, finance and technological solutions. The gap analysis will address locally available resources and supports to people using direct payments and individual budgets, as well as services.

2.5 Commissioners work with other agencies to identify all current expenditure potentially relevant to people with learning disabilities and complex needs and ascertain the main areas of financial pressure and financial opportunity.

2.6 Resources are pooled across agencies and drawn in from mainstream and generic sources, wherever possible, to ensure there is sufficient capacity in the system to encourage diversity in service provision and to respond to changing and evolving needs.

2.7 Services should be audited to establish those that are good at providing support to people with complex needs and/or whose behaviour provides a challenge, those that are not, and the reasons why.

3. Sharing and using information more effectively

Outcome: Local authorities and their partners apply the principles of *Putting people first* so that information about people with learning disabilities and complex needs is shared across agencies and used to deliver improved, personalised services and supports tailored to people's expressed needs and wants.

3.1 Commissioners work across a range of organisations (for example social care, health, housing, employment agencies, leisure, third sector provision, direct and independent providers, etc) to ensure improved information sharing, personalised service planning and co-ordination for people with learning disabilities and complex needs.

3.2 Current and potential providers of services and supports (including voluntary and community organisations) are involved in the development of commissioning strategies, so that information is shared about proposed developments with other agencies such as housing and leisure.

3.3 Commissioning activity is supported and informed by ICT and administrative systems that provide accurate management information, serve commissioner's operational needs and facilitate inter-agency communication and planning.

3.4 Commissioning organisations promote and monitor the demand and uptake of self-directed support.

3.5 Commissioning organisations are effective in monitoring the needs of people with complex needs and the associated take-up of services and supports, including primary and secondary health care. They can demonstrate fair access to services, and actions taken to increase the take-up of services from under-represented groups.

3.6 Commissioners have information systems in place to link individual reviews to service level planning.

3.7 Commissioners ensure that regular, area-level information is available and accessible to people with learning disabilities and complex needs, family carers and user- and carer-led organisations.

4. Assuring high quality providers for all services

Outcome: People with learning disabilities and complex needs have services and supports in place that are personalised according to their needs and reflexive/sensitive to changes in their requirements.

4.1 Commissioning organisations demonstrate a good understanding of local health and social care markets and are developing a diverse range of services to meet people's specific requirements.

4.2 There are effective partnership arrangements with a range of providers (including the council, independent, third sector and user-led organisations) that result in supporting existing good quality services and stimulating new provision. Commissioners make sure that funding arrangements are in place to support these new initiatives.

4.3 Commissioners are explicit with providers about their expectations of quality, the design of services and the developments required to be adaptive to changes in need. These expectations are written into flexible contracts with providers.

4.4 Commissioners are able to demonstrate that through person-centred planning approaches, people are seen regularly and on the basis of this, their needs and wishes are met.

4.5 People with learning disabilities and complex needs and their families actively contribute to health action plans and procedures are in place to ensure they are fully operational.

4.6 Commissioning and contracting arrangements specify required safeguards and are regularly reviewed to ensure the provision of safe services.

4.7 Commissioners support people with learning disabilities and family carers to monitor services and provide feedback to them in order to improve services and support.

5. Recognising the importance of good health services; recognising the interdependence between work, health and wellbeing; recognising human rights

Outcome: People with learning disabilities and complex needs have the right to live a fulfilling life with good, accessible health care, social care and employment opportunities close to home.

5.1 The human rights of people with learning disabilities and complex needs to have the choice and control over their lives that many of us take for granted are explicit in commissioning strategies and demonstrated in actions across adult social care, health and education provision. This results in joined-up strategies resulting in improved health, and improved employment and training outcomes.

5.2 There is an effective and identifiable strategic presence within health organisations and their partners to inform and support the commissioning and delivery of high quality healthcare services. Commissioners are able to demonstrate how this has made a difference to the physical and mental health of people with learning disabilities and complex needs.

5.3 There is fair access to generic health services for people with learning disabilities and complex needs, including fair access to mental health provision. Commissioners ensure that National Service Framework targets for this group are met, and are the subject of regular monitoring and follow-up action if targets are not met.

5.4 The NHS provides specialist mental health assessment and treatment on a short-term basis that is part of a broader integrated pathway of care. This involves, for example, social care, housing, and third sector partners. Services and supports are designed to get the individual back into the community and do not result in unnecessary long-term admissions to specialist hospital inpatient services or result in people not being discharged.

5.5 Commissioning organisations ensure that people with learning disabilities and complex needs can access appropriate services out of hours and can demonstrate that this is the case.

5.6 Out-of-area placements, including those on NHS campuses and in long-stay hospitals, are the subject of regular review and planning. Commissioners have a clear strategy in place to return people to their local community unless the relevant person-centred plan clearly indicates a strong preference to live elsewhere.

5.7 Commissioners ensure that the information used to plan for the return of people from NHS campuses and long-stay hospitals results in good quality, local services that prevent the need for people being placed out of area in the future.

5.8 Family carers are effectively supported to enable them to continue in their employment, to return to work if they wish to, and to pursue their own interests and lifestyle.

