Improving the health and wellbeing of people with learning disabilities
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**Description**  
This document provides practical support for commissioners and contains a range of tools, techniques, key reference documents and case studies to help commissioners to improve the health and wellbeing of people with learning disabilities.

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Foreword

Commissioning services for people with learning disabilities is a true test of working inclusively and in effective partnerships and, through this, securing better health and better care for local people.

This resource, published to support delivery of *Valuing People Now: A New Three Year Strategy for People with Learning Disabilities* has been produced jointly by our two Directorates, working with NHS colleagues. The guide is designed to support Primary Care Trusts (PCTs), with local authorities and Learning Disability Partnership Boards, in commissioning general health services in ways that achieve better health outcomes for people with learning disabilities.

The approach set out in this document is in some ways no different from that involved in commissioning services for any group within a local population. This is about understanding people’s needs, commissioning services that are responsive to those needs and fully engaging service users and their families and carers, alongside clinicians and key partners in local government and other sectors.

There are, however, distinctive features of commissioning services for people with learning disabilities that require their own focus. A succession of reports, including that of Sir Jonathan Michael’s independent inquiry last year, have highlighted basic and serious shortcomings in the way that services are provided for people with learning disabilities, contributing to poorer health outcomes, avoidable suffering and, at worst, premature deaths. All commissioners have a duty to promote equality for disabled people. This means commissioning services in ways that secure reasonable adjustments for people with learning disabilities and ensure a coordinated approach to communications, use of data and partnership working.

Delivering better care for people with learning disabilities should also be seen as an integral part of the NHS Next Stage Review vision of delivering high quality care for all.

The recent report by the Health Service Ombudsman and Local Government Ombudsman on the six cases originally highlighted by MENCAP in ‘Death by Indifference’ has further reinforced the importance of action by commissioners and by provider organisations to provide assurance that they are meeting the needs of people with learning disabilities.

This practical guide is offered as part of a series of resources to support PCTs and their partners in achieving these objectives and making a real difference in health outcomes for local people.

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## Contents

1 Executive summary 7

2 Introduction 12

2.1 Purpose of this document 12

2.2 Definitions 13

3 The case for change 15

3.1 Health inequalities 15

3.2 Service failings 16

3.3 Demographic trends 17

3.4 Legal requirements 17

3.5 Higher quality care for all 18

4 Drivers for change 20

4.1 Valuing People Now 20

4.2 Independent inquiry 20

4.3 Ombudsmen’s report 21

4.4 Operating framework 2009/10 22

4.5 World class commissioning and the NHS Next Stage Review 22

4.6 Transfer of commissioning responsibility for social care 23

5 Distinctive features of commissioning 25

5.1 The role of learning disability partnership boards 25

5.2 Key components of world class commissioning for people with learning disabilities 25

6 World class commissioning competencies 29
7 The commissioning cycle

7.1 Patient and public involvement
7.2 Assessment of needs
7.3 Review of current service provision
7.4 Deciding priorities
7.5 Specifying services
7.6 Shaping the structure of supply
7.7 Managing demand and ensuring appropriate access to care
7.8 Clinical decision making and individual assessment/advice on choices
7.9 Managing performance (quality, performance, outcomes)

8 Developing capacity and skills in commissioning

9 Conclusion and next steps

Appendix 1
Primary care
Specialist learning disability community services
Mental health services
Acute care and ambulance services
Continuing care

Appendix 2

Appendix 3

Appendix 4
1. Executive summary
1. Executive summary

1.1 Purpose of this document

This document is designed to help PCTs, working with local government and Learning Disability Partnership Boards, to commission all health services, including primary care, community health services, mental health and acute care, in ways that are more responsive to – and provide better health outcomes for – people with learning disabilities.

1.2 The case for change: why focus on the health and wellbeing of people with learning disabilities?

People with learning disabilities have higher levels of ill-health and much higher rates of premature death than the population as a whole. It is estimated that people with learning disabilities are 58 times more likely to die prematurely. People with learning disabilities have higher rates of obesity, coronary heart disease, respiratory disease, hearing impairment, dementia, osteoporosis and epilepsy. Some 26% of people with learning disabilities are admitted to hospital each year.

The evidence from a series of reports and inquiries, set out below, shows that the health service is not yet commissioning or providing services in ways that adequately meet these health needs. This contributes to preventable ill-health, poor quality of life and – at worst – premature deaths.

There are approximately 210,000 people in England with moderate or severe learning disabilities and a further estimated million people with mild learning disabilities. People with learning disabilities represent a growing proportion of the population, with prevalence expected to rise by around one per cent per annum for the next ten years. This has potentially significant implications for morbidity, mortality and use of healthcare resources.

Securing the right services for people with learning disabilities is not just a matter of good commissioning practice. The Disability Discrimination Act 1995 places a duty on all health and social care organisations not to discriminate against disabled people or provide them with a poorer quality of service. It obliges organisations to make ‘reasonable adjustments’ to reflect the needs of disabled people.

There is also a strong sense that understanding and acting on the needs of people with learning disabilities can also help commissioners understand how to drive wider improvements for the communities they serve.
1.3 Drivers for change: recent inquiries and reports

Valuing People Now, the Government’s new three-year strategy for people with learning disabilities sets out a range of commitments to improve health and healthcare for people with learning disabilities. Valuing People Now is based on the four key principles of:

- rights
- independent living
- control
- inclusion.

Valuing People Now includes the Government’s response to the independent inquiry chaired by Sir Jonathan Michael. The inquiry found that “people with learning disabilities appear to receive less effective care than they are entitled to receive” and made ten recommendations to address these inequalities. The key recommendations for PCTs concern better leadership, better use of data to commission and monitor care, identifying and acting on health needs (through Joint Strategic Needs Assessments and Local Area Agreements) and securing general health services, including primary care, that make reasonable adjustments for people with learning disabilities.

The then Secretary of State for Health commissioned the independent inquiry following Mencap’s report, Death by Indifference which highlighted the cases of six people with learning disabilities who died while in the care of the NHS. The Parliamentary and Health Service Ombudsman and Local Government Ombudsman have recently reported on these individual cases. The Ombudsmen recommended that all NHS and social care organisations should urgently review the effectiveness of their systems – and their capacity/capability – for understanding and meeting the additional and often complex needs of people with learning disabilities. PCTs and other organisations are expected to report to their Boards by March 2010 on the action they have taken.

The Operating Framework for 2009/10 reinforces the importance of PCTs securing general health services that make reasonable adjustments for people with learning disabilities, monitoring uptake of annual health checks, and having systems in place to improve the overall quality of healthcare for people with learning disabilities.

These objectives align strongly with the emphasis in the NHS Next Stage Review and in the world class commissioning framework on more personalised services, a greater focus on health and wellbeing, and working in partnership with local authorities and other sectors.

Sir Jonathan Michael’s Independent Inquiry built on a number of previous reports highlighting similar shortcomings in access to, and quality of, healthcare for people with learning disabilities. These include the Healthcare Commission’s investigations into service failings in Cornwall and Sutton & Merton, and the 2006 formal inquiry by the Disability Rights Commission.

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5 Death by Indifference, MENCAP, 2007
6 Six lives: the provision of public services to people with learning disabilities, Parliamentary and Health Service Ombudsman and Local Government Ombudsman, 2009
1.4 Distinctive features of commissioning for people with learning disabilities

Learning Disability Partnership Boards are the local multi-stakeholder vehicles responsible for coordinating delivery of the Valuing People Now strategy for adults with learning disabilities. The Partnership Board will be integral to success in commissioning better healthcare services.

PCTs face a number of challenges in commissioning for people with learning disabilities. As described in the 2007 Mansell report, “life for people with major disabilities supported by good services will often look quite ordinary, but this ordinariness will be the product of a great deal of careful planning and management”.

This document describes the distinct challenges involved in commissioning for people with learning disabilities, for instance in relation to:

- legal requirements
- person-centred care
- information sharing
- promoting access to services
- effective communication with people with learning disabilities to ensure informed choices
- the risks of diagnostic overshadowing
- consent and capacity issues
- the knowledge and skills of staff providing care
- lead commissioner arrangements
- resettlement and campus closure.

1.5 World class commissioning

This document sets out a range of practical actions that PCTs can take to address these commissioning challenges and help meet legal duties, mapped to each of the eleven competences in the world class commissioning framework and mapped to each stage in the commissioning cycle. The document includes a range of tools, techniques, key reference documents and case studies to help commissioners as they move through the commissioning cycle.
1.6 Conclusion

The document recommends the following action:

For PCTs

- a comprehensive needs assessment which seeks evidence on the numbers, health needs and experiences of people with learning disabilities;
- PCT board members exercising their Disability Equality Duty by asking tough questions about how commissioned services are meeting the needs of people with learning disabilities;
- building capability so that all those involved in commissioning general health services understand and act on the needs of people with learning disabilities;
- working with service users, families and carers to develop and publish preferred service models;
- bringing providers into the market as necessary to achieve the desired service models and outcomes;
- mainstream services demonstrating ‘reasonable adjustments’ to ensure that they are meeting known needs, and having staff who understand how to make these adjustments;
- working with service users to make sure that provider organisations are consistently delivering high-quality services
- in the current year, ensuring that people with learning disabilities are included in all local responses and planning for swine flu. People with learning disabilities are likely to have underlying clinical conditions that make them more susceptible and will need support in accessing vaccination and health information.

For Learning Disability Partnership Boards

- reviewing services and outcomes and helping develop ambitious public commitments to what will be achieved in the next five years;
- continuously reviewing how to support individuals in improving their own health and wellbeing.

The vision for world class commissioning is “adding life to years and years to life”. Better commissioning for people with learning disabilities exemplifies this vision.
2. Introduction
2. Introduction

2.1 Purpose of this document

This practical guide is designed to help improve commissioning of health and wellbeing services for people with learning disabilities and to act as a catalyst for change.

PCTs are responsible for commissioning services that secure better health outcomes for their local population. PCTs are working towards the aspiration of world class commissioning. This document forms part of a suite of practical support for PCTs as part of the world class commissioning programme.

One of its key messages is that developing services in ways that address the needs of people with learning disabilities should not be regarded as the preserve of specialist commissioners in PCTs. It should instead be part and parcel of world class commissioning for all health services, including primary care, community health services, mental health and hospital services.

Section 3 sets out the reasons why it is so important to improve commissioning for people with learning disabilities, including evidence of high levels of illness and premature mortality, trends in numbers of people with learning disabilities, and the legal obligations for PCTs and healthcare providers in relation to disability and human rights.

Section 4 sets out the recommendations and action for PCT commissioners arising from Valuing People Now, Sir Jonathan Michael’s independent inquiry, the Ombudsmen’s recent report and the Operating Framework for 2009/10. It also highlights key lessons from previous reports and inquiries by the Healthcare Commission, Disability Rights Commission and MENCAP.

Better health for people with learning disabilities is one of the priorities of Valuing People Now. Improving the capability of local commissioners to improve health outcomes is a key part of the strategy.

Section 5 describes the distinctive challenges involved in commissioning services in ways that meet the health needs of people with learning disabilities.

Section 6 sets out:

- how the 11 world class commissioning competencies apply to improving health and healthcare for people with learning disabilities; and
- a range of tools, techniques and case studies to help commissioners as they move through the commissioning cycle.
2.2 Definitions

This document covers the principles of commissioning services for people with learning disabilities. It does not draw out in detail distinctions between approaches for children and for adults. In both cases, the following definition of ‘learning disabilities’ applies:

“a significantly reduced ability to understand new or complex information and to learn new skills, with a reduced ability to cope independently, which started before adulthood with a lasting effect on development.”

The presence of a low intelligence quotient, for example an IQ below 70, is not a sufficient reason for deciding whether an individual receives additional health and social care support. An assessment of social functioning and communication skills should also be taken into account when determining need. Many people with learning disabilities also have physical and/or sensory impairments.

The definition covers adults with autism spectrum condition (ASC) who also have learning disabilities, but not those with a higher level autistic spectrum disorder who may be of average or even above average intelligence, such as some people with Asperger’s Syndrome. However people on the autistic spectrum may have communication difficulties and problems accessing universal health services effectively and should also be treated on the basis of their needs, with similar allowances made as for those with learning disabilities.

