



Improving Health and Lives
Learning Disabilities Observatory



Royal College of
General Practitioners

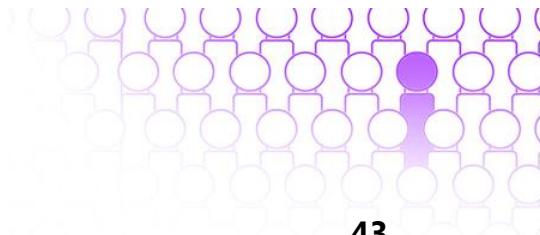


Improving the Health and Wellbeing of People with Learning Disabilities: An Evidence-Based Commissioning Guide for Clinical Commissioning Groups (CCGs)

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Contents

| | |
|--|-----------|
| Foreword | i |
| Executive summary | ii |
| Primary care..... | iii |
| Acute care..... | iv |
| Specialist learning disability services | v |
| Wider health and wellbeing and public health issues..... | v |
| Cross cutting commissioning considerations | vi |
| 1 Introduction | 1 |
| 1.1 Purpose of this document..... | 1 |
| 1.2 What do we mean when we talk about people with learning disabilities?..... | 2 |
| 1.3 How many people with learning disabilities are there?..... | 2 |
| 1.4 People with autistic spectrum conditions | 2 |
| 2. Why focus on the health and wellbeing of people with learning disabilities? | 5 |
| 2.1 Health inequalities | 5 |
| 2.2 Health needs of people with learning disabilities..... | 5 |
| 2.3 Access to health care | 6 |
| 2.4 Reducing inequalities – your statutory duties..... | 7 |
| 3. The policy context..... | 9 |
| 4. Commissioning health services for people with learning disabilities..... | 13 |
| 5. Primary care services | 19 |
| 5.1 General practice | 19 |
| 5.2 Reasonable adjustments..... | 19 |
| 5.3 Annual health checks..... | 20 |
| 5.4 Carers' needs..... | 21 |
| 5.5 Other primary care services..... | 23 |
| 6. Acute hospital services | 24 |
| 6.1 Patient transport and ambulance services..... | 26 |
| 7. Specialist adult learning disability services..... | 27 |
| 7.1 Underpinning principles | 28 |
| 7.2 Community learning disability teams..... | 29 |
| 7.2.1 Health facilitators/acute liaison nurses..... | 30 |
| 7.3 Intensive response teams..... | 31 |
| 7.4 Assessment and treatment in-patient services | 32 |
| 7.5 Forensic services and the Criminal Justice System | 34 |
| 7.6 People with learning disabilities requiring particular commissioning considerations..... | 35 |
| 7.6.1 People with learning disabilities who challenge services | 35 |
| 7.6.2 People with learning disabilities and mental health problems | 38 |
| 7.6.3 People with learning disabilities and dementia | 38 |
| 7.6.4 People with learning disabilities and epilepsy..... | 39 |
| 8. Wider health and wellbeing and public health issues | 40 |



| | |
|---|-----------|
| 9. Cross cutting commissioning considerations | 43 |
| Please note – this section is organised alphabetically. | 43 |
| 9.1 Assistive technology and telecare/telehealth..... | 43 |
| 9.2 Services for children and young people with learning disabilities | 43 |
| 9.2.1 General commissioning issues..... | 43 |
| 9.2.2 Young people with learning disabilities and mental health problems..... | 44 |
| 9.2.3 Young people with a learning disability and epilepsy | 45 |
| 9.2.4 Transition | 45 |
| 9.3 Continence..... | 47 |
| 9.4 Continuing Health Care (NHS) | 47 |
| 9.5 Dysphagia..... | 48 |
| 9.6 End of life care..... | 48 |
| 9.7 Medicines management..... | 49 |
| 9.8 Pain recognition and management..... | 49 |
| 9.9 Parents with learning disabilities..... | 50 |
| 9.10 Personal health budgets (PHBs) | 50 |
| 9.11 Postural care | 50 |
| 9.12 Wheelchair services..... | 51 |
| Appendix I | 52 |
| Appendix II..... | 57 |

Foreword

People with learning disabilities have often been invisible to mainstream health services and health professionals. Many people with learning disabilities experienced considerable life changes with the closure of learning disability hospitals. While some moved to much more inclusive community living arrangements, others moved into new forms of institutionalised care. The extent and growth of 'out of area' placements, including for treatment and rehabilitation in institutions like Winterbourne View, have exposed basic failures in commissioning processes.¹ Effective person-centred planning, regular reviews by skilled care managers and external input by NHS staff, advocates and families could all have been used more effectively to pick up on the poor outcomes, failure to deliver contracted services and risk of abuse.

Commissioning services for people with learning disabilities is a substantial test of working together in effective partnerships and, through this, securing better health and support for local people while safeguarding this most vulnerable group of our population.

This practical guide is designed to support Clinical Commissioning Groups (CCGs), with Local Authorities and Learning Disability Partnership Boards, to commission health services in ways that achieve better health outcomes for people with learning disabilities in a challenging financial climate. Whilst Local Authorities will lead commissioning for a considerable proportion of services, CCGs must take responsibility from PCTs for leading the commissioning of specialist and general health services for people with learning disabilities.

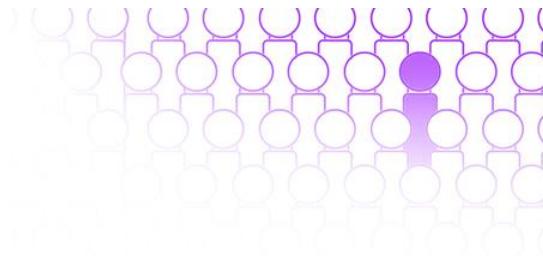
The guidance has had significant input from a number of organisations and groups including the Strategic Health Authority Learning Disability Leads group, the Professional Senate, the Faculty of Psychiatry of Intellectual Disability of the Royal College of Psychiatrists, the Valuing People Now Health Steering Group, the RCGP Intellectual Disability Professional Network and many others. It was created in collaboration with the three Pathfinder CCGs working with the Improving Health and Lives Learning Disability Public Health Observatory. We acknowledge and are grateful for input from the Joint Commissioning Panel for Mental Health, which brings together the Royal Colleges of GPs, Nursing and Psychiatrists, the Association of Directors of Adult Social Services, third sector partners, patients and carers.

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Dr Ian Hall, Chair, Faculty of Psychiatry of Intellectual Disability, Royal College of Psychiatrists

¹ Department of Health (2012). *Department of Health Review: Winterbourne View Hospital. Interim report*. Emerson, E., & Robertson, J. (2008). *Commissioning person-centered, cost-effective, local support for people with learning difficulties*. London: Social Care Institute for Excellence.



Executive summary

This good practice guidance has been written for CCGs to assist them to:

- Commission high quality, cost effective general and specialist health services for people with learning disabilities;
- Jointly commission services for people who challenge services and those with complex needs;
- Work with Local Authorities and others to address the social factors which adversely affect the health of people with learning disabilities.

CCGs need to give particular consideration to commissioning services for people with learning disabilities because they experience poorer health than the general population, differences which are to a large extent avoidable, and thus represent health inequalities.² Some health inequalities relate to the barriers people with learning disabilities face in accessing health care and health screening. These barriers are well documented in numerous reports including *Death by Indifference*,³ which detailed the deaths of six people with learning disabilities while in the care of the NHS and the Disability Rights Commission's report *Equal Treatment*.⁴ The findings of the subsequent independent inquiry chaired by Sir Jonathan Michael are set out in *Healthcare for All*,⁵ along with a number of recommendations for tackling health inequalities. One recommendation resulted in the report from the Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD),⁶ which also contains a number of recommendations. CCGs will find it helpful to familiarise themselves with these reports and others detailed in the policy context section of this document as they have a key role in tackling health inequalities, including those found in general practice.

Events at Winterbourne View also highlighted the importance of good quality commissioning for people who challenge services, and those with complex needs.⁷ CCGs have responsibility for commissioning services for people with learning disabilities detained under the Mental Health Act, and those deemed to be a health responsibility under NHS Continuing Health Care (CHC) criteria. They need to work jointly with Local Authority colleagues, providers and others to ensure that good local services are available to support people who challenge services and those with complex needs to prevent the need for expensive and potentially risky out of area placements. Good

² Emerson, et al. (2012). Health Inequalities and People with Learning Disabilities in the UK: 2012. Improving Health & Lives: Learning Disability Observatory. 1

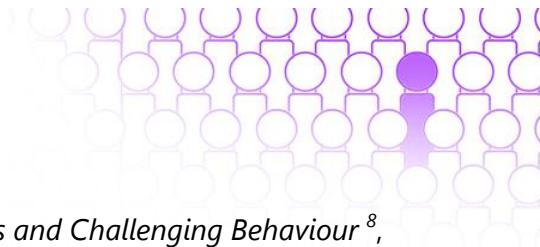
³ Mencap (2007). *Death by Indifference. Following up the Treat me right report*.

⁴ Disability Rights Commission (2006). *Equal Treatment: Closing the Gap*. London: Disability Rights Commission.

⁵ Sir Jonathan Michael (2008). *Healthcare for all: Independent Inquiry into Access to Healthcare for People with Learning Disabilities*.

⁶ Heslop et al (2013). *Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD)*. Final report. <http://www.bris.ac.uk/cipold/>

⁷ Department of Health (2012). *Transforming care: A national response to Winterbourne View Hospital. Department of Health Review: Final Report*.



practice guidance such as *Services for People with Learning Disabilities and Challenging Behaviour*⁸, first published in 1993, has been available for many years, and had this been implemented it is arguable that Winterbourne View would not have happened.

The guidance is separated into five broad areas and recommends some specific commissioning actions for CCGs, primarily related to the Joint Health and Social Care Self-Assessment Framework (JHSCSAF) indicators (see section 6) that will help achieve improved outcomes.⁹ The JHSCSAF indicators are organised into three sections: Staying Healthy, Being Safe and Living Well, but for the purposes of this document, have been organised into indicators relating to primary care, acute care, specialist learning disability services, wider health and wellbeing and those that relate to all services. The wording has been changed slightly to give an overall indication of what is required, rather than the more detailed descriptions in the document.

Self-Assessment (SAF) indicators relating to all services

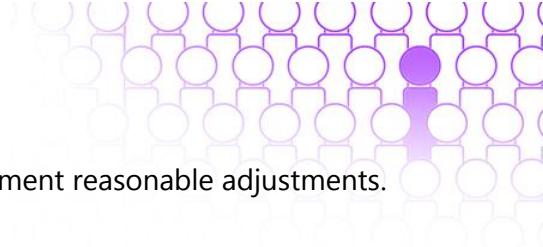
- There is assurance of safeguarding for people with a learning disability in all provided services and support.
- Appropriate learning Disability awareness training is in place.
- Commissioners can show that providers are required to demonstrate that recruitment and management of staff is based on compassion, dignity and respect and comes from a value based culture.
- Commissioners can demonstrate that all providers change practice as a result of feedback from complaints and whistleblowing.
- All appropriate providers have well understood policies in place and routinely monitor implementation of these in relation to, the Mental Capacity Act (including restraint, consent and deprivation of liberty). The provider can evidence action taken to improve and embed practice where necessary.
- People with learning disabilities and their families are involved in service planning and decision making.