6. Developing incentives for commissioning for health and wellbeing

Outcome: There is effective partnership working that results in the development of a health and social care market that puts people first, and delivers the kinds of services that are important to them.

6.1 Commissioners award premiums or 'preferred status' to providers who can demonstrate they are meeting designated outcomes and are committed to improving the quality of life, health and wellbeing of people who use services.

6.2 The use of 'preferred status' models is tailored to encourage diversity within the market and supports the development of new services and third sector initiatives.

6.3 Commissioners ensure that the use of direct payments and individual budgets is promoted across organisations and that staff are confident and able to assist people in designing their own tailored care and support.

6.4 Contracts with providers are outcome based and explicit about what is required so that health and social care needs are met in a way that ensures that people's dignity is maintained and personal goals are met. Contracts outline the consequences of non-compliance with these requirements and commissioners are able to demonstrate contingency planning arrangements.

6.5 Commissioners are able to demonstrate a move towards flexible and contingent commissioning and a move away from block contracting.

6.6 Tendering and contracting processes are simple, easy to follow and do not pose barriers to small or user-led organisations who wish to come forward to deliver outcomes-based, person-centred services.

7. Making it happen: local accountability

Outcome: People with learning disabilities and complex needs, their families and carers are aware of what services and support they can expect, and have a right to receive locally, from councils and the NHS.

7.1 Commissioners report publicly on what has been achieved against strategic plans in ways that are accessible and accountable to people with learning disabilities and complex needs, and family carers.

7.2 Commissioning organisations across health and social care have performance management and quality assurance systems in place to monitor the outcomes for people using services against the relevant standards and outcomes frameworks.

7.3 This information is used to drive up the quality of services and support, improve outcomes for people and to address poor performance.

8. Making it happen: capability and leadership

Outcome: Commitment at a corporate, strategic and operational level means that local authorities and PCTs know what services need to be delivered and how to deliver them to improve the quality of life for people with learning disabilities and complex needs and their families.

8.1 Learning disability partnership boards actively monitor that local agencies are working together to provide effective services for people with learning disabilities and complex needs, and report publicly and to the relevant chief executives when they are not.

8.2 Commissioners monitor review processes to ensure that the services and support they are procuring meet objectives set out in people's person-centred plans and health action plans, are achieving stated outcomes and are therefore demonstrating the effectiveness of commissioning strategies.

8.3 Commissioners work with providers to make sure there is effective staff training on working with people with learning disabilities and complex needs, and can demonstrate that action is taken when it is not.

8.4 Commissioning organisations make sure there is an active recruitment and staff development strategy in place that takes account of the move towards personalisation and self-directed support for individuals and their families, and takes account of the importance of person-centred planning. This strategy should ensure that staff with the skills necessary to deliver this agenda are in place and contributing to the development of services. Commissioners can demonstrate that this is evident at all relevant levels of the organisation.

8.5 Commissioners ensure that providers are aware of and applying recognised* models of good practice in their work with people with learning disabilities and complex needs and can demonstrate this is the case.

* *Valuing people* guidance/requirements

Glossary

Definition of what we mean by ‘people with learning disabilities and complex needs’

The group of people considered as having learning disabilities* and complex needs are 16 years old and over, and experience difficulties because of:

- the extent of their intellectual impairment
- having physical disabilities which severely affect their ability to be independent
- having sensory disabilities which severely affect their ability to be independent
- having a combination of physical and/or sensory disabilities
- any behaviour that can severely challenge services
- having a form of autistic spectrum disorder
- having complex health needs
- having enduring mental health needs, or
- having a forensic history.
- And their needs require health or social care organisations to provide ongoing support and assistance, no matter how this is funded.

* We recognised that people may find the term ‘learning disabilities’ offensive and would prefer ‘learning difficulties’ to be used. However we are aware that ‘learning disabilities’ is a term that the majority of people understand and so we have used this term.



Appendix Two

How the joint reviews were developed and carried out

Staff from the three Commissions worked with an expert reference group, including people with learning disabilities, to develop the review methodology. The Commissions agreed that the review should not cover children but focus on adults with learning disabilities and complex needs, but it would look at how young people moved into adult services.

Thus, for the purpose of the review, people with learning disabilities and complex needs were defined as people aged 16 and over with needs such that they require health or social care organisations to provide ongoing support and assistance and who have both learning disabilities⁴ and complex needs owing to one or more of the following factors:

- the extent of their intellectual impairment
- physical disabilities which severely affect their ability to be independent
- sensory disabilities which severely affect their ability to be independent
- a combination of physical and/or sensory disabilities

⁴ Some people prefer the term 'learning difficulties' to 'learning disabilities.' However, because the term 'learning difficulties' has a more specific meaning within educational settings and 'learning disabilities' is a term that the majority of people use and understand, this is the term used in this report.

- behaviour that can severely challenge services
- autistic spectrum disorder
- complex health needs
- enduring mental health needs, or
- a forensic history.