Learning disabilities does not include all those who have a ‘learning difficulty’ which is more broadly defined in education legislation.

3. The case for change
3. The case for change: why focus on the health and wellbeing of people with learning disabilities?

3.1 Health inequalities

Patterns of ill health in people with learning disabilities tend to manifest differently to patterns of ill health in the general population. Commissioning services to meet the needs of the latter will tend to overlook the needs of the former. Where services fail to meet the specific needs of people with learning disabilities, this can contribute to needless ill-health and poor quality of life. In the worst cases, it may contribute to premature death.

People with learning disabilities tend to have markedly worse health than the population as a whole. The 2006 Disability Rights Commission report estimated that people with learning disabilities are 2½ times more likely to have health problems.

There is widespread evidence of the burden of specific disease10:

- around one person in three with learning disabilities is obese, compared with one in five of the general population
- coronary health disease (CHD) is the second most common cause of death in people with learning disabilities
- the incidence of respiratory disease is three time higher in people with learning difficulties than in the general population
- some 40% of people with learning disabilities have a hearing impairment and many have common visual impairments
- the rate of dementia is four times higher and the rate of schizophrenia three times higher than in the general population
- people with learning disabilities tend to have substantially less bone density and experience higher levels of osteoporosis
- epilepsy is over 20 times more common in people with learning disabilities than in the general population. Sudden unexplained death in epilepsy is five times more common in people with learning disabilities than in others with epilepsy.

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Ill-health has an obvious impact on quality of life for people with learning disabilities. Both adults and children with learning disabilities are at an increased risk of early death. Those under the age of 50 are 55 times more likely to die prematurely. For those over 50, the risk is 58 times more likely\textsuperscript{11}. The Government has agreed Sir Jonathan Michael’s recommendation to establish a confidential inquiry to improve the evidence base on how to reduce the incidence of premature death.

These patterns of illness also have a significant impact on use of secondary care. Some 26\% of people with learning disabilities are admitted to hospital each year, compared with 14\% of the general population\textsuperscript{12}.

### 3.2 Service failings

Sir Jonathan Michael’s independent inquiry (see section 4 below) found that these inequalities arise in part because:

- people with learning disabilities find it harder to access assessment and treatment for general healthcare
- healthcare providers make insufficient adjustments for communication problems, difficulty in understanding, or individual preferences
- parents and carers struggle to be accepted as effective partners in care
- health service staff have very limited knowledge about learning disabilities and are unfamiliar with the legislative framework
- partnership working and communication are poor
- although there are examples of good practice, witnesses have also described appalling examples of discrimination, abuse and neglect.

The independent inquiry identified a number of reasons for these failings. Those most relevant to commissioning are:

- the lack of data and information on people with learning disabilities and their journey through the general healthcare system
- lack of awareness in primary care of the health needs of people with learning disabilities
- a lack of priority given to learning disabilities
- no effective monitoring or performance management of providers’ compliance with the legislative framework
- limited training for healthcare staff about learning disabilities.

\textsuperscript{11} Hollins et al, op cit.
This builds on a number of previous inquiries and investigations, all of which demonstrated inequalities in healthcare and health outcomes for people with learning disabilities:

- a Healthcare Commission audit report issued at the end of 2007\(^{13}\) concluded that the quality of care in the majority of services for people with learning disabilities needed significant improvement. It made recommendations on many areas of commissioning, including better procedures for safeguarding vulnerable adults, specialist services, and Board-level leadership.

- the Healthcare Commission’s 2006 investigation of abuse within services provided by Cornwall Partnership NHS Trust\(^{14}\) was followed in January 2007 by an investigation into learning disabilities services provided by Sutton and Merton PCT\(^{15}\), again highlighting a number of serious issues about the quality of care people were receiving.

- in 2006, the Disability Rights Commission published the results of a two-year formal inquiry into physical health inequalities experienced by people with learning disabilities and/or mental health problems\(^{16}\). This found that people with learning disabilities generally receive fewer health investigations and screening tests than the wider population and that they are less likely to get the healthcare they need.

### 3.3 Demographic trends

People with learning disabilities form a growing proportion of the population. Currently around 985,000 people in England (approximately 2% of the population) have learning disabilities, and 796,000 of these are aged 20 or over. The number of adults with learning disabilities aged over 60 is likely to increase by 36% between 2001 and 2021\(^ {17}\).

### 3.4 Legal requirements

The Disability Discrimination Act 1995 places a legal responsibility on all health and social care organisations not to discriminate against disabled people or provide them with a poorer quality of service. It requires organisations to make ‘reasonable adjustments’ to accommodate the needs of disabled people.

The Mental Capacity Act 2005 provides a legal framework for people who lack capacity and those caring for them by setting out key principles, procedures and safeguards.

Equality and human rights should be seen as core business for the NHS\(^ {18}\). PCT Boards need to be able to assure themselves that they are meeting the Disability, Race and Gender Equality Duties. The Disability Duty is meant to ensure that all public bodies, including commissioning organisations, pay “due regard” to the promotion of equality for disabled people in every area of their work.

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13 A Life Like No Other: A national audit of specialist inpatient healthcare services for people with learning difficulties in England, Healthcare Commission, 2007

14 Joint Investigation into the provision of services for people with learning disabilities at Cornwall Partnership NHS Trust, Healthcare Commission and Commission for Social Care Inspection, 2006

15 Investigation into the service for people with learning disabilities provided by Sutton and Merton Primary Care Trust, Healthcare Commission, 2007

16 Equal Treatment: Closing the Gap, Disability Rights Commission, 2006

17 Statistics provided by Foundation for People with Learning Disabilities.

The *Putting People First* concordat describes a future in which all public service organisations are expected to put citizens at the heart of a reformed system, based on human rights legislation and international obligations such as the UN Convention on the Rights of Persons with Disabilities.

### 3.5 Higher quality care for all

Understanding and acting upon the needs of people with learning disabilities is not only important in its own right. It should be seen as part of a wider commitment to make services more personal, responsive and effective for every member of the public. There is a strong sense that improving the quality of care for people with learning disabilities will help the NHS drive wider improvements in services, for instance through better communication about how access services and more personalised care for individuals.
4. Drivers for change
4. Drivers for change: recent inquiries and reports

4.1 Valuing People Now

Better health is one of the priorities of the Government’s new three-year strategy for learning disabilities, *Valuing People Now*, published in January 2009. Building on the earlier work programme developed in response to the 2006 Disability Rights Commission report, the health commitments focus on implementation of Sir Jonathan Michael’s recommendations (see below).

*Valuing People Now* reaffirms the four guiding principles in *Valuing People*. These are based on feedback from people with learning disabilities and their carers.

**Rights**
People with learning disabilities and their families have the same human rights as everyone else.

**Independent living**
All disabled people should have greater choice and control over the support they need to go about their daily lives; greater access to housing, education, employment, leisure and transport opportunities and to participation in family and community life.

**Control**
Being involved in, and in control of, decisions made about one’s life. This is about having information and support to understand the different options and their implications, so people can make informed decisions about their own lives.

**Inclusion**
Being able to participate in all the aspects of community life – to work, learn, get about, meet people, be part of social networks, access goods and services – and to have the right support to do so.

4.2 Independent inquiry

The independent inquiry set up by the Secretary of State for Health following the March 2007 publication of the Mencap report *Death by indifference* concluded in its final report *Healthcare for All* that “people with learning disabilities appear to receive less effective care than they are entitled to receive.”

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22 Death by indifference: Following up the Tread me right! report, Mencap, 2007
The key recommendations for PCTs are that they:

- ensure they collect the data needed to allow the health service to identify people with learning disabilities and track their pathways of care
- identify and assess the needs of people with learning disabilities and their carers as part of Joint Strategic Needs Assessments (JSNA); consulting with Local Strategic Partnerships, Learning Disability Partnership Boards and relevant voluntary, user-led learning disabilities organisations; and using this information to inform the development of Local Area Agreements
- secure general health services, including primary care services, that make reasonable adjustments for people with learning disabilities and improving data, communications and cross-boundary partnership working.

The Government has fully accepted these recommendations and is working with Strategic Health Authorities (SHAs) to monitor progress.

David Nicholson, the NHS Chief Executive, sent a letter to all PCT and Trust Chief Executives in June 2008, emphasising their responsibility to make sure that their organisations are making ‘reasonable adjustments’ to ensure that people with learning disabilities will not continue to be disadvantaged in our healthcare system.

### 4.3 Ombudsmen’s report

In February 2009, the Parliamentary and Health Service Ombudsman and Local Government Ombudsmen reported on the six individual cases highlighted in *Death by Indifference* of people with learning disabilities who died prematurely while in the care of the NHS. In addition to their conclusions on these individual cases, the report recommends that all NHS and social care organisations should:

- urgently review the effectiveness of the systems they have in place to enable them to understand and plan to meet the full range of needs of people with learning disabilities in their area
- urgently review the capacity and capability of the services they provide and/or commission for their local populations to meet the additional and often complex needs of people with learning disabilities
- report accordingly to their Boards by March 2010.

The Department of Health will be working with SHAs to support PCTs in fulfilling these recommendations and to provide a national report by March 2010 on the implementation of the recommendations subject to ROCR approval.

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4.4 Operating framework 2009/10

The Operating Framework for 2009/10 indicates that:

- in line with the recommendations of Sir Jonathan Michael’s inquiry, PCTs should ensure that they secure general health services that make reasonable adjustments for people with learning disabilities
- the NHS Vital Signs now include an indicator to monitor take-up of annual health checks for people with learning disabilities known to local authorities
- PCTs need to ensure effective arrangements for communication and cross-boundary working to improve the overall quality of healthcare for people with learning disabilities.

4.5 World class commissioning and the NHS Next Stage Review

The DH commissioning framework for health and well-being aims for:

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

All three aims are particularly important for people with learning disabilities.

Each PCT has developed a five-year strategic plan based on the JSNA, setting out the PCT’s vision, its priorities and how they will be delivered, and an annual operational plan. PCTs will build capability and capacity to deliver these plans through their organisational development plans.

Many of the commitments in the final report of the NHS Next Stage Review (NSR), High Quality Care For All, are also particularly relevant to people with learning disabilities, including:

- commissioning comprehensive wellbeing and prevention services, in partnership with local authorities, that are personalised to meet the specific needs of local populations;
- ensuring that everyone with a long term condition has a personalised care plan;
- piloting of personal health budgets.

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26 Commissioning Framework for health and well-being, Department of Health, 2007, Gateway 7361
27 High Quality Care For All: NHS Next Stage Review Final Report, Professor the Lord Darzi of Denham KBE, July 2008, Gateway 10106, Crm 7432
The accompanying NSR primary and community care strategy\textsuperscript{28} referred specifically to the need to build on the programme of annual health checks (for people with learning disabilities who are known to local authorities) agreed with the BMA in 2008. It highlighted the importance of ensuring that health checks translate into individual health action plans and that people with learning disabilities have access to the range of services that will help them maintain and improve their health.

As part of the Next Stage Review, the Department announced plans to pilot personal health budgets. In May 2009, the Department published a list of provisional pilot sites, which included a number of proposals for personal health budgets for people with learning disabilities.

4.6 Transfer of commissioning responsibility for social care

The recent transfer to local authorities of responsibility for commissioning social care for people with learning disabilities\textsuperscript{29} should enable PCTs to focus better on meeting the health needs of people with learning disabilities – responsibility for healthcare, including specialist services and forensics, will remain with PCTs. The transfer relates to commissioning and funding but not to services themselves.

\textsuperscript{28} NHS Next Stage Review: Our vision for primary and community care, July 2008, Gateway 10096.
\textsuperscript{29} Valuing People Now: Transfer of the responsibility for the commissioning of social care for adults with a learning disability, Department of Health, 2008, Gateway 9906
5. Distinctive features of commissioning for people with learning disabilities
5. Distinctive features of commissioning for people with learning disabilities

5.1 The role of learning disability partnership boards

Learning Disability Partnership Boards are the local multi-stakeholder vehicles responsible for overseeing delivery of the Valuing People Now strategy for adults with learning disabilities. They should have strong links with Children’s Trusts and with Connexions Partnerships to promote a seamless transition for young people with learning disabilities between children’s and adult services.