Primary care

CCGs do not commission primary care services, but support quality improvement in primary care, which plays a key role in co-ordinating care for people with learning disabilities. Annual health checks for people with learning disabilities detect unmet health need and are one important 'reasonable adjustment' that general practices can make to tackle health inequalities. Public services are required by law to put reasonable adjustments in place, and CCGs need to assure

⁸ Mansell, J. (2007). *Services for People with Learning Disabilities and Challenging Behaviour or Mental Health Needs. Report of a project group (revised edition)*.

⁹ The Self-Assessment Framework (SAF) originated as a Health Self-Assessment, and was used by most health communities on an annual basis. It has now become a joint Health and Social Care Assessment For further information see: www.improvinghealthandlives.org.uk/projects/hsclsaf



themselves that primary care services have robust strategies to implement reasonable adjustments. Effective primary care services will ensure the following are in place:

SAF indicators relating to primary care

- Learning disability and Down Syndrome QOF registers reflect local prevalence data.
- People with learning disability are accessing disease prevention, health screening and health promotion in each of the following health areas: Obesity, Diabetes, Cardio vascular disease and Epilepsy. Comparative data is available.
- Health check registers are validated on an annual basis, and 80% of people on the register have had an annual health check.
- Comparative data of people with learning disability vs. similar age cohort of the non-learning disabled population is collected for :
 - a) Cervical screening
 - b) Breast screening
 - c) Bowel Screening
- Referral letters to secondary care include information about the person's learning disability any reasonable adjustments required, and a clear indication that capacity and consent issues have been appropriately considered.
- NHS commissioned universal primary and community care services such as Dentistry, Optometry, Community Pharmacy, Podiatry and Community nursing and midwifery put reasonable adjustments in place for people with learning disabilities, and their usage by people with learning disabilities is monitored, along with people's experience of these services.

Acute care

There are still problems with the identification of people with learning disabilities in acute care services. Unless people can be identified, it is not possible to put in place the reasonable adjustments they need. Effective commissioning of acute care services includes ensuring that:

SAF indicators relating to acute care

- A designated learning disability liaison function or equivalent is in place, aligned to data about the prevalence of people with learning disability using the service.
- Commissioners review Monitor Compliance Framework returns and Equality Delivery System compliance including evidence used to agree ratings, and work with non-Foundation Trusts to gather similar evidence.
- Secondary care and other healthcare providers can evidence that they have a system for identifying learning disability status on referrals based upon the learning disability identification in primary care and act on any reasonable adjustments suggested.

Specialist learning disability services¹⁰

CCGs often commission specialist learning disability services in partnership with Local Authorities. Specialist learning disability teams are an important resource for CCGs as well as people with learning disabilities, families and providers, and can support the implementation of reasonable adjustments in general health care. CCGs need to work in partnership with local authorities and others both in terms of joint commissioning of services for people with complex needs and those who challenge services. Effective commissioning of specialist learning disability services includes ensuring that:

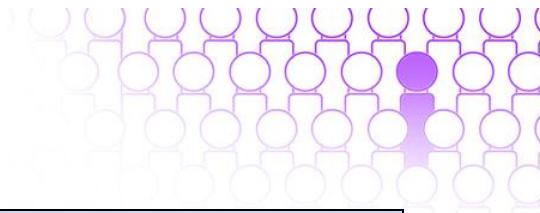
SAF indicators relating to specialist learning disability services

- There is evidence that health and social care commissioned services for people with learning disability have full scheduled annual contract and service reviews, demonstrate a diverse range of indicators and outcomes supporting quality assurance, and there is evidence that the number regularly reviewed is reported at executive board level in both health & social care.
- Commissioners review Monitor Compliance Framework returns and Equality Delivery System compliance including evidence used to agree ratings, and work with non-Foundation Trusts to gather similar evidence.
- There is evidence that services are involving people with learning disability and families in recruitment/ training and monitoring of staff including advocates.
- Commissioners know of all funded individual health and social care packages for people with learning disability, and have mechanisms in place for ongoing monitoring and review.
- Local Authority Strategies in relation to the provision of support, care and housing are the subject of Equality Impact Assessments and are clear about how they will address the needs and support requirements of people with learning disabilities.
- There are well functioning formal partnership agreements and arrangements between health and social care organisations, and clear evidence of pooled budgets or pooled budget arrangements, joint commissioning structures, intentions, monitoring and reporting arrangements.

Wider health and wellbeing and public health issues

People with learning disabilities should be able to access health promotion and screening services in the same way as the general population. The NHS Commissioning Board commissions screening services, and Local Authorities commission health promotion. CCGs need to work with Local Authorities and others to address the social determinants of poorer health.

¹⁰ Refers to services specifically for people with learning disabilities as opposed to 'specialised' services commissioned by the NHS Commissioning Board.



SAF indicators relating to wider health and wellbeing

- Local Commissioners have good data about the numbers of people with a learning disability in the criminal justice system along with information about their health needs.
- People with learning disabilities have access to reasonably adjusted local amenities and transport facilities and services that enable them to participate fully and build / maintain social networks.
- People with learning disabilities have access to reasonably adjusted arts and culture facilities and services that enable them to participate fully.
- People with learning disabilities have access to reasonably adjusted sports and leisure facilities and services that enable them to participate fully.
- People with learning disabilities are supported into employment.
- Young people with learning disabilities have a single education, health and care plan (April 2014), and there are good transition pathways and support.
- Commissioning intentions support people with learning disabilities to be part of their community.
- There is a co-produced family carer strategy based on assessed need.

Cross cutting commissioning considerations

Commissioning services for people with learning disabilities is complex as many people have a wide range of needs that can be the responsibility of a number of services. This section covers the cross cutting commissioning considerations that are most important to people with learning disabilities.

There are a number of resources available to support CCGs to commission services, and web links are provided where available. Local information on Health Checks, the Self- Assessment Framework (SAF) and Partnership Board Reports (now part of the joint SAF) are all available at www.ihal.org.uk. Partnership Boards are excellent sources of information, and can provide links to wider family carer and self-advocacy groups. Specialist Learning Disability Community Teams are also an important resource, and in many areas health facilitators/primary care liaison nurses will already be in regular contact with local GPs and practice staff

1 Introduction

1.1 Purpose of this document

This document is designed to help Clinical Commissioning Groups (CCGs), working with Health and Wellbeing Boards and Learning Disability Partnership Boards, to commission health services for people with learning disabilities (including acute care, wider health and wellbeing and specialist learning disability services) in ways that are more responsive to, and provide better health outcomes for, people with learning disabilities. The guidance is focused on adults with learning disabilities, although brief information on commissioning for children with learning disabilities and young people in transition is included, as getting it right for young people and their families is a crucial first step to better overall outcomes. The guidance contains links to the latest information available on the health of people with learning disabilities in England, and is designed to enable CCGs to demonstrate how they are improving outcomes for people with learning disabilities in line with the national outcomes frameworks. It does not provide detailed analytical tools for commissioners. These can be found at:¹¹ www.pcc-cic.org.uk/

It is the responsibility of all health commissioners to consider the particular needs of people with learning disabilities in commissioning plans, rather than delegate the responsibility to specialist learning disability commissioners.

CCGs need to work closely with Local Authorities, who have lead responsibility for commissioning social care services for people with learning disabilities and family carers, and Public Health Services. Social factors such as poverty, discrimination, unemployment, housing and social isolation adversely affect the health of people with learning disabilities. It is important for health and social care commissioners to develop joined up, person centred services which meet people's needs and are cost effective.

The current financial climate has made effective commissioning even more important. The Quality, Innovation, Productivity and Prevention programme (QIPP) requires NHS organisations to improve the quality of care they deliver while making efficiency savings that can be reinvested in the service to deliver year on year quality improvements. Examples of good practice that have either saved money, or have the potential to save money, are highlighted in the guidance.

¹¹ Primary Care Commissioning (2012) *Analytical Tools to Support Commissioners*



1.2 What do we mean when we talk about people with learning disabilities?

Valuing People,¹² the 2001 White Paper on the health and social care of people with learning disabilities, included the following definition of learning disabilities:

'Learning disability includes the presence of:

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

For a more detailed discussion of definitional issues, please see:

www.ihal.org.uk/about/definition/detail

People with learning disabilities who have a range of additional needs such as challenging behaviour or profound and multiple learning disabilities are sometimes referred to as people with complex needs.¹³

1.3 How many people with learning disabilities are there?

In England in 2012, an estimated 236,000 children and young people under the age of 18 (had learning disabilities while an estimated 908,000 adults had learning disabilities).¹⁴ This means that roughly twenty people in every thousand have a learning disability. For further information on the numbers of people with learning disability expected in each local authority area please see:

www.ihal.org.uk/numbers/howmany/laestimates/

1.4 People with autistic spectrum conditions

Approximately 1% of the population have an Autistic Spectrum Condition. Approximately half of these also have a learning disability. People with Autistic Spectrum Conditions should be able to access learning disability services if they also have a learning disability, and should be able to access mental health services if they have a mental health problem. *Fulfilling and rewarding lives*, the strategy for adults with autism in England¹⁵ and associated documents are available at:

<http://www.autism.org.uk/working-with/autism-strategy.aspx>

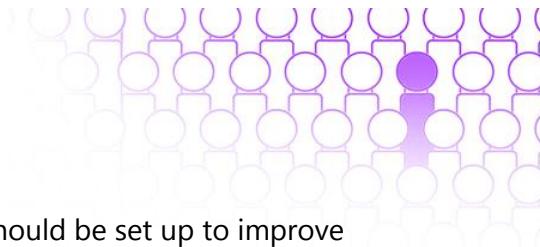
¹² Department of Health (2001). *Valuing People: A New Strategy for Learning Disability for the 21st Century*.

¹³ Commission for Social Care Inspection, Healthcare Commission and Mental Health Act Commission (2009).

Commissioning services and support for people with learning disabilities and complex needs. National report of joint review.

¹⁴ Emerson, E., et al (2013). *People with learning Disabilities in England 2012. Improving Health and Lives* Learning Disability Public Health Observatory.

¹⁵ HM Government (2010) *Fulfilling and Rewarding Lives: The strategy for adults with autism in England*.



The strategy suggests that multi-agency autism partnership boards should be set up to improve outcomes for people with autism locally, and announced the development of a protocol for gathering and sharing information about people with autism. In April 2011, the Department of Health issued a template which local authorities could use to assess their progress towards Autism Strategy goals. Information from the templates submitted has been collated by the Learning Disabilities Public Health Observatory, and is available at:

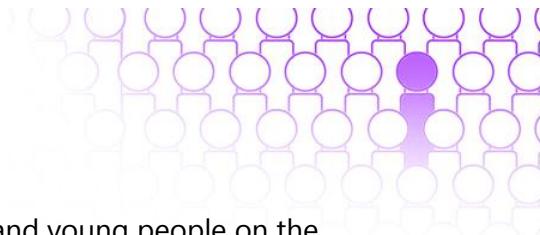
<http://www.improvinghealthandlives.org.uk/projects/autsaf2011>

National Institute for Health and Clinical Excellence (NICE) guidance on adults with autism is available at: <http://guidance.nice.org.uk/CG142/Guidance>

The guidance recommends that the local autism multi-agency strategy group should include representation from managers, commissioners and clinicians from adult services, including mental health, learning disability, primary healthcare, social care, housing, educational and employment services, the criminal justice system and the third sector. There should be meaningful representation from people with autism and their families, partners and carers. Autism strategy groups should be responsible for developing, managing and evaluating local care pathways. The group should appoint a lead professional responsible for the local autism care pathway. The aims of the strategy group should include:

- developing clear policy and protocols for the operation of the pathway;
- ensuring the provision of multi-agency training about signs and symptoms of autism, and training and support on the operation of the pathway;
- making sure the relevant professionals (health, social care, housing, educational and employment services and the third sector) are aware of the local autism pathway and how to access services;
- supporting the integrated delivery of services across all care settings;
- supporting the smooth transition to adult services for young people going through the pathway;
- auditing and reviewing the performance of the pathway.