This is neither a causal definition nor a single clinical condition. It encompasses wide and varying groups of people with learning disabilities. What such people have in common are usually greater needs and, from a social care perspective, a greater likelihood of being assessed within the 'critical' or 'substantial' bands of the Fair Access to Care Services eligibility criteria.

The assessment framework

A specially designed framework was developed to structure the topics to be assessed during the reviews. This assessment framework was based on an extensive policy and literature review and on the eight steps to effective commissioning in the Department of Health's *Commissioning framework for health and well-being* (2007). The framework incorporated the *Valuing people* priorities and the full framework is available at www.dh.gov.uk/en/Publicationsandstatistics/

Publications/PublicationsPolicyAndGuidance/DH_072604. The eight assessment headings were:

1. Putting people at the centre of commissioning.
2. Understanding the needs of populations and individuals.
3. Sharing and using information more effectively.
4. Assuring high quality providers for all services.
5. Recognising the importance of good health services; recognising the interdependence between work, health and well-being; recognising human rights.
6. Developing incentives for commissioning for health and well-being.
7. Making it happen: local accountability.
8. Making it happen: capability and leadership.

An outcomes statement highlighted what each heading would mean for a person with learning disabilities and complex needs.

Selecting the sites

To select the areas for review, a desk exercise examined publicly available information, as well as information held by the three Commissions, and classified the information against the assessment framework. To avoid over-burdening local councils and health organisations, areas were excluded from selection if (a) they were already involved in trials of the new Comprehensive Area Assessments, or (b) if they were included in an ongoing CSCI study of commissioning for vulnerable groups, or (c) if they had or were to have a service inspection or learning disability audit review within six months

of the planned fieldwork. Other areas were also excluded where Commission staff knew that there were sound operational reasons why visits would be inappropriate during the fieldwork period of September to November 2008.

From the areas remaining, selection criteria ensured that the final sample would include:

- a rural county
- an area with a high proportion of people from black and minority ethnic communities
- an area with a mixed economy of services provision
- an area without a mixed economy of provision
- an area including or commissioning a hospital providing secure accommodation
- an area with NHS campus provision
- an In Control pilot area, and
- an area with a national learning disability indicator within its local area agreement.

In this way, nine areas were finally chosen:

- Doncaster
- Dorset
- Dudley
- Gateshead
- Harrow
- Hillingdon
- Lancashire
- Redbridge
- Stoke-on-Trent

Fieldwork

Review teams for each area comprised six people: a reviewer from each of the three Commissions; an expert by experience, with a supporter as appropriate; a family carer; and someone from another area with current experience of commissioning learning disability services – a ‘peer commissioner.’ Prior to the fieldwork, teams received training together to ensure that the reviews were carried out similarly in each site and that they focused on the experiences of people with learning disabilities and complex needs.

Information about the areas held by the three Commissions was available to each review team. Councils and primary care trusts (PCTs) completed a self-assessment document in advance of fieldwork and other agencies, such as the Audit Commission, the Valuing People Support Team and the strategic health authority, were asked to provide information.

Fieldwork activities included:

- ‘A day in the life of ...’
- Mystery shopper
- Focus groups, including with family carers
- Manager and staff interviews
- Existing meetings
- Good practice
- An open public session

In each area, fieldwork was spread over two weeks, with team members planning to spend up to five days on site. Teams gathered information in a variety of ways. Because one of the aims of the review was to place people with learning disabilities and complex needs at the heart of the review, the first two fieldwork days included

‘A day in the life of ...’; that is, time spent with selected people with learning disabilities and complex needs to find out their views and experiences of commissioned services and support. Pairs of team members followed the selected individuals during their day’s activities.

What the team learned on the first day influenced the issues examined on the later days of each review. During the fieldwork, the mystery shopper exercise sought to find out what information was available on learning disability services and whether public buildings were socially inclusive, by making unannounced and anonymous visits, for example, to GP surgeries, dentists, libraries, etc.

Team members met people with learning disabilities and complex needs and their carers and interviewed staff at all levels in the council, the PCT and other organisations active locally in the learning disability field. They also met with focus groups of people involved with different topics and attended meetings of the learning disability partnership board, the resource allocation panel and the single or joint PCT board/senior management team of adult social care, if these meetings took place within or near to the fieldwork period. During the fieldwork, the team followed up examples of good practice suggested by local health and social care officers. Team members also read files and other documents. Local people were invited to an open meeting to express their views about commissioning practice and services.

After the fieldwork

Team members recorded their information in standard ways and prepared a headline feedback document which they presented to senior local area managers shortly after the end of the fieldwork. Draft reports, which included recommendations for action, were sent to the councils and PCTs to check for factual accuracy before the final version was published and made available on the internet. Reviews were not scored but contributed to councils' and PCTs' assessments of performance for 2008/09. Localities were offered support in responding to report recommendations and developing their action plans from the regional Valuing People Support Teams.

Notes

Notes

From April 2009, the Care Quality Commission will take over the work of the Commission for Social Care Inspection, the Healthcare Commission and the Mental Health Act Commission. Website: www.cqc.org.uk

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