The Government expects PCTs and local government to consult with Partnership Boards as their main source of information when planning and taking decisions that affect the lives of people with learning disabilities. The Partnership Board will be integral to success in commissioning better healthcare services.

5.2 Key components of world class commissioning for people with learning disabilities

“Life for people with major disabilities supported by good services will often look quite ordinary, but this ordinariness will be the product of a great deal of careful planning and management.”

The table overleaf summarises the particular issues that anyone commissioning health services (be they primary care, community health services, mental health or hospital services) should take into account to ensure that services are accessible to - and provide quality of care for – people with learning disabilities.

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30 Valuing People Now: From progress to transformation, Department of Health, 2008
31 Services for people with learning disabilities and challenging behaviour or mental health needs, guidance, Department of Health, 2007 (Mansell report (revised edition 2007)), Gateway 9019, page 13
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<th>Key considerations for PCT commissioners</th>
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<td>• <strong>legal requirements</strong>: ensuring that healthcare providers make reasonable adjustments, as required by the Disability Discrimination Act</td>
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<td>• <strong>person-centred care</strong>: ensuring that services are based around a person-centred care plan and health action plan. These plans seek to promote social inclusion and improve health</td>
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<td>• <strong>information sharing</strong>: ensuring that GP practices, PCTs, local authorities and local Learning Disability Partnership Boards work together to share information about the health and care needs of people with learning disabilities. This will develop community and system wide information.</td>
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<td>• <strong>promoting access to services</strong>: taking proactive steps to help people access general health services that meet the individual needs identified in annual health checks, including individual and system wide adjustments.</td>
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<td>• <strong>effective communication</strong>: ensuring that particular care is given to communicating with service users and their families and carers to ensure that their needs, choices and preferences are understood and that services are available to reflect individual choices</td>
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<td>• <strong>diagnostic overshadowing</strong>: overcoming the risk that people's reports of physical ill health or unusual behaviours are viewed as part of learning disabilities – and so are not investigated or treated</td>
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<td>• <strong>consent and capacity issues</strong>: ensuring that staff involved in providing healthcare understand issues of confidentiality, consent and mental capacity legislation[^32] for adults with learning disabilities and have access, where necessary, to expert advice</td>
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<td>• <strong>knowledge and skills</strong>: improving the training of those providing healthcare across primary care, community services and hospital care, in relation to leadership, values and culture; understanding and working with the law; knowledge of - and responding to - healthcare needs; communication with people with learning disabilities; person-centred planning; partnership working with patients, advocates, families and across professional boundaries; challenging behaviours and mental health needs</td>
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<td>• <strong>lead commissioner arrangements</strong>: establishing lead commissioner arrangements (e.g. through social care) and appropriate governance to ensure a coordinated approach to the support provided by health, education, employment and social care. This includes managing the interface between NHS services that are free at the point of use and local authority services that are means-tested</td>
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<td>• <strong>resettlement and campus closure</strong>: meeting Government commitments to re-provide NHS campus accommodation in order to enable people with learning disabilities to live in community-based housing by 2010. Research has raised significant concerns about quality of life for people living in NHS residential campuses</td>
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[^32]: Mental Capacity Act 2005
In all these areas, commissioners also need to take into account the specific needs of individuals and their families from all communities, including those from black and minority ethnic communities and other groups to ensure that they are meeting the Race Equality Duty.
6. World class commissioning competencies
6. World class commissioning competencies

Effective commissioning\textsuperscript{33} makes the best use of allocated resources to achieve the following goals:

- improving health and wellbeing and reducing health inequalities and social exclusion
- securing access to a comprehensive range of services
- improving the quality, effectiveness and efficiency of services
- increasing choice for patients and ensuring better experience of care through greater responsiveness to individual needs.

The world class commissioning programme seeks to transform the way in which PCTs commission services, with the overarching aim of “adding life to years and years to life”. The DH vision for world class commissioning, published in December 2007, is for better health and wellbeing, better care and better value for all. The programme aims to help commissioners of health services deliver a more strategic and long-term approach, with a clear focus on improving outcomes.

The DH has worked with the NHS to develop a set of commissioning competencies, covering the knowledge, skills and behaviours needed to become world class, and an assurance system to drive up PCT performance and support PCT development. No PCT will be considered world class unless it can show how it is applying these competencies to address areas of known inequality. World class commissioners will need to demonstrate how commissioned services meet the needs of all sections of local communities, with particular emphasis on race, disability, gender, sexual orientation, age, and religion/belief.\textsuperscript{34}

Although designed for PCTs, the 11 world class commissioning competencies are relevant to all partners contributing to better outcomes for people with learning disabilities. The examples below show how world class commissioning for people with learning disabilities can be demonstrated against each competency. PCTs and Partnership Boards could usefully assess themselves against these competencies and identify areas for development.

1. **Locally lead the NHS**

Leadership will be evidenced by senior engagement, participation in the Learning Disability Partnership Board and a track record of achievements in improving health and healthcare for people with learning disabilities. Senior leaders across health and social care should jointly commission well-defined, integrated support to maximise independence. The PCT Board will be able to demonstrate best practice in complying with its disability equality duties.


2  **Work with community partners**

PCTs and local authorities will have a joint commissioning approach, informed by the Learning Disability Partnership Board and will work with a network of community partners (including housing, education, transport and leisure services, third sector organisations and advocacy services).

3  **Engage with public and patients**

People with learning disabilities and their families and carers, together with advocacy and carers’ organisations, will be fully engaged in the assessment of needs and the design and delivery of services. Engagement processes will seek to raise individual and community aspirations for improved health outcomes and develop a shared vision for achieving them. PCTs will ensure that all healthcare providers can also demonstrate this level of engagement. People with learning disabilities and their families will be involved in training for healthcare professionals.

4  **Collaborate with clinicians**

Commissioners will engage experts and professionals in improving the evidence base for commissioning decisions and in redesigning services to meet health needs. PCTs will work with a broad range of clinicians and professionals across both general and specialist health services to support improvements in training, information sharing, communications and partnership working. This should include mental health, maternity, A&E and ambulance services.

5  **Manage knowledge and assess needs**

Commissioners will have access to information specific to people with learning disabilities, through the JSNA process. This will include benchmarked information on numbers of people with learning disabilities and their current and future health needs and the extent to which existing services are meeting these needs (e.g. access rates and screening rates). Primary care providers will systematically identify people with learning disabilities and make sure that appropriate information is shared with other providers, so that reasonable adjustments are made and so that people can be tracked through pathways of care. Commissioners will use a range of methods to gather qualitative information about the experiences of people with learning disabilities and their families and carers and their preferences for accessing services. Evidence of identifying and prioritising patients at risk and monitoring trends in outcomes, which are indicators of the higher end of performance in this competency, have particular relevance for people with learning disabilities.

The JSNA will enable the PCT, local authority and Partnership Board to prioritise their activities, describe these priorities in local agreements, and hold partners to account for delivery.

6  **Prioritise investment**

Commissioners will be able to demonstrate that investment and disinvestment decisions are based on evidence of what interventions will be most effective in improving the quality of healthcare and health outcomes for people with learning disabilities in different financial scenarios using different methods such as JSNAs and Equality Impact Assessments (EqIA).
7 Stimulate the market

Commissioners will use the market to develop innovative ways of providing services that deliver more personalised and effective care for people with learning disabilities. A range of providers will ensure effective choice for people with learning disabilities and their carers. In line with the *Principles and Rules for Cooperation and Competition*[^35], PCTs will commission services from the providers who are best placed to deliver the needs of patients and populations. PCTs will ensure that people with learning disabilities have the support they need to exercise free choice in elective care and to make informed choices.

8 Promote improvement and innovation

PCTs will promote, recognise and reward best practice in involving people with learning disabilities and their carers and in improving quality of care. PCTs will draw upon and share national and international best practice.

9 Secure procurement skills

Commissioners will develop specifications and contracts that specify the outcomes that need to be achieved in relation to people with learning disabilities and enable providers to be held to account for quality of care. People with learning disabilities and their families will be involved in decision-making and monitoring.

10 Manage the local health system to ensure quality and value for money

Commissioners will monitor all health services in ways that assess access and quality of care for people with learning disabilities. They will seek evidence that providers are making reasonable adjustments, track the extent to which people with learning disabilities are accessing different services, and measure patient experience. Commissioners will take action where there is evidence that providers are failing to make reasonable adjustments or provide high-quality care.

11 Ensure efficiency and effectiveness of spend

Robust analysis of spend and its impact on health benefit enables commissioners to make well informed investment decisions for people with learning disabilities. By identifying and unlocking efficiency and productivity improvements across all commissioned activity, commissioners will deliver both better health outcomes and greater value for money.

There will be transparency and effectiveness in the deployment of resources, in order to deliver the highest level of health benefit and quality of care for a given level of spend. Health and local authority partners will make effective use of the budget-pooling powers in section 75 of the NHS Act 2006 (which replace powers originally introduced in the Health Act 1999), together with other arrangements such as lead commissioning and integrated provision.

[^35]: *Principles and rules for Cooperation and Competition*, Department of Health, 2007, Gateway 9244
7. The commissioning cycle
7. The commissioning cycle

The DH commissioning framework sets out the cycle of activities involved in delivering better health, better care and better value. This section uses the commissioning cycle to illustrate ways of securing good health outcomes for people with learning disabilities.

More specific guidance on primary care, mental health, acute care and ambulance services is contained in Appendix 1.

7.1 Patient and public involvement

Patient and public involvement is an integral component of every aspect of the commissioning cycle. This is not just about listening to the views of patients and carers, but about actively engaging them in making commissioning decisions and supporting service improvement.

PCT boards need to have robust mechanism for collecting, understanding and reporting on patients’ and carers’ views, particularly in areas of known inequality.

PCTs will also need to seek evidence that service providers, including GP practices, have systematic ways of listening to and engaging with patients and carers, acting on their views and providing evidence of the improvements made.

<table>
<thead>
<tr>
<th>Best practice</th>
<th>Engage with public and patients</th>
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<tr>
<td><strong>Working Together for Change: using person-centred information for commissioning</strong> (DH July 2009) is a practical guide that describes a process for planning change with people which provides powerful insights into what is working and not working in their lives as well as their aspirations for the future. Working Together for Change can be used to ensure that active partnerships with local people and families are the driving force behind social care transformation programmes, as a vehicle for ensuring effective community engagement in the joint strategic needs assessment (JSNA) and as a tool for strategic commissioning and service development. <a href="http://www.dhcarenetworks.org.uk/Personalisation/Topics/Browse/General/?parent=2734&amp;child=5802">http://www.dhcarenetworks.org.uk/Personalisation/Topics/Browse/General/?parent=2734&amp;child=5802</a></td>
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<td><strong>NHS Quality Improvement Scotland</strong> has devised a set of six service quality indicators for people with learning disabilities. This is used to assess performance in NHS Board areas throughout Scotland. The first of these indicators, ‘Involvement of Children and Adults with Learning Disabilities and their Family Carers through Self-Representation and Independent Advocacy’, provides a useful reference tool to determine how current involvement compares. <a href="http://www.nhshealthquality.org/nhsqis/files/Learning%20Disability%20Quality%20Indicators.pdf">www.nhshealthquality.org/nhsqis/files/Learning%20Disability%20Quality%20Indicators.pdf</a></td>
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37 Health reform in England: update and commissioning framework, Department of Health, 2006, Gateway 6865
NHS Leicestershire County and Rutland is consulting with people with learning disabilities and their carers about how to best work with them. It has developed an easy read consultation booklet which explains plans and encourages direct feedback, as advocated in the report of Sir Jonathan Michael’s independent inquiry.

NHS Westminster undertakes an annual Ask Your Patient Week, which includes disseminating an accessible survey. Feedback highlighted training of receptionists as a key area. ‘Understanding learning disability’ is now covered as part of the annual refresher training under the heading of equality and diversity.

7.2 Assessment of needs

The first stage in any commissioning cycle is a thorough assessment of local population health needs.