The Joint Commissioning Panel (JCP) will be developing best practice guidance on Autism Spectrum Disorders. This work is being supported by the Department of Health.



NICE guidance on the recognition, referral and diagnosis of children and young people on the autism spectrum is available at: <http://guidance.nice.org.uk/CG128>. The guidance recommends that a local autism multi-agency strategy group should be set up, with managerial, commissioner and clinical representation from child health and mental health services, education, social care, family carers, service users, and the voluntary sector. The group should appoint a lead professional to be responsible for the local autism pathway. The aims and composition of the group are contained in the guidance.

For information on the prevalence of people with learning disabilities and autism go to:
www.ihal.org.uk/projects/autism

An autism online resource centre is available at:
<http://nursingstandard.rcnpublishing.co.uk/supplements/autism-online-resource-centre>

2. Why focus on the health and wellbeing of people with learning disabilities?

2.1 Health inequalities

People with learning disabilities die younger and have poorer health than the general population. These differences are, to some extent, avoidable. As such, they represent health *inequalities*. These inequalities are the result of the interaction of several factors including increased rates of exposure to common 'social determinants' of poorer health (e.g., poverty, social exclusion), experience of overt discrimination and barriers people with learning disabilities face in accessing health care.¹⁶ CIPOLD considered that 42% of the deaths reviewed were premature. The most common reasons for premature death were delays or problems with diagnosis or treatment, problems with identifying needs and providing appropriate care in response to changing needs.¹⁷ CCGs need to work in partnership with Local Authorities, Health and Wellbeing Boards and wider public services to improve the health of the population and tackle inequalities, and need to commission services for people with learning disabilities taking into account the health inequalities they face.^{18 19} It is not sufficient to commission services to meet the needs of the general population and assume this covers everyone.

2.2 Health needs of people with learning disabilities

A study based on information from death certificates found two causes of death which stood out because they are to an extent preventable, and were connected to large numbers of deaths across most groups of people with learning disabilities.²⁰ They were:

- Lung problems caused by solids or liquids going down the wrong way (14% of deaths where a condition associated with learning disabilities was reported)
- Epilepsy or convulsions (13% of deaths where a condition associated with learning disabilities was reported).

For further information see: www.ihal.org.uk/projects/deaths

There are a number of syndromes associated with learning disabilities which are also associated with specific health risks.

¹⁶ Emerson et al. (2012) *Health Inequalities and People with Learning Disabilities in the UK: 2012*. Improving Health and Lives Learning Disabilities Public Health Observatory.

¹⁷ Heslop et al. (2013). *Confidential Inquiry into premature health of people with learning disabilities (CIPOLD). Final report*.

¹⁸ The King's Fund (2011). *Improving the Quality of Care in General Practice. Report of an independent inquiry commissioned by the King's Fund*.

¹⁹ The Marmot Review (2010). *Fair Society, Healthy Lives: Strategic Review of Health Inequalities in England Post - 2010*. The Marmot Review: London.

²⁰ Glover G. & Ayub M. (2010). *How People with Learning Disabilities Die*. Improving Health and Lives Learning Disability Observatory.



For further information please see:

[www.improvinghealthandlives.org.uk/publications/1165/Health Inequalities & People with Learning Disabilities in the UK: 2012](http://www.improvinghealthandlives.org.uk/publications/1165/Health%20Inequalities%20&%20People%20with%20Learning%20Disabilities%20in%20the%20UK%202012)

Common health problems among people with learning disabilities include:

- Respiratory disease
- Coronary heart disease
- Physical impairment with associated risk of postural distortion, hip dislocation, chest infections, eating and swallowing problems, gastro-oesophageal reflux, constipation and incontinence
- Underweight
- Obesity
- Mental health problems (including dementia)
- Epilepsy
- Sensory impairments

For further information see: www.ihal.org.uk/projects/particularhealthproblems

For information on visual impairments see: www.seeability.org/about_us/research/default.aspx

2.3 Access to health care

The Confidential Inquiry into premature deaths of people with learning disabilities found that almost a half (48.5%) of the deaths reviewed were avoidable with good quality healthcare or public health measures, using the Office for National Statistics national indicators of avoidable mortality. The corresponding proportion in England for people without learning disabilities was 24%.

Barriers to accessing health services include problems with understanding and communicating health needs, lack of support to access services, discriminatory attitudes among health care staff and failure to make 'reasonable adjustments' to services so that they can be used easily and effectively by people with learning disabilities. Reasonable adjustments include removing physical barriers to access but importantly also include making whatever alterations are necessary to policies, procedures, staff training and service delivery to ensure that they work equally well for people with learning disabilities.²¹ Accessible information on health is available at www.easyhealth.org , www.apictureofhealth.southwest.nhs.uk and www.improvinghealthandlives.org.uk/adjustments/ . Commissioners should ensure that providers implement reasonable adjustments including the use of accessible information in all health services.

²¹ Hatton, C., Roberts, H, & Baines, S. (2010). *Reasonable adjustments for people with learning disabilities in England: A national survey of NHS Trusts*. Improving Health and Lives Learning Disabilities Observatory.



With the right support, most people with learning disabilities can access health screening services that are available to the general population. While the NHS Commissioning Board commissions screening services, CCGs commission specialist learning disability services which often provide support both to people with learning disabilities and screening/health promotion services to enable access. Reasonable adjustments regarding the three national cancer screening programmes have been collated and are available at:

www.improvinghealthandlives.org.uk/publications/1126/Making_Reasonable_Adjustments_to_Cancer_Screening²²

A number of studies have reported low uptake of health promotion or screening activities among people with learning disabilities. These include:

- Assessment for hearing or visual impairments
- Cervical smear tests
- Breast self-examination and mammography

Low uptake is sometimes due to ill-founded assumptions on the part of primary care teams who think that women with learning disabilities are less at risk than other women.²³ Bowel cancer, diabetic retinopathy and Abdominal Aortic Aneurysm screening also need to be considered.

2.4 Reducing inequalities – your statutory duties

The Health and Social Care Act 2008 (Regulated Activities) Regulations 2010 came into force on the 1st April 2010. Commissioners need to ensure that providers with whom they do business pay proper attention to the requirements set out in the regulations, and regularly assess and monitor the quality of their services. Part 4, paragraph 9 (iv) includes the requirement to make reasonable adjustments and avoid unlawful discrimination. For further information see:

www.cqc.org.uk/content/health-and-social-care-act-2008-regulated-activities-regulations-2010

Putting reasonable adjustments in place is a legal duty, and it is 'anticipatory', meaning that health service organisations are required to consider *in advance* what adjustments people with learning disabilities need. Reasonable adjustments may include accessible information and appointment systems, longer appointments and extra support. For further information see:

www.ihal.org.uk/projects/reasonableadjustments

The Health and Social Care Act 2012 contains the first ever specific legal duties on health inequalities. These include duties for CCGs. Under the Act, CCGs have a duty to have regard to the need to reduce inequalities in access to health services and the outcomes achieved for patients. They have further duties around integration of health services with social care and other health related services where they consider this would reduce inequalities. For further information, see:
www.gov.uk/government/publications/health-and-social-care-act-2012-fact-sheets

²² Turner, S., Emerson, E., Glover, G. & the Cornwall Cancer Screening Team (2012). *Making Reasonable Adjustments to Cancer Screening*. Improving Health and Lives.

²³ Emerson et al (2011). *Health Inequalities and People with Learning Disabilities 2011*. Improving Health and Lives Learning Disability Observatory.



The Public Sector Equality Duty (section 149 of the Equality Act), came into force in April 2011. The equality duty replaces the disability, race and gender equality duties. It requires public bodies to have due regard to the need to eliminate discrimination, advance equality of opportunity, and foster good relations between different people when carrying out their activities. Public bodies are required to be transparent, and publish information about how they are responding to the Equality Duty. For further information see: www.gov.uk/equality-act-2010-guidance

Good practice example

Gloucestershire PCT amended their service specification to support the implementation of the Gloucestershire Reasonable Adjustments tool by the 2gether Foundation Trust. The tool gives an indicator of how learning disability services have supported individuals to better access mainstream services, and can also be applied to show how reasonable adjustments are being implemented across services and geographically. The tool is helping staff embed a culture of reasonable adjustments throughout the health community, and has enabled the capture of better quality data compared to previous contract monitoring which focused on caseload and contact data. For further information please see: www.ihal.org.uk/adjustments/index.php?adjustment=133

The Equality Delivery System (EDS) is designed to help NHS organisations improve equality performance, embed equality into mainstream NHS business and meet their duties under the Equality Act.

For further information go to: <http://healthandcare.dh.gov.uk/equality-delivery-system/>

The Mental Capacity Act 2005 was implemented in England and Wales in 2007. The Act provides the legal framework for supporting people to make decisions, while protecting those who are unable to make decisions by ensuring they participate as much as possible in any decisions made on their behalf. Professionals have a duty to comply with The Mental Capacity Act Code of Practice (2005)²⁴ which provides guidance on its implementation. The RCGP developed a Mental Capacity Act toolkit which includes a process for Best Interest decision making.²⁵ The toolkit is available at: www.rcgp.org.uk/clinical-and-research/clinical-resources/~/media/Files/CIRC/CIRC%2076%20-%2080/CIRC%20Mental%20Capacity%20Act%20Toolkit%202011.ashx

CCGs should check that use of the Mental Capacity Act 2005 is monitored by provider organisations.

²⁴ The Stationery Office (2007). *The Mental Capacity Act (2005) Code of Practice*.

²⁵ RCGP (2011). *RCGP Mental Capacity Act (MCA) Toolkit for Adults in England and Wales 2011*.

3. The policy context

The White Paper *Valuing People* (2001)²⁶ and the subsequent document *Valuing People Now* (2009)²⁷ set the overall policy context for the commissioning of learning disability services.

Learning Disability Partnership Boards were set up to oversee the delivery of this policy, and membership should include NHS commissioners. *Valuing People Now* has been adopted by this government and 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 independent inquiry was commissioned by the then Secretary of State for Health, following Mencap's report *Death by Indifference* which detailed the cases of six people with learning disabilities who died while in the care of the NHS. The inquiry found that "people with learning disabilities receive less effective care than they are entitled to receive", and made ten recommendations to address these inequalities. Sir Jonathan Michael's Inquiry follows a number of previous reports setting out shortcomings in access to, and quality of, both specialist and mainstream health services for people with learning disabilities. These include the Healthcare Commission's investigations into service failings in Cornwall²⁸ and Sutton and Merton,²⁹ and the 2006 formal inquiry by the Disability Rights Commission.³⁰

Key recommendations for CCGs to consider:

- Better use of data to commission and monitor care, identifying and acting on health needs (through Joint Strategic Needs Assessments);
- Better leadership;
- Commissioning general health services, (*and the provision of primary care*), that make reasonable adjustments for people with learning disabilities;
- Involving family and other carers in the provision and treatment of care;
- Ensuring that people with learning disabilities and family carers are involved and consulted on regarding the planning and development of services.

²⁶ Department of Health (2001). *Valuing People: A New Strategy for the 21st Century*.

²⁷ Department of Health (2009). *Valuing people Now. A new three year strategy for people with learning disabilities – Making it happen for everyone*.

²⁸ Healthcare Commission and Commission for Social Care Inspection (2006). *Joint investigation into the provision of services for people with learning disabilities at Cornwall Partnership NHS Trust*.

²⁹ Healthcare Commission (2007). *Investigation into the service for people with learning disabilities provided by Sutton and Merton Primary Care Trust*.

³⁰ Disability Rights Commission (2006). *Equal Treatment: Closing the Gap*.



The recommendations included the establishment of a learning disabilities Public Health Observatory supplemented by a time-limited Confidential Inquiry into premature deaths in people with learning disabilities. For more information about the Learning Disabilities Public Health Observatory (LDPHO) see www.ihal.org.uk

The final report from the Confidential Inquiry³¹ found that the quality of health and social care for people with learning disabilities was deficient, and many professionals did not put reasonable adjustments in place to meet people's needs. They made eighteen recommendations including (in summary):

- Clear identification of people with learning disabilities in all healthcare record systems;
- Reasonable adjustments required by, and provided to, individuals, to be audited annually and examples of best practice to be shared across agencies and organisations;
- A named healthcare coordinator to be allocated to people with complex health needs;
- Patient-held health records to be introduced and given to all patients with learning disabilities who have multiple conditions;
- People with learning disabilities to have access to the same investigations and treatments as anyone else, with appropriate reasonable adjustments;
- Barriers in individual's access to healthcare to be addressed by proactive referral to specialist learning disability services;
- Adults with learning disabilities to be considered a high-risk group for deaths from respiratory problems;
- Mental Capacity Act advice to be easily available 24 hours a day, and training and regular updates to be mandatory for staff involved in the delivery of health and social care;
- Advanced health and care planning to be prioritised. Commissioning processes to take this into account, and to be flexible and responsive to change;
- All decisions that a person with learning disabilities is to receive palliative care only to be supported by the framework of the Mental Capacity Act and the person referred to a specialist palliative care team.

The full report can be downloaded from: www.bristol.ac.uk/cipold/

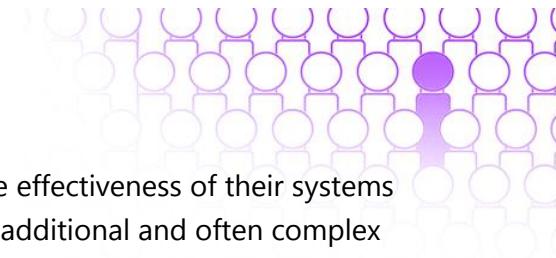
The government's response to the Confidential Inquiry can be found at:

www.gov.uk/government/publications/response-to-the-confidential-inquiry-into-learning-disability

The Parliamentary and Health Service Ombudsman and Local Government Ombudsman reported on the individual cases in *Death by Indifference* in the *Six Lives* report.³² The report recommended

³¹ Heslop et al (2013). *Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD). Final report.*

³² Parliamentary and Health Service Ombudsman and Local Government Ombudsman (2009). *Six Lives: The provision of public services to people with learning disabilities.*



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, and report to their Boards by March 2010 on actions taken. In October 2010 the government published the *Six Lives Progress Report*³³ in response to the recommendations in the *Six Lives* report. The report showed that while progress had been made, serious issues remain. Progress often relied on individual staff or local groups, and was not embedded. The report set out five key priorities for health services to focus on:

- Training for mainstream staff – particularly making reasonable adjustments and improving communication;
- Annual health checks – improving quality and the number of people getting them;
- Capacity and consent – making sure the law is followed;
- Advocacy – support to people to make choices and speak up when they are not happy;
- Complaints procedures – more accessible, quicker and with transparent outcomes.

In February 2012, Mencap published *Death by indifference: 74 deaths and counting*.³⁴ The report noted that while there had been progress, there are still major problems with use of the Mental Capacity Act, poor complaints procedures, failure to recognise pain, delays in diagnosis and treatment, poor communication and lack of basic care. The second Six Lives progress report was published in July 2013.³⁵ The report notes that there are still problems with:

- Delays in diagnosis, care and treatment
- Poor quality health checks
- Inaccessibility or a lack of communication and information
- Failure to recognise or treat pain
- Not involving people in decisions about their care

There are also three other developments that will help to improve the health and wellbeing of people with a learning disability:

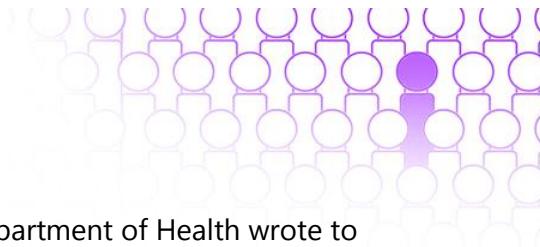
- work on identifying the determinants of good healthcare, addressed in the Health Equalities Framework for People with Learning Disabilities: See: www.ndti.org.uk/publications/other-publications/the-health-equality-framework-and-commissioning-guide1
- The development of Personal Health Budgets, including the commitment that everyone receiving Continuing Health Care will be offered a Personal Health Budget by April 2014, and will be entitled to one (subject to clinical and financial considerations) from October 2014.
- Developments on safeguarding in the Care Bill.

For further information see: www.gov.uk/government/publications/six-lives-department-of-health-second-progress-report

³³ Department of Health (2010). *Six Lives Progress Report*.

³⁴ Mencap (2012). *Death by indifference: 74 deaths and counting. A progress report 5 years on*.

³⁵ Department of Health (2013) *Six Lives. Progress Report on Healthcare for People with Learning Disabilities*



Following events at Winterbourne View Hospital in May 2011, the Department of Health wrote to PCT and Local Authority Chief Executives in order to remind commissioners of the minimum action they were expected to take to improve quality locally. Actions included continuing to support the improved uptake of health checks and completion of the annual Learning Disability Health Self-

Assessment (see below).³⁶ The final report on Winterbourne View published by the Department of Health³⁷ and associated Concordat³⁸ also contain a number of actions for commissioners including the need for health and social care commissioners to come together to focus on commissioning prevention and early intervention services, and the need to develop person centred approaches across commissioning and care. For further information on recommendations relating to Winterbourne View please see page 34.

Information on the Winterbourne View Joint Improvement Programme is available at:

www.local.gov.uk/adult-social-care/-/journal_content/56/10180/3912043/ARTICLE

The Government's Mandate to the NHS Commissioning Board³⁹ says:

"The NHS Commissioning Board's **objective** is to ensure that CCGs work with local authorities to ensure that vulnerable people, particularly those with learning disabilities and autism, receive safe, appropriate, high quality care. The presumption should always be that services are local and that people remain in their communities; we expect to see a substantial reduction in reliance on inpatient care for these groups of people." (para. 4.5)

³⁶ Department of Health (2012). Letter from David Behan and David Flory to PCT Chief Executives, LA Chief Executives, Directors and Adults and Children's Social Services. Gateway reference: 17155

³⁷ Department of Health (2012). *Transforming care: A national response to the Winterbourne View Hospital Department of Health Review: Final Report*. www.gov.uk/government/publications/winterbourne-view-hospital-department-of-health-review-and-response

³⁸ Department of Health (2012). *DH Winterbourne View Review. Concordat: Programme of Action*.

³⁹ Department of Health (2012). *The Mandate. A Mandate from the Government to the NHS Commissioning Board: April 2013 to March 2015*. www.gov.uk/government/publications/the-nhs-mandate

4. Commissioning health services for people with learning disabilities

CCGs are responsible for the commissioning of specialist and general health services for people with learning disabilities. For details of the respective responsibilities of CCGs, the NHS Commissioning Board, Local Authorities and Public Health England see:

wwwcommissioningboard.nhs.uk/files/2012/07/fs-ccg-respon.pdf. Although many specialist health services, such as community teams, are commissioned via joint commissioning arrangements with the local authority, health service commissioners remain responsible for the health funded component of the service. It is important that the Joint Strategic Needs Assessment (JSNA) includes good information about the local learning disabilities population, including the needs of children and young people with learning disabilities, as this will form the basis of collectively agreed priorities for action set out in the health and wellbeing strategy.⁴⁰ The recently issued statutory guidance on JSNAs⁴¹ says "*Health and wellbeing boards will need to consider: how needs may be harder to meet for... vulnerable groups who experience inequalities, such as children and young people with special educational needs or disabilities people with learning disabilities or autism who also have mental health conditions or behaviours viewed as challenging.*" However, a recent review of JSNAs suggests that many do not contain sufficient information on the health of adults or children with learning disabilities to be of value when planning future services.⁴² The strategy should address the needs of the whole population, and should aim to reduce the number of people using in-patient assessment and treatment services.⁴³ For further information on the commissioning cycle, see Appendix I. The *Clinical commissioning group authorisation: Draft guide for applicants*⁴⁴ required the following evidence for authorisation referring specifically to people with learning disabilities:

1.3a. Arrangements in place for CCG to involve and seek advice from healthcare professionals from learning disabilities and social care.

4.3.1a. The CCG has the capacity and capability to commission improved outcomes for the people it serves, including...people with learning disabilities.

⁴⁰ Department of Health (2011). *Joint Strategic Needs Assessment and joint health and wellbeing strategies explained.*

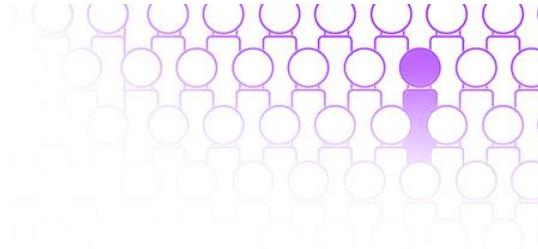
⁴¹ Department of Health (2013). *Statutory Guidance on Joint Strategic Needs Assessments and Joint Health and Wellbeing Strategies.*

⁴² Baines et al (2013). *Joint Strategic Needs Assessments: How well do they address the needs of people with learning disabilities.* Improving Health and Lives Learning Disabilities Public Health Observatory.

www.improvinghealthandlives.org.uk/publications/1174/Joint%20Strategic%20Needs%20Assessments:-How%20well%20do%20they%20address%20the%20needs%20of%20people%20with%20learning%20disabilities?

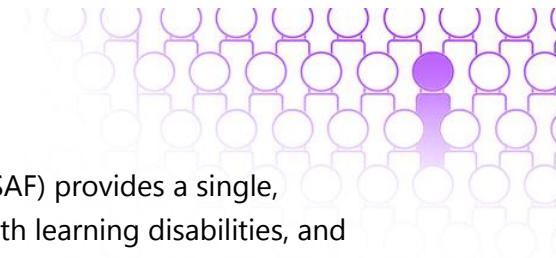
⁴³ Flynn, M., & Citarella, V. (2012). *Winterbourne View Hospital. A Serious Case Review.* South Gloucestershire Adult Safeguarding Board.

⁴⁴ NHS Commissioning Board (2012). *Clinical commissioning group authorisation. Draft guide for applicants.*



Good practice example

In the North East and Cumbria, all CCGs have a learning disability lead. The leads belong to the North East & Cumbria Learning Disability Clinical Network which sets overall objectives on the reduction of health inequalities for people with learning disabilities in the region, and supports commissioning and provider organisations to achieve these objectives, including commitments regarding Winterbourne View. The network is supported by subscriptions from CCGs and NHS Foundation Trusts.