The Joint Strategic Needs Assessment (JSNA) informs - and is in turn informed by – both the PCT’s Strategic Plan and local authority’s and in particular Learning Disability Partnerships’ (LDP) strategic planning. The JSNA is a shared statutory duty between the Directors of Children’s Services, Adult Social Services and Public Health which describes the health and wellbeing of the local population, models future needs and identifies health inequalities; these will inform the LDP and the leads for children with disabilities services. The LDP is responsible for commissioning a wide range of services for adults with learning disabilities and they will review service data and evaluate universal and specialist services for people with learning disabilities to identify met and unmet needs; this, together with reviews of evidence of effective interventions will support commissioning decisions to improve services and outcomes for people with learning disabilities. The LDP Partnership Board will use information in its work with partner organisations responsible for universal services in order that they are better able to respond to the needs of people with learning disabilities. The priorities coming from the LDP planning and commissioning processes will then feed back to inform the JSNA’s overarching picture as it is updated.

The JSNA process and LDP should both support strategic commissioning and investment for people with learning disabilities. Many of the wider social and environmental determinants of people with learning disabilities’ health and wellbeing such as jobs, housing, transport and leisure facilities are the prime responsibility of other partners; while all services are required to consider and cater for the needs of those with disabilities, LDP commissioners can use the LDP process to ensure that wider partners respond to their core priorities through the JSNA process owned by the Local Strategic Partnership (LSP), more effectively than the LDP alone.

The JSNA and LDP planning process should address both the healthcare and the health promotion needs of the local population. LDP Boards would also be expected to endorse the arrangements they have made locally to ensure effective early intervention and access to services to meet the needs of people with learning disabilities. The LDP would also consider the needs of families and carers who provide crucial support for people with learning disabilities and improving their outcomes.
Both as a matter of good practice and to reflect the disability, race and gender equality duties, the JSNA should include listening to and engaging with people with learning disabilities, alongside other groups whose voices might otherwise not be heard (see Working Together for Change in box above).

The assessment should particularly identify people with the most complex needs, those who are most vulnerable (irrespective of level of need) and those less likely to access current services. This might include those living with long term illnesses or underlying health conditions, those from an ethnic minority, those who challenge services, those in custody, those living with older family carers, parents with learning disabilities and those living in particularly deprived areas.

Responsibility for assessing and meeting the needs of people on the autistic spectrum (some of whom may not be considered to have learning disabilities based on their IQ) must be clearly agreed. Assessment of numbers and needs of people with Autistic Spectrum Disorder (ASD) should be included in the JSNA, both for those who have learning disabilities through the LDP and those that have a higher IQ. Commissioners of universal health services will need to ensure that people with ASD have access to appropriate services to meet their needs.

The LDP will need to engage with the Children’s Trust as their Children and Young People’s Plan (CYPP) will be essential to understanding children’s needs and will include the numbers and varying needs of children and young people supported within jointly funded educational placements or in schools as they move through the system and into transition to adult services. Similarly, the Children’s Trust will liaise with paediatric and health visiting services to assess the needs of very young children requiring support and incorporate this into their Children and Young People’s Plan as well as the PCT’s strategic plan and the JSNA.

PCTs and local authorities will need to obtain reliable statistics of people with learning disabilities and the distribution of people with learning disabilities living at home and in other settings. Definitions of severity will need to be reviewed locally alongside any national definitions. Local health services will need to be aware of all people with learning disabilities within the local area, including those who have been placed from elsewhere. Research in Kent has demonstrated that ‘out-of-area’ placements can double the number of people in residential care in a given area.

The JSNA should take into account future needs, including how these are likely to change over a five-year cycle, in particular the needs of young people coming through the transition from children’s to adult care. A Learning Disability Task Force report in 2004 predicted that, on a conservative assumption, there would be an 11% increase in the total number of adults with learning disabilities between 2001 and 2021, including a 36% increase in the number aged over 60. Other resources also offer estimates.

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40 Transforming the quality of people’s lives – How it can be done, Learning Disability Task Force, 2004

World Class Commissioning: Competencies, Department of Health, 3 December 2007, Gateway 8754.

World class commissioning guidance on strategic planning for PCTs can be found at: www.wccassurance.dh.gov.uk/Pages/Public/home_pctplans.asp – registration required through the PCT.

The Commissioning Specialist Library can be found at: www.library.nhs.uk/commissioning/

**Guidance on services for people with learning disabilities**

*Action for Health – Good practice guidance for partnership boards, Department of Health, 2002.*

*Action for Health – Health Action Plans and Health Facilitation, updated guidance, Department of Health, March 2009.*

*Good practice guidance on working with parents with a learning disability, Department of Health and Department for Education and Skills, 1 June 2007, Gateway 7428.*

*Meeting the health needs of people with learning disabilities: Guidance for nursing staff, Royal College of Nursing, February 2007.*

*Mental health nursing of adults with learning disabilities, Royal College of Nursing, September 2007.*

*The National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care, Department of Health, 26 June 2007, Gateway 8427.*

*Services for people with learning disabilities and challenging behaviour or mental health needs, guidance, Department of Health, 6 November 2007 (Mansell report (revised edition, 2007)), Gateway 9019.*

A range of further documents can be located through the National Library for Health – Learning Disability specialist library – at: www.library.nhs.uk/learningdisabilities/

Peer support and advice can be provided through the UK health and learning disability network hosted by the Foundation for People with a Learning Disability). To join, log on to: www.learningdisabilities.org.uk/ldhn

Easyhealth is a simple-to use, easy-to-understand website that makes it straightforward for people to find health information: www.easyhealth.org.uk
Options for seeking this information include:

- using information from a termly census of schools to identify the numbers, location and characteristics of children with learning disabilities who are coming through the system
- developing systems for validating and aggregating practice-based registers across the PCT
- using local authority disability registers.

The JSNA core dataset suggests using the Referrals, Assessments and Packages of Care figures published for councils with social services responsibilities, to quantify known demand and service response.

The new local performance framework identifies many areas of relevance for people with learning disabilities that should be reviewed. The specific learning disabilities indicators are:

- NI 145: adults with learning disabilities in settled accommodation (PSA 16)
- NI 146: adults with learning disabilities in employment (PSA 16)
- NI 135: the number of carers receiving needs assessment or review and a specific carers service or advice and information.

The JSNA should include evidence of the numbers of people with learning disabilities known to the local authority who are receiving annual health checks, in line with the Vital Signs indicator, and ensuring that appropriate actions are taken to meet needs identified, including accessing screening and health promotion services.

Learning Disability Partnership Boards will be compiling annual reports which will have additional helpful information.

Appendix 3 provides some useful checklists for action. Checklist 1 sets out the information vital for planning services for people with learning disabilities - What you need to know about your local population.

**Best practice**  
**Creating a JSNA**

**Sheffield Learning Disability Partnership Board** has undertaken a needs assessment specifically for people with learning disabilities, as a result of a dedicated information-gathering approach. A large amount of local evidence has been assembled from the Sheffield case register (in existence since 1975), the social care information system and a range of local research, surveys and project work. This rich dataset looks at understanding needs and supports planning for the future. See [www.sheffield.gov.uk/safe--sound/social-services/scap/future-plans/for-people-with-a-learning-disability#downloads](http://www.sheffield.gov.uk/safe--sound/social-services/scap/future-plans/for-people-with-a-learning-disability#downloads)

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42 The JSNA core dataset, Association of Public Health Observatories, 2008, Department of Health, Gateway 10262  
43 Community Care Statistics 2007–2008: Referrals, Assessments and Packages of Care, for Adults, National Statistics and Department of Health, 2008  
44 An introduction to the local performance framework – delivering better outcomes for local people, DCLG, 2007, LGSRU 04949
Scoping the population and forecasting future need through a JSNA

**NHS Bristol** has specifically considered the needs of people with learning disabilities in its JSNA. This estimates the number of adults and children from different data sources and forecasts future trends and demand. See http://www.bristol.gov.uk/item/search/?query=jsna

**NHS Cambridgeshire** has a JSNA for People with Learning Disabilities which contributes to the Combined JSNA for Cambridgeshire. There is also an Easy Read Summary. See all 3 documents at: http://www.cambridgeshire.nhs.uk/default.asp?id=656

An accessible JSNA

**NHS Stoke** has written their JSNA in an accessible format. The link to their JSNA is below: www.stoke.nhs.uk/publication/list/Other_Publications

### 7.3 Review of current service provision

The second stage in the commissioning cycle is to develop a deep understanding of the existing healthcare context, in order to understand how services are currently provided, to assess their quality and to identify any gaps that may need to be addressed through new initiatives. There should be particular emphasis on access to services (compared with that of the general population) and how well current services optimise health, wellbeing and independence.

This requires drawing together a number of data strands, benchmarked wherever possible against national or cluster averages. Opportunities in Read Coding in primary care could be explored. The development of benchmarks for people with learning disabilities could be addressed by liaising with the Valuing People health networks and advocacy forums in each region.

A PCT will be able to demonstrate world class commissioning only when it can show not just the range of services it commissions, but the quality and outcomes these services offer. Commissioners should work with Learning Disability Partnership Boards to agree what would constitute good outcomes and to develop associated quality indicators. Addressing these outcomes will need to be a key element of any PCT’s strategy.

Service reviews need to include assessing capacity against current and future population needs. Areas of highest need can sometimes have low levels of current services. A good needs assessment relating to children coming through the system will enable commissioners to compare the availability and appropriateness of services with projected needs.

This review of service provision enables the PCT to identify whether it has an overall capacity gap and to pinpoint particular hotspots where investment and capacity may need to be enhanced. Where the PCT identifies areas of higher spend which are not justified by a higher level or quality of service, this may suggest opportunities for service improvement.

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45 It is assumed that all identified people are resettled from long-stay beds and NHS residential campuses are closed. If this is not the case then this area will need to be addressed.
The health performance framework piloted in the Yorkshire and Humber region (see Appendix 2) includes a whole systems self-assessment tool for PCTs, NHS Trusts and local Learning Disability Partnership Boards.

Checklist 2 in Appendix 3 - What you need to know about your existing capacity – provides useful information to support service reviews.

### 7.4 Deciding priorities

The final step in establishing the baseline is to overlay the needs assessment with the analysis of the current pattern of provision, in order to identify the key implications. These will vary widely by PCT, but may include:

- a misalignment between those segments of the population that have the highest health needs and the existing pattern of investment
- areas or services that offer poor access or show widespread patient dissatisfaction
- different outcomes for people with learning disabilities compared with the general population
- communities that have limited choice of services
- services that are not achieving basic quality standards
- the need to transform services to meet changing population needs, for instance as increasing numbers of children reach adulthood or as older people with learning disabilities develop more complex health needs.

This analysis will form a vital plank in the second phase of this work – determining the vision for the future. It is at this stage that key priorities for development should be emerging. These should be developed and agreed with the Partnership Board, ensuring engagement with partners such as social care, housing and education services. The PCT process for decision making, including any ethical framework, will need to apply equally to this area. Most importantly, priorities will have been developed with people with learning disabilities and their carers. The agreements should flow into a joint commissioning plan for learning disabilities, which should be reflected in the PCT strategic plans, the Local Strategic Partnership (LSP) and, where relevant, the Local Area Agreement (LAA).

### Strategic plan

As part of world class commissioning, every PCT has developed an overarching five-year strategic plan, setting out the PCT’s vision, its priorities and how they are to be delivered, and an annual operational plan. The strategic plan will be based on the JSNA, and the PCT should build its capability and capacity to deliver these plans through its organisational development plan.

It is vital that the plan for services to meet the needs of people with learning disabilities is firmly rooted in the broader context of the five-year strategic plan. The challenge for PCTs is to take the overall picture painted by the five-year strategy, and ensure that equal access and quality of care are
Improving the health and wellbeing of people with learning disabilities. The actions and resources for implementation need to be identified.

Checklist 3 in Appendix 3 covers specific considerations to address in joint commissioning plans.

### Best practice

**Whole system strategic planning**

Two strategic health authorities – **East Midlands and the South West** – developed separate NHS NSR workstreams to ensure that the needs of people with learning disabilities were incorporated into NSR implementation. These workstreams connect the particular needs of people with learning disabilities to the eight existing NSR workstreams (staying healthy, children’s health, long term conditions, urgent care, planned care, mental health, maternity, end-of-life), outlining how the distinct features of commissioning for people with learning disabilities will be embedded in the wider quality initiatives.

### Operational plan

In addition to its strategic plan, each PCT should prepare an annual operational plan. This plan will set out in some detail what is to be done in the coming year to implement its strategy. This should include the changes to which the PCT has committed itself to improve services for people with learning disabilities.