The Joint Health and Social Care Self-Assessment Framework (JHSCSAF) provides a single, consistent way of identifying the challenges in supporting people with learning disabilities, and documenting the extent to which the shared goals of providing support are met. Locally, this should help Learning Disability Partnership Boards, Health and Wellbeing Boards, CCGs and Local Authorities identify the priorities, levers and opportunities to improve care and tackle health and social care inequalities in their areas. It should also provide a sound evidence base against which to monitor progress. Nationally, it will be used to report publicly and to Ministers on the progress in providing services in every part of the country. It originated as a health self-assessment, used by most health communities on an annual basis, enabling comparison on a year by year basis, and with other areas. For the purposes of this document, the SAF indicators have been organised into indicators relating to primary care, acute care, specialist learning disability services, wider health and wellbeing and those that relate to all services. The wording has been changed slightly to give an overall indication of what is required, rather than the more detailed descriptions in the document. Details of the SAF can be found at:

www.improvinghealthandlives.org.uk/projects/hscldsaf

and assessment results can be found at:

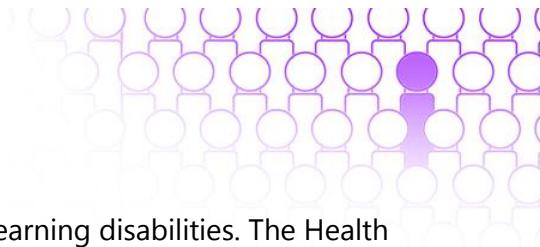
www.improvinghealthandlives.org.uk/projects/self_assessment/regions/

Strategic Health Authorities and PCTs led the SAF process with support from specialist learning disability services, Learning Disability Partnership Boards and others. PCTs were expected to have a representative on Partnership Boards, and consult with them on the provision of health services. This is a helpful model for CCGs to follow. Learning Disability Partnership Boards include people with learning disabilities and family carers and provide helpful links to wider self-advocacy and family carer groups. Most Partnership Boards have health sub-groups which include representation from learning disability health professionals, and have expert knowledge about good health services for people with learning disabilities. It is for CCGs to maintain strong links with Partnership Boards in order to draw on this expertise.

Commissioning of all services should focus on outcomes. Outcomes for the NHS and Public Health Services are set out in *The NHS Outcomes Framework 2012/13*⁴⁵ and *Improving Outcomes and Supporting Transparency*⁴⁶. A Clinical Commissioning Group Outcomes Indicator Set (CCGOIS) has been developed, based on a set of indicators that will demonstrate improvement in overall outcomes. See: www.nice.org.uk/aboutnice/cof/cof.jsp. The primary aim of the CCGOIS is to support and enable clinical commissioning groups and health and wellbeing partners to plan for health improvement by providing information for measuring and benchmarking outcomes of services commissioned by CCGs. It is also intended to provide clear, comparative information for patients and the public about the quality of health services commissioned by CCGs and the associated health outcomes. Although all the above outcomes frameworks apply to people with

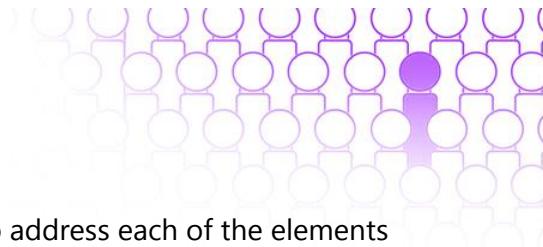
⁴⁵ Department of Health (2012). *The NHS Outcomes Framework 2012/13*

⁴⁶ Department of Health (2012). *Improving Outcomes and Supporting Transparency. Part 1: A public health outcomes framework for England, 2013-16*.

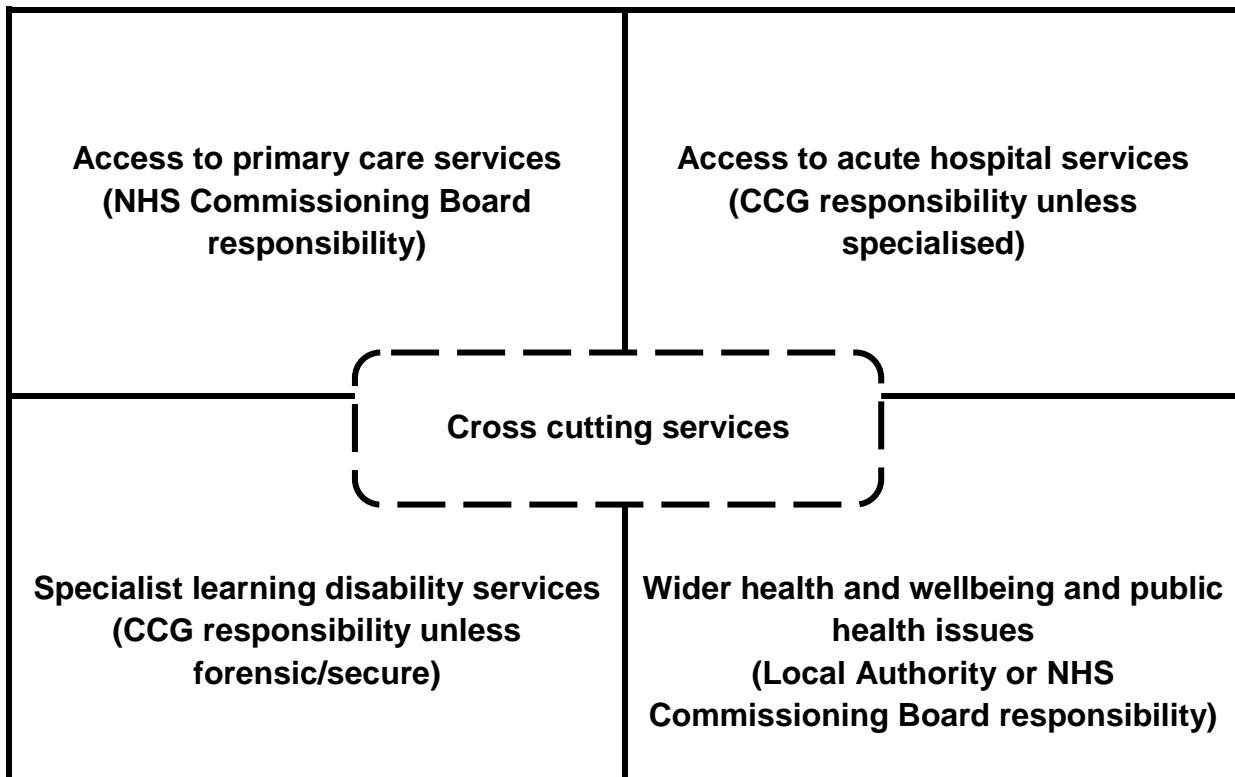


learning disabilities, they contain little that is specific to people with learning disabilities. The Health Equalities Framework, an outcomes framework based on the determinants of health inequalities has been developed for learning disability services, and is referred to in the Six Lives progress report⁴⁷ as a helpful tool for improving the health and wellbeing of people with learning disabilities. The framework and associated documents can be downloaded from: www.ndti.org.uk/publications/other-publications/the-health-equality-framework-and-commissioning-guide1. In the sections that follow, relevant outcome measures are listed after the SAF indicators.

⁴⁷ Department of Health (2013) Six Lives. Progress Report on Healthcare for People with Learning Disabilities
Department of Health (2012).



A comprehensive learning disability commissioning strategy needs to address each of the elements set out below:



Commissioning mental health services for people with learning disabilities is not covered in this document as the Joint Commissioning Panel for Mental Health has published good practice guidance on this subject.⁴⁸ The full range of mental health services should be accessible to people with learning disabilities and mental health problems, and mental health and learning disability services should work together to ensure that there is a single point of access and robust local pathways for people with overlapping needs that are delivered in the least restrictive way possible. The JSNA should include information about the needs of people with learning disabilities and mental health problems, and Health and Wellbeing Boards should facilitate joint working.

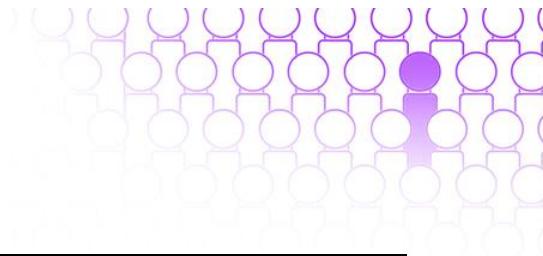
*Reasonably Adjusted?*⁴⁹ a report commissioned by the NHS Confederation on behalf of the Department of Health, contains a number of examples of reasonable adjustments that have been put in place to improve access for people with learning disabilities and people with autism.

Examples of reasonable adjustments that mental health services can make to improve access to people with learning disabilities or autism are available at:

www.improvinghealthandlives.org.uk/mhra/

⁴⁸ Joint Commissioning Panel for Mental Health (2013). *Mental health services for people with learning disabilities*: www.jcpmh.info/resource/guidance-for-commissioners-of-mental-health-services-for-people-with-learning-disabilities/

⁴⁹ National Development Team for Inclusion (2012). *Reasonably Adjusted? Mental Health Services and Support for People with Learning Disabilities and People with Autism*: www.ndti.org.uk/major-projects/reasonably-adjusted/



SAF indicators relating to all services

- There is assurance of safeguarding for people with a learning disability in all provided services and support.
- Appropriate learning Disability awareness training is in place.
- Commissioners can show that providers are required to demonstrate that recruitment and management of staff is based on compassion, dignity and respect and comes from a value based culture.
- Commissioners can demonstrate that all providers change practice as a result of feedback from complaints and whistleblowing.
- All appropriate providers have well understood policies in place and routinely monitor implementation of these in relation to, the Mental Capacity Act (including restraint, consent and deprivation of liberty). The provider can evidence action taken to improve and embed practice where necessary.
- People with learning disabilities and their families are involved in service planning and decision making.

5. Primary care services

5.1 General practice

CCGs do not commission primary care services, but GP practices play a key role in coordinating healthcare for adults with learning disabilities. The GMC website: www.gmc-uk.org/learningdisabilities/default.aspx aims to help doctors provide better care for people with learning disabilities by:

- identifying the issues
- highlighting patient perspectives
- showing how to put GMC guidance into practice.

Specialist learning disability services and primary care liaison nurses/health facilitators are an excellent resource to support GP practices in this role.

Mencap has developed a charter for CCGs to help them eliminate health inequalities in the NHS. For further information see: www.mencap.org.uk/CCGcharter

CCGs will find it helpful to have a learning disability lead to co-ordinate service improvement. A draft job description can be found at appendix II.

5.2 Reasonable adjustments

GP practices are required by law to ensure that there are reasonable adjustments in place to enable disabled people to access services. Annual health checks are one important reasonable adjustment that GP practices can make. Other reasonable adjustments include providing longer appointments and accessible letters and information. For guidance on reasonable adjustments⁵⁰ please see: www.ihal.org.uk/gsf.php5?f=10541&fv=11084

- A reasonable adjustments database is available at www.ihal.org.uk/adjustments/
- Easyhealth: www.easyhealth.org.uk has lots of health information in accessible formats.

Mencap's Getting it Right from the Start project is about better access to primary health care for people with learning disabilities. The project will share information across England so that all primary health care services plan properly for people with a learning disability. For further information see: www.mencap.org.uk/what-we-do/our-projects/getting-it-right-start

⁵⁰ Turner, S., & Robinson, C. (2011). *Reasonable Adjustments for People with Learning Disabilities. Implications and actions for commissioners and providers of healthcare*. Improving Health and Lives learning Disabilities Observatory.

5.3 Annual health checks

There is clear evidence that annual health checks detect unmet health need, including those associated with life threatening illness. A systematic review of the evidence⁵¹ is available at: www.ihal.org.uk/uploads/doc/vid_7646_IHAL2010-04HealthChecksSystemicReview.pdf Given the specific difficulties faced by people with learning disabilities, targeted health checks should be considered to constitute an effective and important adjustment to the operation of primary health care services in the UK as required by the Equality Act 2010. A Directed Enhanced Service (DES) is currently in place to support the provision of health checks. The DES only includes those known to social services, but some areas have offered health checks to everyone on the QOF register.

There is currently a wide variation in the number and quality of health checks delivered. CIPOLD found that many were so poorly documented, that it was difficult to determine whether a full health assessment had been conducted. CIPOLD have recommended that annual health checks are standardised, and that there is a clear pathway between annual health checks and Health Action Plans.⁵² For information on the number of health checks locally please see:

www.ihal.org.uk/numbers/checks/maps2012/

For guidance on health checks please see: www.ihal.org.uk/gsf.php5?f=8482&fv=8915

A health check audit tool is available at:

[www.ihal.org.uk/publications/975/Health Checks for People with Learning Disabilities: An Audit Tool - Indicators of Success](http://www.ihal.org.uk/publications/975/Health_Checks_for_People_with_Learning_Disabilities:_An_Audit_Tool_-_Indicators_of_Success)

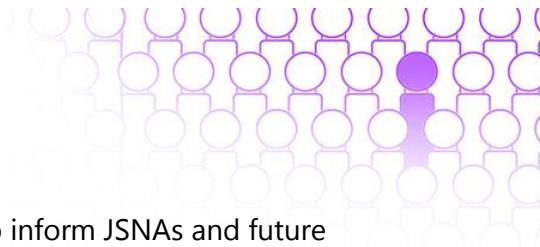
Detecting and treating unmet health needs has the potential to save money, as untreated health needs can result in challenging behaviour and can lead to costly physical complications. *Hospital Admissions That Should Not Happen*⁵³ found that people with learning disabilities are 25% more likely to be admitted as an emergency, and 70% more likely to be admitted as an emergency for an Ambulatory Care Sensitive Condition (ACSC). ACSC's are defined as conditions which, given effective management at primary care level, should not normally result in admission to hospital. The most frequent cause for admission for people with learning disabilities was convulsions and epilepsy. Other ACSCs which led to a higher number of people with learning disabilities being admitted were constipation, complications of diabetes and influenza/pneumonia. The King's Fund suggests that management of ACSCs should be one of the ten top priorities for commissioners in the reformed NHS.⁵⁴

⁵¹ Robertson, J. Roberts, H. & Emerson, E (2010). Health Checks for People with Learning Disabilities: A Systematic Review of the Evidence. Improving Health and Lives Learning Disabilities Observatory

⁵² Heslop et al (2013). *Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD). Final report*.

⁵³ Glover, G & Evison, F. (2013) *Hospital Admissions That Should Not Happen. Admissions for Ambulatory Care Sensitive Conditions for People with Learning Disabilities in England*. Improving Health and Lives Public Health Observatory.

⁵⁴ The King's Fund (2013). *Transforming our healthcare system. 10 priorities for commissioners*.



Data from primary care information systems should be aggregated to inform JSNAs and future commissioning decisions. Currently QOF registers identify 4.33 people with learning disabilities per 1,000 population (see: www.ihal.org.uk/profiles/), whereas the estimated prevalence of people with learning disabilities in the population is 2%.⁵⁵ CCGs may find it helpful to examine GP registers locally and devise a strategy to increase the accuracy of their registers. They may also find it helpful to develop a data strategy with their local Information Management and Technology Unit. Using anonymised data on health needs identified from individual health checks will help inform the commissioning of appropriate services.

Summary Care Records are being rolled out nationally, and can be particularly useful when patients need to use out of hours services and Accident and Emergency Departments. Additional information can be added to the Record following discussion between the patient and GP, and can include information regarding a person's learning disability, other conditions they may have and any reasonable adjustments that need to be in place to enable appropriate healthcare to be given. Commissioners can also specify what additional information they would like added to the Record, so that there is a consistent approach across a locality. For further information on the Summary Care Record please see: <http://systems.hscic.gov.uk/scr>

Easy read information on the Summary Care Record is available at:

www.connectingforhealth.nhs.uk/systemsandservices/scr/staff/aboutscr/comms/pip/screread.pdf

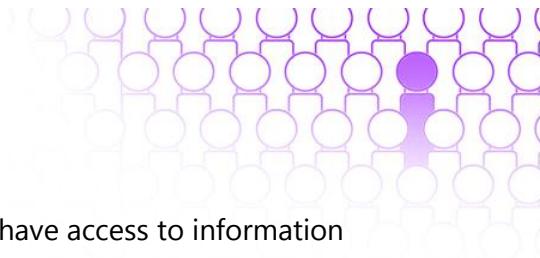
Good practice example

The North East SHA have developed an electronic Annual Health Check template, based on the Cardiff Health Check, which identifies health issues, facilitates reasonable adjustments and helps to develop a Health Action Plan. The template has been developed in SystmOne and EMIS LV, with ongoing development in Vision, EMIS PCS and EMIS Web. For further information please contact dbaker1@nhs.net

5.4 Carers' needs

Most people with learning disabilities are supported by their families, and therefore the needs of the whole family should be taken into account when commissioning services. Family carers need support to carry out their caring role, many family carers are ageing, and are more likely to suffer from ill health than the general population. The likelihood increases with the intensity of the caring role. Some health needs are directly related to the caring role. Enhancing quality of life for carers is an improvement area under domain two of the NHS Outcomes Framework. The NHS Mandate states that 'the NHS Commissioning Board's objective is to ensure the NHS becomes dramatically better at involving patients and their carers, and empowering them to manage and make decisions about their own care and treatment. Achieving this objective would mean that by 2015 the five

⁵⁵ Emerson, E. & Hatton, C (2008). *People with Learning Disabilities in England*. Centre for Disability Research.



million carers looking after friends and family members will routinely have access to information and advice about the support available – including respite care.⁵⁶ The carers strategy⁵⁷ includes a number of suggestions to support family carers and minimise the impact of caring on their health, including health checks for carers, appropriate support and information, and breaks from care. The strategy can be downloaded at: www.gov.uk/government/publications/recognised-valued-and-supported-next-steps-for-the-carers-strategy. Helpful guidance for CCGs on commissioning for carers can be found at www.carers.org/news/new-resource-clinical-commissioning-groups-launched

Further information is available in an independent evaluation of 25 Carers Strategy Demonstrator Sites: *New Approaches to Supporting Carers' Health and Well-being: Evidence from the National Carers Strategy Demonstrator Sites programme*: www.sociology.leeds.ac.uk/circle/news/new-approaches.php

The RCGP and the Princess Royal Trust have published a helpful guide for general practitioners and their teams about supporting carers. See: www.rcgp.org.uk/clinical-and-research/clinical-resources/carers-support.aspx

Some people with learning disabilities living at home with older family carers who start to need support themselves develop mutual caring relationships, meaning that both the older person and the person with learning disabilities are looking after each other. See: www.learningdisabilities.org.uk/content/assets/pdf/publications/need_2_know_mutual_caring.pdf?view=Standard. Some people with learning disabilities are also living with and supporting other people with learning disabilities. CCGs need to be aware of these issues, particularly when hospital admissions or other life changes are being planned.

⁵⁶ Department of Health (1012). *The Mandate. A Mandate from the Government to the NHS Commissioning Board: April 2013 to March 2015*

⁵⁷ HM Government (2010). *Recognised Valued and Supported. Next Steps for the Carers Strategy*.

5.5 Other primary care services

CCGs should ensure that the needs of people with learning disabilities are reflected in contracting for Improving Access to Psychological Therapies (IAPT) and community podiatry services.

Commissioning of other primary care services such as GP out of hours services, primary dental services, community pharmacy, primary ophthalmic services and audiology are the responsibility of the NHS Commissioning Board, although specialist learning disability services often play a role in enabling people to access these services.

An eye care pathway for adults and young people with learning disabilities is available at:

www.lochs.co.uk/enhanced-services-pathways/community-eye-care-pathway-for-adults-and-young-pe

SAF indicators relating to primary care

- Learning disability and Down Syndrome QOF registers reflect local prevalence data.
- People with learning disability are accessing disease prevention, health screening and health promotion in each of the following health areas: Obesity, Diabetes, Cardio vascular disease and Epilepsy and comparative data is available.
- Health check registers are validated on an annual basis, and 80% of people on the register have had an annual health check.
- Comparative data of people with learning disability vs. similar age cohort of the non-learning disabled population is collected for:
 - a) Cervical screening
 - b) Breast screening
 - c) Bowel Screening
- Referral letters to secondary care include information about the person's learning disability and any reasonable adjustments required.
- NHS commissioned universal primary and community care services such as Dentistry, Optometry, Community Pharmacy, Podiatry and Community nursing and midwifery put reasonable adjustments in place for people with learning disabilities, and their usage by people with learning disabilities is monitored, along with people's experience of these services.

Expected outcomes (NHS Outcomes Framework improvement areas)

Reducing health inequalities by:

- Improving access to primary care services;
- Enhancing the quality of life for carers.

6. Acute hospital services

Reports such as *Death by indifference*, *Death by indifference: 74 deaths and counting* and the *Confidential Inquiry* demonstrate that much still needs to be done in acute services to address inequalities. CCGs should ensure that healthcare providers are discharging their responsibility to put in place systems to regularly assess and monitor the quality of the service they provide specifically (amongst other things) with respect to avoiding unlawful discrimination through making reasonable adjustments where applicable. Monitor's Compliance Framework⁵⁸ includes six criteria for meeting the needs of people with a learning disability, based on recommendations set out in *Healthcare for All*:

- A mechanism in place to identify and flag patients with learning disabilities, and protocols that ensure pathways of care are reasonably adjusted to meet their needs;
- Readily available and comprehensive information to patients with learning disabilities about treatment options, complaints procedures and appointments;
- Protocols in place to provide suitable support for family carers;
- Protocols in place to routinely include training on providing healthcare to patients with learning disabilities for all staff;
- Protocols in place to encourage representation of people with learning disabilities and their family carers;
- Protocols in place to regularly audit practices for patients with learning disabilities and to demonstrate the findings in routine public reports.

In addition, *Death by indifference: 74 deaths and counting* highlighted a number of issues that required attention:

- Lack of basic care;
- Poor communication;
- Delays in diagnosis and treatment;
- Failure to recognise pain;
- Inappropriate use of Do Not Resuscitate orders (DNAR) and failure to fully implement the Mental Capacity Act 2005;
- Poor handling of complaints.

The *Confidential Inquiry* found that people with learning disabilities experienced difficulties or delay in diagnosis, further investigation and referral, as well as problems with treatment.

Reasonable adjustments were not routinely put in place, and lack of them was a contributory factor in a number of deaths. In order to address these issues CCGs will want assurance that the following are in place:

- A named Board level Executive Lead with responsibility for learning disabilities;
- An acute liaison nurse function. See: www.ihal.org.uk/gsf.php5?f=14265
- for an acute liaison nurse business case including evidence of effectiveness, a draft job description and indicative costs;

⁵⁸ Monitor (2012). *Compliance Framework 2012/13*

- Sign up to Mencap's "Getting it right charter" which sets out the key principles of care for people with learning disabilities. See: www.mencap.org.uk
- A 'care pathway' for people with learning disabilities which includes pre-admission and discharge planning, a risk assessment and use of a 'Patient Passport';
- Use of a recognised pain identification tool. See: www.disdat.co.uk/
- Care co-ordinator arrangements, so that the individual and their family have an identified person they can talk to;
- A learning disability resource pack and communication aids available on each ward;
- Learning disability awareness training and Mental Capacity Act training in place for all appropriate staff;
- Checks to ensure staff understand the Mental Capacity Act, and resuscitation policies, including the appropriate use of DNAR orders;
- An exemption clause in Trust DNA policies for people with learning disabilities as they are vulnerable patients, and there may be good reasons why they do not attend appointments;⁵⁹
- Emergency healthcare plans and personal resuscitation plans for adults and children with profound and multiple learning disabilities;
- Access to Paediatric Neuro-disability specialist care for children with profound and multiple learning disabilities;
- Changing places toilets;
- The use of Summary Care Records (SCR) to ensure that records are available to out of hours services and acute hospital trusts.