In addition to local priorities, the national expectations around learning disabilities described in the Operating Framework need to be addressed. For the last two years these have been as follows:

- **2008/09**

  “Organisations will need to agree local action plans setting out what they are doing to address the shortcomings identified in the Healthcare Commission’s audit”;

  “PCTs need to work closely with local authorities, to identify local priorities and pursue service improvements in line with the vision (set out in Valuing People Now) of ensuring both quality of care and equality of access, with a particular focus on making progress on campus closures and developing and implementing plans with individuals on their care and health needs”; and

  “PCTs need to prepare for the transfer of learning disability funding to local authorities, as set out in Valuing People Now”; and

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46 The NHS in England: The operating framework for 2008/09, Department of Health, 2007, Gateway 9120
• **2009/10:**

“In line with the recommendations of the recent independent inquiry by Sir Jonathan Michael, PCTs should ensure they secure general health services that make reasonable adjustments for people with learning disabilities. To support these improvements, we have introduced a directed enhanced service for annual health checks for people with learning disabilities who are known to local authorities, and the NHS Vital Signs indicator reflects the take-up of these health checks. PCTs need to ensure there are effective arrangements for communication and partnership working between primary care and other healthcare providers to improve the overall quality of healthcare for people with a learning disability.”

There are also requirements concerning mixed-sex accommodation:

“Plans for mental health and learning disability inpatient services should address the issues of:

• ensuring men and women do not share bedrooms or bed bays; and
• widening the availability of women-only day areas.”

The Operating Framework also included the release of the standard NHS contract for mental health and specialist learning disability services.

**Best practice**

**Creating a set of priorities**

Nottingham Learning Disability Partnership Board has undertaken a needs assessment specifically for people with learning disabilities. This needs assessment has been used to draw up a set of recommendations and priorities for developing service responses for people with learning disabilities. See [www.nomadplus.org.uk/secure/Intelligence/Health%20and%20social%20care/Joint%20Strategic%20Needs%20Assessment/Adults%20LD%20final%20April%2008.pdf](http://www.nomadplus.org.uk/secure/Intelligence/Health%20and%20social%20care/Joint%20Strategic%20Needs%20Assessment/Adults%20LD%20final%20April%2008.pdf)

**Responding to Sir Jonathan Michael’s report**

Leicestershire County and Rutland NHS developed a briefing document on Sir Jonathan Michael’s Healthcare for All report, including a comprehensive action plan to respond to the report. It has created an easy read version and is using this to consult with people with learning disabilities and their carers.

### 7.5 Specifying services

The next stage is for the PCT to set out a clear, compelling vision of what it wants local health services to look like in future from the point of view of people with learning disabilities and to reflect this in specifications for both general and specialist services. This can be described as the service model.

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47 The NHS in England: The operating framework for 2009/10, Department of Health, 2008, Gateway 10967
48 Best Practice Guidance: Guidance on the standard NHS contract for mental health and learning disability services, Department of Health, 2008, Gateway 11040
It should be informed by the needs assessment, the strategic plan and the ongoing involvement of patients, carers, clinicians and other local partners.

The PCT will need to ensure that all commissioned services offer safe care and support that are person-centred and evidence-based. This means both commissioning mainstream services in ways that address the health needs of people with learning disabilities and commissioning more specialist services for those with complex needs.

7.6 Shaping the structure of supply

This phase is about working with partners to shape markets so as to make them more responsive to the desired service model and changing local need. PCTs will need to understand providers, meeting with them to encourage services to be innovative and flexible. While the re-provision programme has developed a more mixed economy for residential and supported care, the provision of community health services may not demonstrate the same level of market development.

It may also be essential in some areas to use the market to create effective provider choice for people with learning disabilities.

Commissioners can shape markets by using open tendering, by using ‘Any Willing Provider’ models, and by working with existing providers to re-shape services, for instance by investment in training. Market development may also involve decommissioning services that no longer contribute to priorities, that are shown to be ineffective, or are no longer based on best evidence.

The 2007 report by Professor Jim Mansell offers compelling evidence from four best practice examples that reviewing the shape of service provision can create better solutions for learning disabilities, particularly for those who challenge services. He states that “since cost is sometimes given as a reason why adequate services for this group of people are not developed, it is worth noting at the outset that these services were all developed within the existing resource framework available to their host agencies. Resources are a question of priorities as well as of the amount available."

An effective and efficient approach to market development relies on creating solutions in partnership, not just amongst organisations within a PCT area but also through Partnership Boards working collaboratively across PCT and local authority boundaries.

In most cases, services will be commissioned at the local level, but in some cases more specialised and lower volume services may be more appropriately commissioned at sub-regional, regional or national levels.

For example, a number of specialised forensic services are commissioned under the NHS national and specialised commissioning arrangements. Learning Disability Partnership Boards will wish to develop links with these services to ensure that they fully meet the needs of people with learning disabilities in their area.

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49 Health reform in England: update and commissioning framework, Department of Health, 2006
50 Services for people with learning disabilities and challenging behaviour or mental health needs, p.13, Department of Health, 2007, Gateway 9019
There will also be times when commissioners need to shape the market on a case-by-case basis – for example, when a person has a severe physical disability and needs a comprehensive care package that brings together a range of different services from different sectors (e.g. health, social care, education and housing).

**Contracting for services**

In order to address inequalities, PCTs should regularly review provider contracts to check how far they address the needs of people with learning disabilities and equalities. For each contractual agreement, the PCT will need to ensure that there are appropriate policies and compliance with areas such as:

- protection of vulnerable adults from abuse (POVA)
- consent to treatment
- the Mental Capacity Act 2005 provisions on deprivation of liberty
- the Disability Equality Duty.

See Checklist 4 in Appendix 3 – *Longer term goals and challenges to factor into supplier negotiations* – for further advice.

Appendix 1 provides examples of effective contracting in primary care, community health services, mental health, acute care and ambulance services. The Healthcare Commission audit report, *A Life Like No Other*, provides significant learning on commissioning for specialist inpatient services.52

### 7.7 Managing demand and ensuring appropriate access to care

PCTs should work closely with GP practices and with community health services to make sure people with learning disabilities receive the most appropriate care in the right setting. As set out in the Operating Framework, this means not only making sure that people with learning disabilities have regular health checks but that there are good liaison systems in place to make sure that they can access a range of services to help maintain good health, such as dental services, podiatry and sight testing.

### 7.8 Clinical decision making and individual assessment/advice on choices

It is critical that patients and their families are able to feel a level of control over their journey through the healthcare system. It is likely that health services will need to make reasonable adjustments to enable people with learning disabilities to exercise choice and to support them in making informed choices.

Valuing People Now sets out the following key policy objectives for maximising independence:

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52. *A Life Like No Other: A national audit of specialist inpatient healthcare services for people with learning difficulties in England*, Healthcare Commission, 2007
All people with learning disabilities and their families will:

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

Commissioners can use a range of means of communication, including leaflets, DVDs and audio to support people in accessing services. There are many publications and video products already developed which can help prepare a person with learning disabilities as to what to expect. Examples can be found at www.easyhealth.org.uk

7.9 Managing performance (quality, performance, outcomes)

This involves regular monitoring of performance and early intervention when performance suggests that quality or outcomes may suffer. It includes assessing delivery against quality standards and outcomes, reviewing the knowledge and skills of staff, and reviewing whether resources are being used as effectively as possible against priorities.
PCTs have a range of commissioning levers and tools at their disposal to support performance improvement, including:

- transparent use of information
- agreeing performance measures
- reviewing performance and supporting quality improvement
- promoting patient choice and use of individual budgets (see 7.8 above)
- practice-based commissioning
- the Commissioning For Quality And Innovation payment framework (CQUIN).

**Transparent use of information**

The first step in supporting high-quality services is to have good information with which to measure and compare quality. This is important in helping providers understand how they can improve services for people with learning disabilities, in helping patients, carers and families understand the relative merits of different services, and in enabling commissioners to review performance.

Some PCTs use balanced scorecards, drawing together data from a range of sources to provide an objective and rounded view of how services are performing. PCTs should consider what information can be provided as part of balanced scorecards to assess the quality of services for people with learning disabilities. Data collected as part of such scorecards could feed into monitoring tools for Learning Disability Partnership Boards.

**Agreeing performance measures**

PCTs should have agreed frameworks and processes for reviewing the performance of all the contracts they hold, whether they are for primary care, community health services, mental health or hospital care. This process needs to be clearly documented and publicly available and should enable providers to answer the following questions:

- what are the standards that we are expected to meet?
- when and how will our performance be reviewed?
- what will happen if our performance is below the agreed standards?
- what support will the PCT offer us to help us to improve?
- what is the process for review of financial performance and demonstration of best value?
Standards will generally fall into two areas:

- minimum standards that must be met: these will typically be contractual standards and failure to meet them will generally trigger a formal intervention by the PCT
- aspirational or developmental standards to be worked towards: these will set out how the PCT would like services and outcomes to improve and will often be backed by development programmes.

Checklist 5 in Appendix 3 (‘Key criteria for ongoing benchmarking, tracking and evaluation’) suggests possible areas to include in performance monitoring.

**Best practice**

Core and developmental standards

**NHS Westminster** used core and developmental standards in its Local Enhanced Services (LES) scheme for primary care for people with learning disabilities. The PCT took a stepped approach to implementing the LES. In the first year, the focus was on embedding the scheme. In the second year, the focus was on outputs and outcomes, namely the provision of annual health checks and health action plans. In its third year, the developmental standards were used to improve quality and outcomes for users as well as ensure value for money.

**Reviewing performance and supporting quality improvement**

A clear performance cycle is needed to agree standards, review performance and take action as appropriate, setting out what will happen and when. Key components are likely to include those set out in Checklist 6 in Appendix 3 (‘Recommended actions and dates for agreeing objectives and developments’).

Where a service is meeting minimum standards, but performance monitoring suggests that there are areas for particular development, PCTs should consider what support it may be possible to make available to providers to improve.

Where there are concerns that performance is falling below agreed standards, there need to be clear arrangements for escalation, covering:

- how the PCT will respond to different kinds of challenge:
- arrangements for more intensive monitoring where necessary, including:
  - frequency of reviews
  - any requirement for recovery plans setting out actions and milestones
  - how long a service will remain on an intensive regime
  - what support the PCT will provide, for example training.
The aim of placing a service on an escalation regime is to help it recover and meet the required standards as quickly as possible.

**Practice based commissioning**

Practice based commissioning (or ‘clinical commissioning’) enables GP practices, working with other professionals from primary care, community health services, specialist services and social care, to play a key role in shaping how resources are used to provide better health, better care and better value for their lists of registered patients\(^{53}\).

PCTs will wish to consider how to support clinical commissioners in understanding the needs of people with learning disabilities within their practice populations and ensuring that these needs are taken into account in reviewing patient pathways and redesigning services.

### Best practice

**Using CQUIN**

NHS Bristol agreed to use CQUIN as part of its drive to improve the experiences of people with learning disabilities using the local acute trust. The target set is that 70% of those admitted with learning disabilities, and a stay of longer than 48 hours, will have a learning disabilities assessment completed. The information will be audited and evaluated for future years. If the target is achieved, there is a commitment on the part of the acute trust to use at least part of the additional income to develop a better range of accessible information for people with learning difficulties using hospital services.

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\(^{53}\)  Clinical commissioning: our vision for practice-based commissioning, Department of Health, March 2009, Gateway 11073.
8. Developing capacity and skills in commissioning
8. Developing capacity and skills in commissioning

PCTs will wish to consider how their commissioning teams can best develop the capacity and skills to ensure that the needs and experience of people with learning disabilities are reflected in the commissioning cycle, whether this is in relation to primary care, community health services, hospital services or specialist learning disabilities services.

PCTs may need to consider how they build and share resources, including:

- improving the expertise and knowledge of staff engaged in all stages of the commissioning cycle
- ensuring that commissioning staff have access to expert advice on learning disabilities
- pooling resources across PCTs or collaborating on particular topics
- buying support, for example through the use of the Framework for Procuring External Support to Commissioners.