Good practice example

The East of England QIPP project⁶⁰ provides acute hospital Trusts, Commissioners and Learning Disability Partnership Boards with a number of frameworks and tools to improve acute hospital patient pathways for adults with a learning disability and adults with autism. Used over a period of time, these will enable Trusts and their partners to:

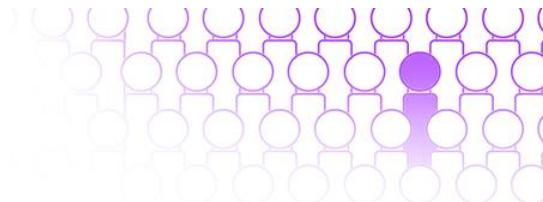
- Improve health outcomes;
- Achieve cost savings and efficiencies;
- Deliver greater consistency of service delivery within Trusts and across the east of England;
- Reduce patient and corporate risks.

Lack of good data has been a consistent theme and is one of the key recommendations for improved quality and cost savings. This has limited the evidence that can be used to quantify possible savings. However a conservative estimated saving of £196,500 per year for an acute hospital serving a 350,000 population has been calculated. For further information see:

www.eoe.nhs.uk/page.php?page_id=2159

⁵⁹ Pillning, R. (2011). *The management of visual problems in adult patients who have learning disabilities*. The Royal College of Ophthalmologists.

⁶⁰ NHS East of England (2011). *East of England Learning Disability QIPP. Improving Acute Hospital Pathways for Adults with a Learning Disability and Adults with Autism*.



Good practice example

NHS South West worked with commissioners to co-ordinate a peer review of acute hospitals' ability to meet the needs of people with learning disability throughout the region in the autumn of 2010. The process included:

- a baseline of existing performance;
- identification of innovative practice;
- recommendations and action plans for each acute hospital;
- a South West regional report and action plan.

The review has already improved performance and showed a clear association between better performing hospitals and the presence of an acute liaison nurse. Details about the process along with innovative practice identified can be found at:

www.swacutehospitalreview4ld.org.uk/ The review can be adapted and used in local areas.

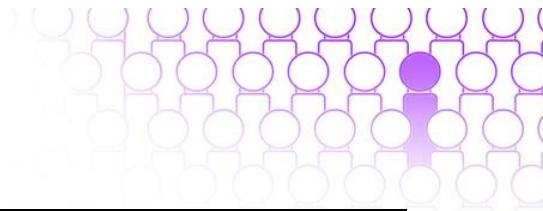
6.1 Patient transport and ambulance services

Patient transport services are responsible for ensuring that patients with learning disabilities are afforded the same quality of healthcare as other patients, and therefore need to make reasonable adjustments to their services, as set out in the Health and Social Care Act 2008 (Regulated Activities) Regulations 2010, and the Equality Act 2010. CCGs may want to check that patient transport services have the following in place:

- The provision of an escort for patients with learning disabilities who are carried on the Patient Transport Service (PTS);
- PTSs provided from the patient's home direct to the Department (rather than the hospital);
- Risk assessments of complex patient transport needs to ensure that all difficulties are overcome;
- Training for Contact Centre staff on how to deal with difficult callers, and callers who have difficulties in communicating.

The North West Ambulance Service created a Pictorial Communication Handbook which aims to overcome communication barriers with patients with learning disabilities and patients with language barriers or communication problems using Patient Transport Services. See:

www.nwas.nhs.uk/internet/AboutUs/Involvingourcommunity/EqualityDiversity/PictorialCommunicationHandbook/tabid/492/Default.aspx



SAF indicators relating to acute care

- A designated learning disability liaison function or equivalent is in place, aligned to data about the prevalence of people with learning disability using the service.
- Commissioners review Monitor Compliance Framework returns and Equality Delivery System compliance including evidence used to agree ratings, and work with non-Foundation Trusts to gather similar evidence.
- Secondary care and other healthcare providers can evidence that they have a system for identifying learning disability status on referrals based upon the learning disability identification in primary care and act on any reasonable adjustments suggested.

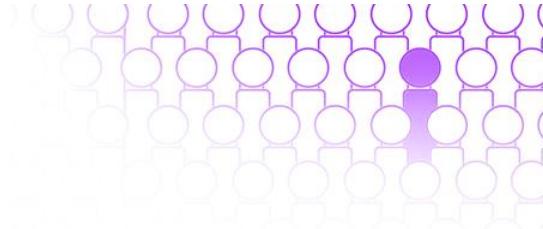
Expected outcomes (NHS Outcomes Framework improvement areas)

Reducing health inequalities by:

- Reducing premature death in people with learning disabilities;
- Reducing time spent in hospital with long-term conditions;
- Improving people's experience of outpatient care;
- Improving hospitals' responsiveness to personal needs;
- Improving people's experience of accident and emergency services;
- Improving outcomes from planned procedures;
- Reducing the incidence of avoidable harm.

7. Specialist adult learning disability services

Because specialist learning disability services are quite complex, this section includes brief descriptions of the services available.



7.1 Underpinning principles

The White Paper *Valuing People* (2001)⁶¹ and the subsequent document *Valuing People Now* (2009)⁶² identified the four guiding principles that should underpin all services for people with learning disabilities:

- Rights
- Independence (having as much choice and control as possible over the support you need)
- Control (being involved in and in control of decisions made about your life)
- Inclusion (being able to participate in all aspects of community, and have the support to do so).

Specialist learning disability services support these principles by striving to reduce the health inequalities experienced by people with learning disabilities. They aim to minimise the impact of:

- Exposure to social determinants of poorer health such as poverty, lack of personalised, meaningful activity, poor housing, unemployment and social isolation;
- Health problems – including those associated with specific genetic and biological conditions associated with learning disabilities;
- Personal health risks and behaviours such as self-harm, poor diet and lack of exercise;
- Communication difficulties and reduced understanding of health issues (health literacy);
- Deficiencies related to access to healthcare provision.

A core service specification for learning disability services (children and adults) is being developed by the National Commissioning Board and ADASS working with the Department of Health. The specification will be published in the Autumn of 2013.⁶³ The Department will also work with the NHS Commissioning Board to agree how to embed Quality of Health Principles⁶⁴ in the system using NHS contracting and guidance. Information about the principles can be found at:

www.changingourlives.org/

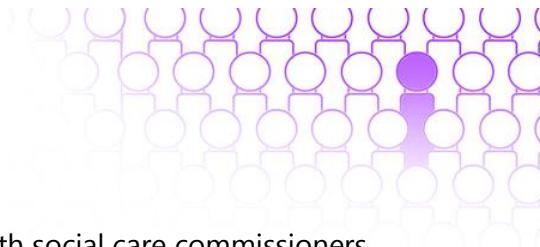
⁶¹ Department of Health (2001). *Valuing People: A New Strategy for the 21st Century*.

⁶² Department of Health (2009). *Valuing people Now. A new three year strategy for people with learning disabilities – Making it happen for everyone*.

⁶³ Department of Health (2012). *Transforming care: A national response to Winterbourne View Hospital. Department of Health Review: Final Report*

⁶⁴ Changing our Lives(2012). *Quality of Health Principles*.

7.2 Community learning disability teams



Community teams are often (but not always) jointly commissioned with social care commissioners.

However health commissioners retain overall responsibility for health services even if commissioning has been delegated to social care.

There are a variety of models of community teams. Teams can include, or have access to, a range of professionals such as community nurses, psychologists, psychiatrists, occupational therapists, physiotherapists, speech and language therapists, arts therapists and dieticians. A number of areas have employed consultant nurses, who play an important leadership role within services.

Community teams have two main roles:

1. Enabling access to other services including:

- Health facilitation and support to primary care on the implementation of health checks and health action plans (see below re health facilitator role);
- Support to secondary care to ensure reasonable adjustments are in place to allow people with learning disabilities to access services (see below re acute nurse liaison role);
- Teaching, advice, and support to both mainstream and specialist services including access to those responsible for wider health and wellbeing issues such as housing and employment;
- Service development;
- Health promotion.

2. Specialist provision including:

- Direct support to people and their families when their needs cannot be met by mainstream services alone, including liaison with mainstream and other specialist services including children's services/transition;
- Assessment and formulation of needs to inform support needs;
- Planned, evidenced based interventions including a variety of treatments and therapy;
- Support to service providers and others in the provision of longer term support for people with complex and continuing health needs;
- Emergency support, sometimes in partnership with mental health colleagues.

See Section 7.6 for information related to specific conditions.

CCGs should ensure there is an appropriate balance between the two roles, reflecting the needs of the local population.

Good practice guidance on commissioning specialist adult learning disability services is available at:
www.debramooressociates.com/Resources/DH%20Commissioning%20Specialist%20LD%20Adult%20health%20services.pdf



Information on the role of learning disability nurses can be found at:

<http://cno.dh.gov.uk/2012/04/25/strengthening-the-commitment-the-report-of-the-uk-modernising-learning-disabilities-nursing-review/>

Good practice guidance on the role of psychiatrists working with people with learning disabilities is available at: www.rcpsych.ac.uk/pdf/FutureroleofpsychiatristsinLD%20services.pdf

Good practice on the role of psychologists is available at: http://dcp-ld.bps.org.uk/dcp-ld/publications/publications_home.cfm

Good practice guidance on the commissioning of Speech and Language Therapy Services is available at:

www.rcslt.org/speech_and_language_therapy/commissioning/resource_manual_for_commissioning_and_planning_services

Recommendations on the role of occupational therapists are available at:

www.cot.co.uk/cotss-people-learning-disabilities/resources

Information about the role of physiotherapists in learning disability services can be found at:

<http://acppld.csp.org.uk/learning-disabilities-physiotherapy>

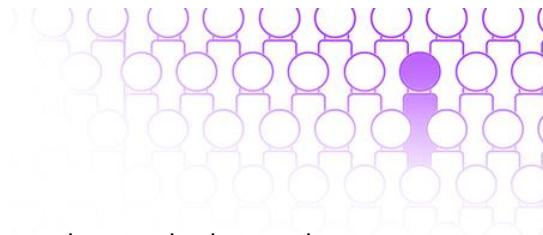
7.2.1 Health facilitators/acute liaison nurses

Primary care liaison nurses/health facilitators may be attached to the team or separately employed. They have had a significant impact on enabling people with learning disabilities to access primary care, and work with GPs and primary care staff to support the implementation of reasonable adjustments, including health checks. One of the *Confidential Inquiry*⁶⁵ recommendations states that 'Barriers in individual's access to healthcare to be addressed by proactive referral to specialist learning disability services'.

Acute liaison nurses work to improve mainstream hospital care for people with learning disabilities. They are generally more effective when they are employed or 'owned' by the hospital Trust. The acute liaison nurse business case: www.ihal.org.uk/gsf.php5?f=14265 brings together evidence of effectiveness, suggested qualitative and quantitative performance measures for wide liaison services, cash releasing and non-cash releasing benefits, a template job description and outline costs of employment.