The good practice guide for commissioning specialist adult learning disabilities services\(^{54}\) suggests that it is critical to ensure an effective and identifiable strategic presence within the PCT to inform and support the commissioning and delivery of services in ways that address the needs of people with learning disabilities. In many places ‘strategic health facilitators’ have been appointed to undertake this role. They can be instrumental in providing strong leadership and in promoting health facilitation and health action planning for people with learning disabilities. Such a role can also act as a resource to public health colleagues.

PCTs should also promote a collaborative approach to commissioning services, based on close working with local authorities and Learning Disability Partnership Boards and underpinned by the right leadership and governance.

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\(^{54}\) Commissioning Specialist Adult Learning Disability Health Services: Good Practice Guidance, Department of Health, 2007, Gateway 8530
| **Best practice**  
<table>
<thead>
<tr>
<th><strong>Creating capacity in commissioning</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Westminster PCT has put the following roles in place to undertake commissioning for people with learning disabilities. All are within the service development team:</td>
</tr>
<tr>
<td>• one full time equivalent (FTE) Joint Commissioner</td>
</tr>
<tr>
<td>• one FTE Service Development Manager (Strategic Health Facilitator) based within the PCT</td>
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<tr>
<td>• one FTE Service Development Manager based within the local authority</td>
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<tr>
<td>• one FTE Person Centred Planning Officer</td>
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<tr>
<td>• one FTE Information and System Officer.</td>
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</table>
9. Conclusion and next steps
9. Conclusion and next steps

The Operating Framework for 2009/10 underlines the importance attached to commissioning services in ways that make reasonable adjustments for people with learning disabilities and provide higher quality care and better health outcomes. This document shows how the systematic use of the commissioning cycle can help PCTs achieve this objective.

In line with the recommendations of the Ombudsmen’s report, PCTs will be expected to report to their Boards by March 2010 on the actions they have taken as a result of reviewing the effectiveness of their systems – and their capacity/capability – for understanding and meeting the needs of people with learning disabilities.

The Department will continue to work with SHAs to support and review progress.

Key areas of world class commissioning for the health and wellbeing of people with learning disabilities will include:

- a comprehensive needs assessment which seeks evidence on the numbers, health needs and experiences of people with learning disabilities
- PCT board members exercising their Disability Equality Duty by asking tough questions about how commissioned services are meeting the needs of people with learning disabilities
- Learning Disability Partnership Boards reviewing services and outcomes and helping develop ambitious public commitments to what is to be achieved in the next five years
- building capability so that all those involved in commissioning general health services understand and act on the needs of people with learning disabilities
- working with service users, families and carers to develop and publish preferred service models
- bringing providers into the market as necessary to achieve the desired service models and outcomes
- mainstream services demonstrating ‘reasonable adjustments’ to ensure that they are meeting known needs, and having staff who understand how to make these adjustments
- adjustments will be at both individual and service and strategic level depending on the nature of the change required
• working with service users to make sure that provider organisations are consistently delivering high-quality services

• Partnership Boards continuously reviewing how to support individuals in improving their own health and wellbeing.

Better commissioning for people with learning disabilities exemplifies the world class commissioning vision of “adding life to years and years to life”.

We would very much welcome any comments on this document, together with further examples of good practice and/or tools you have developed locally to support better commissioning.

Best practice
Making a difference

NHS Leicestershire County and Rutland have developed their conclusions on what needs to happen next in an easy read format and published these for consultation:

10 ways to make healthcare better

1. Teach people good ways to support people with learning disabilities
2. Keep better information
3. Support for families and carers
4. Different groups working together
5. Find out how to help people stay healthy and live longer
6. Rules about healthcare
7. Check that healthcare is good
8. Extra ways to support people with learning disabilities
9. Find out what people think about healthcare
10. Show how we are changing things to make healthcare better.

See: www.lcrpct.nhs.uk/site/Internet/home/0/FINAL%20VERSION%20Michaels%20Report%20Easy%20Read.pdf
Appendix 1: Commissioning services in different settings

Commissioners should refer to the guidance on the standard NHS contracts for mental health and learning disability services.

This guidance states that, in addition to the behaviours expected of providers and commissioners in their contractual relationship, stakeholders agreed the following principles which should underpin the delivery of mental health and learning disability services and should therefore be noted by both providers and commissioners:

- Care should be based on an individualised assessment of the Service User’s needs, including consideration of their mental and physical health and their social circumstances. This should include risk assessment and result in an individualised plan of care that is reviewed. In adult and older age services this will be represented by the Care Programme Approach (CPA) for those with complex needs, in learning disability services by a health action plan and in child and adolescent mental health services (CAMHS) by family-centred or person-centred planning.

- Care should promote recovery, social inclusion, independence and harm reduction (including wider familial and community harms).

- Carers should be appropriately involved in planning care and their needs should be assessed.

- Care should be provided as near to home as is reasonably possible.

- Care, if in residential or hospital setting, should be provided at the lowest level of security based on an individualised assessment of risk. Alternatives to residential or hospital care such as home treatment, crisis intervention, care packages in the community should be available.

- Care should be provided in an age appropriate environment. The decision about the location of care for any individual should be based on their assessed needs and maturity, not simply their age or existing service configurations.

- An appropriately skilled and trained workforce should provide care.

- Monitoring of care should be focused on outcomes for the individual whenever possible.

- Where care is provided by more than one individual, service and/or more than one agency clear agreement about coordination of care for the individual must be in place. This should be facilitated by the appropriate operational agreements. Care should be taken to ensure that clients clearly understand the confidentiality boundaries in which their care is set.
Commissioners and providers will agree non-tariff prices and, where applicable, will be required to comply with the Code of Conduct for Payment by Results (PbR) and with applicable Department of Health PbR guidance.

**Primary care**

GP practices should play a key role in coordinating healthcare for families and adults with learning disabilities. NHS Primary Care Commissioning has produced a primary care services framework on learning disabilities for practitioners with special interests available to download at [www.pcc.nhs.uk/pwsi](http://www.pcc.nhs.uk/pwsi).

Key areas to consider may include:

- reasonable adjustments to ensure equitable access to services
- people on the learning disability register who do not have a GP
- uptake of annual health checks
- the percentage of people with learning disabilities with a health action plan
- patient satisfaction from surveys
- jointly developed literature to promote access and choice for primary care and wider services
- evaluation of support provided to practices
- the assessment of carers’ needs.

PCTs should also make sure that other primary care services, including GP out-of-hours services, dental services, community pharmacy and primary ophthalmic services ensure equitable access and quality of care for people with learning disabilities.

Swine flu preparation presents an example of a mainstream health issue which requires particular approaches if it is to work for people with learning disabilities. Local plans and action need not just to include people with learning disabilities, but also recognise additional vulnerabilities due to underlying conditions and make reasonable adjustments to reflect individual risk factors as well as wider issues, such as difficulties accessing information and screening.

**Access to GP services**

Access to primary medical care will have a significant impact on how frequently and appropriately people with learning disabilities access wider services. Poor systems of access can both discourage patients from seeking help from primary care and detract from the quality of the consultation.

The Disability Equality Duty provisions of the Disability Discrimination Act 2005 require PCTs to ensure there are ‘reasonable adjustments’ to enable people with a disability to access services. This goes beyond physical access to encompass areas such as providing appointments and communicating with patients. Sending only letters and offering only telephone access to appointments may not be seen as reasonable adjustments.
PCTs should set out clearly for GP practices what standards they expect them to meet in providing essential and additional services, together with any requirements associated with providing enhanced services, and how they will monitor and manage performance.

Access can be measured in a number of ways. The national GP Patient Survey measures patient satisfaction with opening times, 48-hour access, advance booking, telephone access and ease of seeing a specific GP. The Survey has been expanded to include wider measures of patient experience, e.g. helpfulness of reception staff, quality of GP and nurse consultations etc. The results – available since July 2009 – can be disaggregated by long term conditions, including learning disabilities. The Survey has been carried out quarterly since April 2009.

In order to assess patient experience for people with learning disabilities, PCTs may wish to seek evidence from patient feedback gathered directly by GP practices. ‘Mystery shoppers’ and focus groups have also been used to good effect.

Examples of improving access for people with learning disabilities include making available longer appointment times and appointments at the beginning or end of a surgery. The PCT will wish to check with practices how they are making reasonable adjustments such as these to ensure that people do not face any barriers in accessing services.

**Annual health checks**

PCTs have a duty to offer all GP practices in their area the opportunity to participate in a scheme that remunerates them for providing annual health checks for people with learning disabilities who are known to local authorities. Health checks are designed to be part of the overall process for health action planning and person-centred planning. The Directed Enhanced Service for health checks sets out service standards and remuneration for practices. It also sets out requirements for training for practice staff, which is an essential element of the scheme.

PCTs need to map both the uptake of the scheme by GP practices and the uptake of health checks by people with learning disabilities.

PCTs have been developing approaches to annual health checks and more advice can be found via the link to the PCC primary care service framework at: www.pcc.nhs.uk/uploads/primary_care_service_frameworks/primary_care_service_framework__ld_v3_final.pdf?ref=08786. The website also hosts a number of documents to support the Directed Enhanced Services scheme for annual health check such as training, electronic templates and frequently asked questions.
Best practice
Establishing annual health checks in general practice

Berkshire West PCT has been working with practices in Wokingham to offer annual health checks for their residents with learning disabilities. This has been very much welcomed and has ensured appropriate referrals to further services. This initiative was resourced with a health facilitator, training for the practices and enhanced service funding.

Key lessons from the West Berkshire initiative include the following:

- take time to discuss face to face with practice staff the factors involved in working effectively with people with learning disabilities
- support practices the first time they carry out the health checks
- offer in-house training in practices and bring people with learning disabilities into the process
- find a practice champion
- resource an enhanced service with clear quality standards (Enhanced Service standards are now available)
- audit the work and feed back to the practice
- let practices hear the positive feedback – of which there was lots
- sending letters can cause anxiety – personal contact and explanation is essential.

Clinical quality of GP services

For general practice, clinical quality can be mapped using indicators such as:

- QOF scores in the clinical domain
- QOF exception rates
- screening uptake rates
- immunisation rates
- smoking cessation rates
- compliance with Standards for Better Health core standards.

The PCT should consider with practices if and how these measures differ in relation to people with learning disabilities.
A review of the Healthcare Commission metrics for people with learning disabilities could suggest building the following into discussions with GP practices and potentially into enhanced services:

- the number of people with learning disabilities known to the GP practice but not yet coded using a locally agreed and appropriate READ code
- the number of people with learning disabilities who have been invited in the past year for a comprehensive health check if they have not visited the GP practice in the last three years
- the number of people with learning disabilities who have been screened for dysphagia in the last three years
- the number of people with learning disabilities who have had or been offered a comprehensive health check prior to a health action plan in the last three years
- the number of people with learning disabilities with a health action plan (compared with the numbers offered).

**Patient choice**

GP practices should play a key role in helping people with learning disabilities make choices about how they manage their health and how they access services. It is likely that reasonable adjustments will need to be made to help people with learning disabilities make choices. Leaflets and language will be key considerations, as well as the right support for the person to hear and understand the information. PCTs should consider how to support good practice, for instance by providing materials for practices to use. Refer to [www.easyhealth.org.uk](http://www.easyhealth.org.uk) for good practice examples of accessible health information.

**Other primary care services**

PCTs should ensure that the needs of people with learning disabilities are also reflected in contracting for GP out of hours services, primary dental services, community pharmacy and primary ophthalmic services.
**Best practice**  
**Development of an enhanced eye care service for people with learning disabilities**

Sutton and Merton PCT used data from its adult learning disability registers to find out that 44% of people with learning disabilities reported having visual impairments.

Attendees at a local stakeholder event, comprising people with learning disabilities, carers, commissioners, practitioners and service providers, raised the difficulties experienced when accessing eye care services. These were echoed in the JSNA.

A sub-group of the Eye Care Commissioning Board was formed with the aim of developing a pathway. The sub-group membership consisted of a GP, the optical adviser to the PCT, nursing team leaders from the local learning disability teams, a PCT commissioner and a representative from SeeAbility. Input was also provided by two ophthalmologists and an advanced clinical nurse specialist in ophthalmology.

Once complete, the pathway was approved as a commissioned service under a Local Enhanced Service model and has now been implemented.

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**Specialist learning disability community services**

Commissioning Specialist Adult Learning Disability Health Services: Good Practice Guidance lays out the key issues. The key issues for service level agreements are likely to be:

- specialist community staff in their clinical and therapeutic role agreeing outcomes from deployment across the areas given below:
  - mainstream services
  - people who may have complex and continuing health needs
  - emergency support.
- the role of specialist staff – and the PCT’s priorities – in relation to the following complementary tasks
  - health promotion
  - health facilitation
  - teaching
  - service development.

Commissioners will need to understand how clinical and therapeutic resources can be balanced between these and other areas and ensure that the service level agreement reflects the priorities identified (with local authorities and Learning Disability Partnership Boards) through the needs.

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57 Commissioning Specialist Adult Learning Disability Health Services: Good Practice Guidance, Department of Health, 2007, Gateway 8530
assessment. These priorities will then need to be reflected in the activity, quality and outcomes measures agreed in the contract.

The good practice guidance describes the following functions (acknowledging that the same titles or terminology will not necessarily be used):

- **early intervention** – community-based treatment and support, including a focus on young people and their families
- **crisis resolution** – preventing admission to hospital by providing 24-hour community-based treatment
- **assertive outreach** – supporting people with complex and enduring needs within the community.

### Best practice
**Looking at services from a user’s perspective**

Hambleton and Richmondshire have developed a process whereby a report on the treatment and assessment service can be fully informed and written from the perspective of those who use it, and this can then drive recommendations for improvement as necessary. For more information, contact diane@hradvocacy.org.uk

The self-assessment tool, which can be filled and submitted electronically or printed off and filled in, can be found at [www.debramooreassociates.com/6CsForm/SelfAssessment.htm](http://www.debramooreassociates.com/6CsForm/SelfAssessment.htm)

The model itself, with the key principles and examples of evidence, is available at [www.debramooreassociates.com/6Cs.htm](http://www.debramooreassociates.com/6Cs.htm)

### Mental health services

The green light toolkit provides a useful reference for improving mental health support services for people with learning disabilities. It describes what good mental health support services for people with learning disabilities look like and provides a way of assessing how well your local services measure up to this.

The NHS standard contract will be the base from which services are specified.

### Acute care and ambulance services

Learning from reports such as *Death by Indifference* demonstrates that there is much to do in our acute services to address inequalities. The first step is to establish that acute hospitals and ambulance services have systems in place to ensure that people with learning disabilities are identified, and that appropriate support is provided. This support will need to be reflected in contractual discussions with provider, however it is as much about ensuring that the appropriate culture exists within the organisation.
The Disability Equality Duty provisions of the Disability Discrimination Act require public authorities to make reasonable adjustments to enable a person with a disability to access services. The PCT needs to assure itself that each provider is making these reasonable adjustments to meet legal requirements. This will go beyond physical access and will include approaches to providing appointments and means of communication.

The legal requirements apply to urgent care responses, and therefore reasonable adjustments need to be made, as necessary, on a 24-hour basis.

**Best practice**

**Integrated care pathway for adult patients with learning disabilities attending general hospitals**

NHS South Central adapted work undertaken by Lothian University Hospitals Trust, Lothian Primary Care NHS Trust, Sheffield Trust Hospitals and Hereford PCT to create a collaborative protocol. It has been developed to support the care of people with learning disabilities as they go into, through and out of acute hospital services. [www.learningdisabilities.scnetworks.nhs.uk/pdf/scsha%20ICP%20final%20v2%20300908.pdf](http://www.learningdisabilities.scnetworks.nhs.uk/pdf/scsha%20ICP%20final%20v2%20300908.pdf)

The South Central Learning Disability Network protocols offer flowcharts for acute services dealing with consent, emergency admission and other areas.59

**Acute liaison nurses**

South Staffordshire and Shropshire Healthcare NHS Foundation Trust has developed the role of the Acute Liaison Nurse (ALN) to assist the experience of people with learning disabilities and their family/carers. The Shropshire model has enabled the coordination of investigations and procedures so that they occur during the same ‘theatre appointment’, e.g. dental examination together with venepuncture, audiology screening etc. Close relationships have been established with each department so that the ALN is contacted as necessary. With adequate support, patients with complex conditions such as renal dialysis are now managed at home thanks to strong and empathetic working relationships.

Family carers will often offer extensive support to their relative and ‘camp’ at the bedside. The trust will offer support such as:

- comfortable chairs
- meals
- a bleep so carers can have a break
- a badge
- involvement in care.

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This and further examples of good practice can be seen on the A2A (Access to Acute Hospital) Network website at [www.nnlndn.org.uk/a2a](http://www.nnlndn.org.uk/a2a), at [http://valuingpeople.gov.uk/dynamic/valuingpeople118.jsp](http://valuingpeople.gov.uk/dynamic/valuingpeople118.jsp) or at [http://valuingpeople.gov.uk/dynamic/valuingpeople145.jsp](http://valuingpeople.gov.uk/dynamic/valuingpeople145.jsp).

### Vulnerable In-Patient card (VIP card)

South West Yorkshire Mental Health NHS Trust, Calderdale and Huddersfield NHS Foundation Trust and NHS Kirklees have developed a VIP card for people with learning disabilities. This can be filled with information which folds down into a credit-card size. The card is easy to carry around and includes 16 boxes of key information such as medicine, preferred ways of communication and any specific concerns or fears the cardholder has. This card can be given to staff in health settings to help ensure that the appropriate care and styles of interactions are offered.

### Complaints process

Barnsley PCT and Metropolitan Borough Council uses a system of blue and yellow cards to enable a person with disabilities to indicate if they are happy or otherwise with a service. This card system is linked into the complaints system service and supported by a buddy service.

### Generating awareness amongst ambulance service front-line personnel

East Midlands Ambulance Service (EMAS) NHS Trust has incorporated awareness training on the Protection of Vulnerable Adults (POVA) into its 2009/10 essential training programme for accident and emergency, control room and patient transport service staff, as well as operational managers and service improvement managers. Posters, leaflets and a prompt card will reinforce awareness and almost 3,000 frontline staff will have received their training by March 2010. Volunteers working with the Trust (as community first responders or as volunteer car drivers) will also receive awareness training as part of their induction.

Clinical education staff have passed the POVA course and Trust teaching materials have been adjusted accordingly. A senior clinician is among those delivering the essential training. EMAS is to have a nominated tutor for this area.

“We feel we are making good progress,” says Director of Business Development and Community Relations Chris Boyce. “There is a lot of competition for inclusion on our essential training schedule, so it can be seen that we are taking this seriously in order to make a real difference.”

### Continuing care

*Commissioning Specialist Adult Learning Disability Health Services: Good Practice Guidance* offers advice on approaches for continuing healthcare. The Mansell report is also relevant in addressing behaviours that challenge services.60 The national guidance on continuing care61 addresses issues of eligibility and review of placement.

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60 Services for people with learning disabilities and challenging behaviour or mental health needs, guidance, Department of Health, 2007 (Mansell report (revised edition 2007), Gateway 9019

61 The National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care, Department of Health, 26 June 2007, Gateway 8427
Appendix 2: A regional ‘whole system’ approach to improving the health of people with learning disabilities and tackling the health inequalities they may face

In 2007, the Care Services Improvement Partnership commissioned Jackie Sochocka, an independent learning disabilities consultant, to develop a systematic and comprehensive regional working approach that could be tailored to each region and that would allow marked progress to be made on the Valuing People health objectives, tackling the previous blocks to progress.

The resulting ‘whole system’ approach is designed to provide a consistent local and regional approach and provide a direct channel of communication, information and influence from service user to government. It aims to be dynamic and flexible enough to be able to weather the changes, variations and developments that are always present in a complex system.

Yorkshire and the Humber region stepped forward as the national pilot site for this ‘whole system’ approach. The SHA worked closely with the Valuing People Regional Adviser, PCT chief executives, local specialist trusts and Jackie Sochocka to shape a programme of work relating to the health and wellbeing of people with learning disabilities in their region. Central to the development of that programme was the Learning Disabilities Performance and Self-Assessment Framework, which was further developed and approved by health and social care commissioners and health service providers from across the region.

The Yorkshire and the Humber SHA Board, PCT chief executives and the regional Association of Directors of Social Services approved the programme of work to be taken forward under four ‘top target’ headings for health.

All Learning Disability Partnership Boards in the region then completed early in 2008 their first annual health self-assessment using this framework. Following feedback meetings with people from all localities, the framework and linked process were further improved and refined, and the Year 2 process is currently under way. This systematic and inclusive annual process offers Learning Disability Partnership Boards and the regional overview group and its members a clear agenda of work in each locality – and regionally – for the coming year.
Each local area’s self-assessment is reported annually to the SHA, in much the same way as the mental health autumn assessment.

Jackie Sochocka was then commissioned to lead work to introduce this approach in all regions of England. Self-assessment exercises are now either completed or underway in four more SHA regions and by the end of 2009 all SHA regions will have completed the assessment process.

Contact details are:
jackie.sochocka@talktalk.net
**Learning disabilities best practice self-assessment checklist, key objectives and progress criteria (summary)**

<table>
<thead>
<tr>
<th>Key objectives</th>
<th>Level 1</th>
<th>Level 2</th>
<th>Level 3</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>1.0</strong> Plans are in place and resources identified to meet White Paper/DH learning disability targets for resettlement and campus closure</td>
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<tr>
<td>1.1 The resettlement of identified people from long-stay hospitals is complete</td>
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<td>1.2 All NHS residential campuses are to be closed by 2010</td>
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<tr>
<td><strong>2.0</strong> PCTs are working closely with local partnership boards and statutory and other partners to address the health inequalities faced by people with learning disabilities</td>
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<tr>
<td>2.1 Systems are in place to ensure that the following are identified within GP registers:</td>
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<tr>
<td>• children and adults with learning disabilities</td>
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<td>• older family carers</td>
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<td>• those from minority ethnic groups</td>
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<td>• carers of those from minority ethnic groups</td>
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<tr>
<td>• parents or carers with learning disabilities</td>
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<td>2.2 Primary care teams are tackling health inequalities and promoting the better health of those with learning disabilities registered with their practice</td>
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<tr>
<td>2.3 People with learning disabilities access disease prevention, screening and health promotion activities in their practice and locality, to the same extent as the rest of the population</td>
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<tr>
<td>2.4 The wider primary care community (dentists, pharmacists, physiotherapists, podiatrists, optometrists, etc) is demonstrably addressing and promoting the better health of people with learning disabilities</td>
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<tr>
<td>2.5 Service agreements with providers of general, specialist and intermediate healthcare demonstrably secure a range of treatment choices and equity of access to treatment; a positive experience of care; and effective admission and discharge procedures for people with learning disabilities</td>
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<td>2.6</td>
<td>National Service Frameworks – and clinical networks and projects developed to implement them – apply equally to people with a disability. The needs of people with learning disabilities are explicit in all such networks across the SHA area</td>
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<tr>
<td>2.7</td>
<td>The benefits for patients derived from the development of computer technology (in the context of the NHS plan to improve the way it holds and uses patient information) are of equal benefit and equally open to people with learning disabilities and those who provide services to them</td>
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<td>2.8</td>
<td>PCTs have agreed with local partner agencies a long-term ‘across system’ strategy to address services for people with learning disabilities from ethnic minority groups and their carers (see also 2.1 above)</td>
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<tr>
<td>2.9</td>
<td>There is a long-term strategy in place to achieve inclusion and equality of healthcare and outcomes for people with profound disabilities and their carers</td>
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<tr>
<td>3.0</td>
<td><strong>People with learning disabilities who are in services that the NHS commissions or provides are safe</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3.1</td>
<td>Commissioners and service providers are systematically addressing any areas of concern, relative to the learning points from recent Healthcare Commission investigations, national audit outcomes and Healthcare for All</td>
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</tbody>
</table>
| 3.2   | Each health organisation has in place transparent and well understood policies and procedures relating to:  
- consent to treatment by people with learning disabilities  
- Mental Capacity Act  
- Disability Equality Duty  
- Bournewood provisions |
<p>| 3.3   | The review and analysis of complaints and adverse incidents affecting people with learning disabilities leads to altered or improved practice in all organisations |
| 3.4   | There are effective partnerships with local agencies, and across care sectors and localities, to ensure a coherent approach to the protection of vulnerable adults from abuse |</p>
<table>
<thead>
<tr>
<th>4.0</th>
<th><strong>Progress is being made in implementing the service reforms and developments described in Valuing People Now</strong></th>
</tr>
</thead>
</table>
| 4.1 | Discharge planning is in place for adults and young people (not already included in the campus target) both in and out of district, and in both NHS and private sector hospital provision, whose treatment is either complete or nearing completion  
Note: This includes people with learning disabilities whose care is purchased via NHS continuing care |
| 4.2 | There is a comprehensive range of specialist learning disability services available to sustain and support people in their local community, avoiding unnecessary admissions or re-admissions to hospital |
| 4.3 | Plans are in place to ensure more locally available provision of the future mainstream and specialist health services needed to support young people approaching adulthood – and their families |
| 4.4 | People with learning disabilities and their families/supporters are supported and empowered to fully contribute to and participate in discussion, as well as in the planning, prioritisation and delivery of health services generally |
| 4.5 | There are thorough, well functioning partnership agreements and protocols between organisations, guiding day-to-day commissioning and service provision |
| 4.6 | Plans are in place to meet the particular needs of people with learning disabilities who are ageing. These are taken into account in local older people’s planning, and derive equal benefit from policy improvements and initiatives linked to the Older People’s National Service Framework, the Dementia Strategy, A New Ambition for Old Age, etc. |
| 4.7 | PCTs have agreed with local partner agencies a long-term ‘whole system’ strategy to address the needs of people with autism spectrum condition (ASC), which includes reference to adults with learning disabilities, and also to young people with learning disabilities approaching transition to adulthood (see also 4.1 and 4.3 above) |
| 4.8 | There is a range of local services available for individuals who challenge services (see also 4.2 above). Such services take account of key standards from policy and best practice |
| 4.9 | The National Service Framework for mental health is equally and equitably applied to people with learning disabilities who require psychiatric services |
| 4.10 | There is a coherent workforce plan in each local area guiding the future training and development of people working in learning disability services, in both specialist and mainstream healthcare areas. The plan is set within the context of the objectives and timescales of the reforms required by national policy, and of the strategies and business plans of local partnership boards |
Appendix 3: Useful checklists for action

Checklist 1: What you need to know about your local population

The following information is essential to planning services for people with learning disabilities:

- number of people with learning disabilities
- levels of complexity
- the age profile of people with learning disabilities
- predictions of how needs and numbers will change

Key information relevant to health commissioning which could be considered includes:

- number of people approaching the transition from childhood to adulthood\(^ {62}\)
- number of people approaching the transition to older age
- number of people placed in the area and funded by other commissioning organisations
- number of people placed out of the area by the commissioner
- number of people in hospital or living on NHS campuses or in other NHS-provided settings
- number of people resettled from long-stay beds or NHS residential campuses to community provision
- number of people living at home on their own and not receiving services
- number of people living at home with family carers and not receiving services
- number of people living at home with older family carers
- number of people supported by housing agencies with Supporting People funding
- numbers of people from different ethnic backgrounds with learning disabilities
- number of people expressing the need to have support for lifestyle, religion, sexual orientation etc.

\(^{62}\) Includes examples extracted from The commissioning of services and support for people with learning disabilities and complex needs: Assessment Framework, Healthcare Commission, Mental Health Act Commission and Commission for Social Care Inspection, 2008
• number of people using self-directed support (direct payments and individual budgets)
• number of people experiencing complex health needs
• number of people experiencing or having experienced forensic intervention
• number of people exhibiting challenging behaviour
• number of people with a diagnosis of autism spectrum condition (ASC)
• number of people known to the local authority who have no GP
• number of people known to the local authority who have a health action plan and those who have declined one
• number of people known to the local authority whose behaviour presents serious challenges to services
• detained patients
• carers, their age distribution and ethnicity
• EqIAs for mainstream services as they relate to people with learning disabilities
• access to disease prevention, screening and health promotion activities compared to that for the rest of the population
• placements which break down within a year
• the ratio of out-of-area placements to in-area placements, supported living and living at home
• benchmarked measures of activity/demand, such as
  - emergency referrals per 1,000 weighted population
  - A&E activity per 1,000 weighted population
  - Better Care Better Value (BCBV) indicators for ambulatory care sensitive emergency admissions
  - BCBV indicators for outpatient referrals
Checklist 2: What you need to know about your existing capacity

Key areas to consider that are relevant to commissioning health services for people with learning disabilities include:

- findings of client surveys about services (face-to-face surveys will be more appropriate than postal ones)
- number of disability strategic health facilitators working in the PCT
- number of disability acute liaison nurses working in hospital trusts
- number and quality of health action plans against preset standards of good practice
- number of inpatients (including those in long-stay and campus provision) receiving independent health advocacy services
- urgent access for mental health or other specialist services for people with learning disabilities
- percentage of treatment plans of patients in NHS-funded hospital beds (in and out of district) reviewed in last 12 months by a qualified clinician
- number of people in NHS-funded hospital beds whose duration of stay has exceeded 12 months (and who have not been detained under the Mental Health Act 2007 and are not receiving active treatment)
- use of mainstream mental health services versus specialist learning disability services as a percentage of comparable services accessed
- number of people in out-of-area treatment provision who are assessed by an appropriately qualified specialist clinician as severely challenging or who have a mental health or forensic need
- number of available community teams and other community support staff, in total and by specialism
- community team response times and waiting lists
- community capacity/activity devoted to health promotion, health facilitation, teaching and service development (see good practice guidance on commissioning specialist services63)
- levels of employment, educational attainment and independence (e.g. employment and settled accommodation levels as per PSA 16)

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63 Commissioning Specialist Adult Learning Disability Health Services: Good Practice Guidance, para 28, Department of Health, 2007, Gateway 8530
value for money, using denominators of people with learning disabilities from the GP Quality and Outcomes Framework (QOF) register, numbers on local authority registers and the full population. Areas to test:

- specialist learning disability services spend per patient
- community team services spend per patient
- out-of-area placements spend per patient
- joint partnership grant spend per patient
- total people with learning disabilities spend per patient
- programme budgeting comparators

**Checklist 3: Specific considerations to address in joint plan between PCT and LA**

Key areas to consider that are relevant to commissioning health and wellbeing services for people with learning disabilities include:

- needs assessment
- local context
- prioritisation of initiatives/ developments
- implications of changes for the market (health and social care)
- workforce issues including training and development on learning disabilities for staff
- access to primary care
- added value of partnership arrangements – LA, PCT, voluntary sector etc.
- review and reprioritisation of existing services
- shorter-term initiatives planned

In setting out the above, commissioners should ensure that they are:

- ensuring that standards in all national service frameworks apply equally to people with learning disabilities
- demonstrating how commissioners are systematically addressing any areas of concern relating to the learning points from Healthcare Commission investigations and national audits
• addressing the needs of carers from different age groups and ethnic backgrounds
• addressing the particular needs of older people with learning disabilities
• addressing the needs of people with autistic spectrum disorder
• addressing the needs of people with learning disabilities from ethnic minority groups
• addressing the needs of parents with learning disabilities
• addressing the needs of young people with learning disabilities who are approaching adulthood
• ensuring that all people with learning disabilities and their families are supported and empowered to contribute fully to the development and planning process

Checklist 4: Longer term goals and challenges to factor into supplier negotiations

Key areas to consider that are relevant to commissioning health services for people with learning disabilities include:

• how to secure effective and responsive primary care for all
• how community teams can maximise health and wellbeing
• how to offer timely and optimal care support to people whose behaviour challenges the services
• what the expectations for reasonable adjustments are and how these will be tested and monitored
• how to manage transition to adulthood
• how high-quality continuing care and forensic services can be provided as locally as possible
• how to ensure that all providers, including acute care and mental health services, meet the needs of people with learning disabilities
• where and how choice is offered and exercised
Checklist 5: Key criteria for ongoing benchmarking, tracking and evaluation

Key areas to consider that are relevant to commissioning health services for people with learning disabilities include:

- ensuring that the PCT has resourced the ongoing management of the contract
- jointly identifying the outcomes to be achieved
- involving clinicians and team members in agreeing the metrics which can be collected to assess quality and outcomes
- regularly reviewing performance against these measures
- providing feedback to service providers
- agreeing arrangements for the role of liaison staff or health facilitators
- ensuring regular surveys to ascertain how easy people with learning disabilities and their family carers found it to understand information provided about their health and treatment
- ensuring engagement of people with learning disabilities on any patient forums (for example, seeking to achieve representative numbers in Foundation Trust membership and GP practice patient participation groups)
- ensuring where appropriate that people with learning disabilities receive support from independent health advocacy services
- ensuring swift access to local mental health services
## Checklist 6: Recommended actions and suggested timeline for agreeing objectives and developments

<table>
<thead>
<tr>
<th>When</th>
<th>What</th>
<th>Product</th>
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<tbody>
<tr>
<td>Month 1 - 2</td>
<td>Negotiate objectives and development plan for the year, ensuring that there is an appropriate blend of qualitative and quantitative performance measures. Objectives will flow from the PCT’s strategy (e.g. actions to tackle high priority areas such as NHS campus closure)</td>
<td>Draft agreement covering:</td>
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<tr>
<td></td>
<td></td>
<td>• community health teams</td>
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<td></td>
<td></td>
<td>• GP practices and other primary care providers</td>
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<tr>
<td></td>
<td></td>
<td>• specialist services</td>
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<td></td>
<td></td>
<td>• acute services (addition into main contract)</td>
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<td></td>
<td></td>
<td>• mental health services</td>
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<tr>
<td>Month 3</td>
<td>Sign off agreement with every provider</td>
<td>Written plan, signed by both parties</td>
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<tr>
<td>Month 6</td>
<td>Publish key performance metrics</td>
<td>Data published on PCT website</td>
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<tr>
<td>Month 10</td>
<td>Formal mid-year review</td>
<td>Letter outlining main points of review meeting</td>
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<tr>
<td>Month 11 - 12</td>
<td>Review of performance</td>
<td>Revised framework (if appropriate) published</td>
</tr>
</tbody>
</table>
Appendix 4: Useful reference documents

Legislative framework and guides


Mental Health Act 2007, The Stationery Office.

Wider health and social care policies


*Our health, our care, our say: a new direction for community services*, Department of Health, 31 January 2006.
Reports on learning disabilities

A Life Like Any Other? Human Rights of Adults with Learning Disabilities, Joint Committee on Human Rights, 6 March 2008.


Death by indifference: Following up the Treat me right! report, Mencap, March 2007.

Equal Treatment: Closing the Gap – A formal investigation into physical health inequalities experienced by people with learning disabilities and/or mental health problems, Disability Rights Commission, September 2006.


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

Joint Investigation into the provision of services for people with learning disabilities at Cornwall Partnership NHS Trust, Healthcare Commission and Commission for Social Care Inspection, 2006.


The nature of support provided upon the admission of people with learning difficulties to hospital – Association for Real Change on behalf of the Welsh Assembly Government, 2008.

Treat me right! Better healthcare for people with a learning disability, Mencap, June 2004.

Commissioning resources: learning disabilities

A simple guide to estimating local populations of people with learning disabilities can be found in ‘Key Highlights’ of research guidance on the health of people with learning disabilities, at:
http://valuingpeople.gov.uk/dynamic/valuingpeople118.jsp

Estimates of the prevalence of learning disabilities are available at:
www.lancs.ac.uk/fass/ihr/research/learning/download/currentneed.pdf

See also a report produced for Mencap by Lancaster University, summarising nationally representative statistics on various aspects of learning disability: www.mencap.org.uk/displaypagedoc.asp?id=3160

Commissioning guidance: learning disabilities

The commissioning of services and support for people with learning disabilities and complex needs: 


Commissioning Specialist Adult Learning Disability Health Services: Good Practice Guidance, Department of Health, 31 October 2007, Gateway 8530.


Primary Care Service Framework: Management of Health for People with Learning Disabilities in Primary Care, NHS Primary Care Commissioning, July 2007.


Commissioning guidance: general


The JSNA Core Dataset, Association of Public Health Observatories and Department of Health, July 2008, Gateway 1026.

More details of the Joint Strategic Needs Assessment can be found at: www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_081097