Both roles reduce the impact of health inequalities on people with learning disabilities and should be considered when CCGs develop commissioning plans.

⁶⁵ Heslop et al (2013). *Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD)*. Final report.



7.3 Intensive response teams

Some areas have developed specialist teams to support people with complex needs close to home. They are an important part of the model of care recommended in *Transforming care*.⁶⁶ These may be either part of the community team or be separate teams. Their functions include:

- Intensive intervention/assertive outreach to support people with complex behavioural (and sometimes physical) needs in the community
- Crisis resolution to prevent admission to hospital by providing out of hours support

They may also have a role in supporting people to return from out-of-area placements.

CCGs should consider investment in these teams to avoid reliance on inappropriate hospital placements.

⁶⁶ Department of Health (2012). *Transforming care: A national response to Winterbourne View Hospital. Department of Health Review: Final Report*.

7.4 Assessment and treatment in-patient services

Although commissioning services for people with learning disabilities should be based on preventing problems arising in the first place, a small number of people with learning disabilities may need time limited access to Assessment and Treatment services as part of their pathway of care. People with learning disabilities who have mental health problems should be enabled to access mainstream mental health services where possible, if needed with the support of the Community Learning Disability team. For those people who require extra support, then emergency support/intensive response teams should be the next option. Where active assessment and treatment is required for a time limited period, it should be as near to home as possible, be person centred and provide evidence based assessment and treatment with demonstrable positive outcomes. The aim should always be to return the person to their home setting wherever possible. Where a period of inpatient Assessment and Treatment is required, the Community Learning Disability Team should be involved in planning the admission, monitoring progress and planning and supporting the person's discharge from the in-patient service.

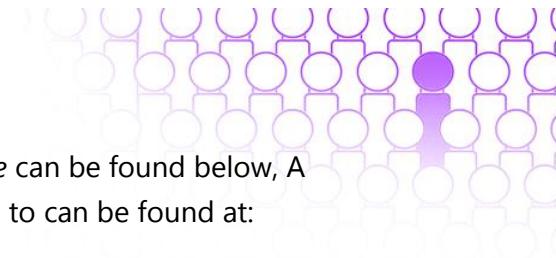
Commissioners should have good knowledge of the track record of provider services, and should be commissioning required services, according to an agreed pathway, with agreed timescales and standards. Pooled budget arrangements between health and social care are strongly recommended, and health and care commissioners should use contracts to hold providers to account for the quality and safety of the services they provide.⁶⁷

CCGs should check that people with learning disabilities in Assessment and Treatment services are reviewed on a regular basis. People with learning disabilities and their families should be given the support they need to ensure they can take an active part in these reviews, including access to independent advocacy. Discharge planning should commence on admission, and length of stay should be carefully monitored. Commissioners should be clear about the respective roles of organisations in relation to commissioning and care co-ordination arrangements, and there should be a formally agreed communication schedule, which includes the role of the care co-ordination team regarding input into the Care Programme Approach Process, and on-going communication with families, carers and advocates. All patients should have easy access to complaints procedures and independent, good quality advocacy services including Independent Mental Capacity Advocates.

Commissioning services should be based on need identified in the JSNA and on evidence of best practice as set out in the Model of Care in *Transforming Care*⁶⁸. Currently there is wide variation in the number and type of assessment and treatment services available, and too many people are in in-patient services for too long. Health and care commissioners should also plan strategically to develop local services that meet the needs of children and young people in the area where they

⁶⁷ Department of Health (2012). *Transforming care: A national response to Winterbourne View Hospital. Department of Health Review: Final Report.*

⁶⁸ Department of Health (2012). *Transforming care: A national reponse to Winterbourne View Hospital. Department of Health Review: Final Report.*



live. A summary of key actions for CCGs set out in *Transforming Care* can be found below, A Driving up Quality Code for commissioners and providers to sign up to can be found at: www.drivingupquality.org.uk/home

In-patient services should achieve the Standards for the National Accreditation Programme for Inpatient Learning Disability Units: www.rcpsych.ac.uk/pdf/LD%20standards_Pilot%20version.pdf

People placed out-of-area in medium or low secure units should be reviewed at least on a six monthly basis, and be moved to community based settings as soon as possible. The Royal College of Psychiatrists has produced a toolkit⁶⁹ to reduce the use of out of area placements for mental health service users which also has information that is applicable to people with learning disabilities. See: www.rcpsych.ac.uk/pdf/insightandinmind.pdf

Robust safeguarding procedures should be in place. *Guidance on Safeguarding adults: The role of health services*⁷⁰ is available at: www.gov.uk/government/publications/safeguarding-adults-the-role-of-health-services

Deprivation of Liberty Safeguards should also be applied systematically to all relevant patients.

The recent CQC report on learning disability services found that the use of restraint was poorly understood by staff, and monitoring of restraint was poor.⁷¹ Restraint should only be used as a last resort. CCGs should check that staff receive training on preventive and de-escalation techniques, as well as minimal restraint techniques if these are necessary. Positive Behavioural Support (PBS) is the preferred approach when working with people with learning disabilities who challenge. See: www.bild.org.uk/our-services/positive-behaviour-support/ The RCN is currently leading on updating Department of Health guidance on use of restraint, with a focus on PBS. The use of restraint should be robustly monitored.⁷²

⁶⁹ Royal College of Psychiatrists (2011). *In Sight and In Mind. A toolkit to reduce the use of out of area mental health services*.

⁷⁰ Department of Health (2011). *Safeguarding adults: The role of health services*.

⁷¹ Care Quality Commission(2012). *Learning disability services inspection programme. National Overview*.

⁷² SCIE (2009). *Managing risk, minimising restraint*. www.scie.org.uk/publications/ataglance/ataglance16.pdf

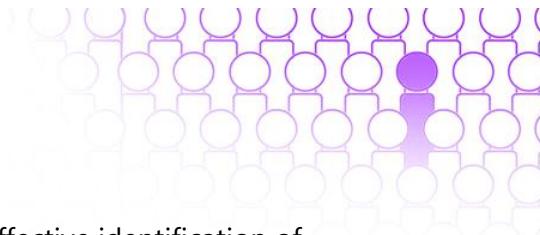
Transforming care – key actions for CCGs

- Maintain a local register of all people with challenging behaviour in NHS-funded care;
- Review individuals care with the Local Authority, and identify who should be the first point of contact for each individual;
- By 1 June 2013, health and care commissioners, working with service providers, people who use services and their families will review the care of all people in learning disability or autism inpatient beds and agree a personal care plan for each individual based around their and their families' needs and agreed outcomes
- Plans should be put into action as soon as possible, and all individuals should be receiving personalised care and support in the appropriate community settings no later than June 2014;
- By April 2014, CCGs and local authorities will set out a joint strategic plan to commission the range of local health, housing and care support services to meet the needs of people with challenging behaviour in their area.

7.5 Forensic services and the Criminal Justice System

Services that support people who offend or are at risk of offending are an important part of specialist learning disability health services. Such services may include a specialist team, or expertise may be embedded in the community team. Forensic services need good links with other services such as mental health services, social care and the Criminal Justice System (CJS), and the involvement of agencies such as housing, employment and education, to facilitate pathways away from the CJS. CCGs should check that JSNAs include information about people with learning disabilities at risk of offending/reoffending, and Health and Wellbeing Boards should facilitate integrated working to reduce the likelihood of individuals coming into contact with the CJS. *The Bradley Report*⁷³ notes the importance of partnership working, along with early identification of people with learning disabilities and people with mental health problems in the CJS. The offender health collaborative is supporting a cross government health and CJ transition programme to provide access to liaison and diversion services for every court and police custody suite. The aims of this programme are to promote better identification, assessment and care for people entering the CJS to improve health outcomes and reduce reoffending. At agency level this is supported by Equalities based approaches such as that articulated in the National Offender Management

⁷³ Department of Health (2009). *The Bradley Report: Lord Bradley's review of people with mental health problems or learning disabilities in the criminal justice system*.



Service (NOMS) commissioning intention for 2013/14⁷⁴ 'to ensure 'effective identification of offenders with learning disabilities and/or difficulties and make reasonable adjustments to ensure services are legal, decent and responsive to need'. Identifying people who may have learning disabilities enables appropriate liaison and diversion services to operate; ensuring people with learning disabilities receive appropriate support. Learning disability services should co-work with liaison and diversion services to ensure joined up support is provided. *Prisoners Voices*⁷⁵ highlights the specific issues people with learning disabilities face on the CJS pathway, and includes a number of recommendations. For further information see:

www.prisonreformtrust.org.uk/Publications/vw/1/ItemID/89

Health care in prisons (and police custody) is commissioned by the NHS Commissioning Board, but CCGs need to collaborate with the NHS Commissioning Board to ensure there is a joined up pathway between services. Prison liaison nurses are being introduced in some areas to ensure that people with learning disabilities receive good healthcare whilst in prison.

7.6 People with learning disabilities requiring particular commissioning considerations

7.6.1 People with learning disabilities who challenge services

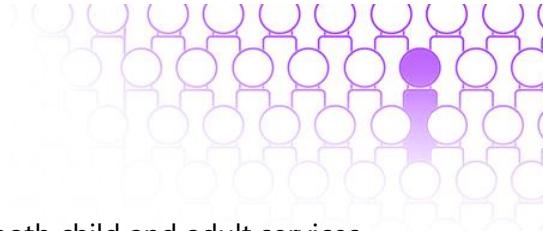
People whose behaviour presents a significant challenge to services are often described as 'people with challenging behaviour', but the original description was "intended to emphasise that problems were often caused as much by the way in which a person was supported as by their own characteristics". It is likely that 24 adults per 100,000 of the total population present a serious challenge at any one time.

Most people with learning disabilities who challenge services are not an NHS responsibility per se. CCG and social care commissioners should develop strategies regarding partnership working to prevent problems arising in the first place, manage them when they do, and put in place skilled, longer term support to enable people to live as independently as possible in the community. In addition to community teams, some areas have specialist challenging behaviour support services to work with people who have the most complex and challenging needs. For a description of what good services look like please see *Out of Sight*⁷⁶ www.mencap.org.uk/outofsight-report which

⁷⁴ Ministry of Justice; National Offender Management Service (2012). *NOMS commissioning intentions 2012-13. Discussion document*. www.justice.gov.uk/downloads/about/noms/commissioning-intentions-2013-14.pdf

⁷⁵ Talbot, J. (2008). *Prisoners' voices. Experiences of the criminal justice system by people with learning disabilities and learning difficulties*. The Prison Reform Trust.

⁷⁶ Mencap (2012). *Out of Sight. Stopping the abuse of people with a learning disability*. <http://www.mencap.org.uk/outofsight-report>



includes a description of services in Salford. A core service spec. for both child and adult services will be available shortly. Failure to develop good local support and services can lead to expensive, out-of-area placements that may not be of good quality. Professor Jim Mansell⁷⁷ recommends that commissioners:

- Give priority to improving services for people with learning disabilities whose behaviour presents challenges to services;
- Demonstrate value for money through improvements in the outcomes identified in *Valuing People* – rights, inclusion, independence and choice – as well as on the specific treatment of challenging behaviour;
- Demonstrate value for money by a low number of placement breakdowns and of out of-area placements;
- Replace low-value, high-cost services with better alternatives;
- Avoid increasing the burden on family carers by reducing levels of service.

The full document can be accessed at:

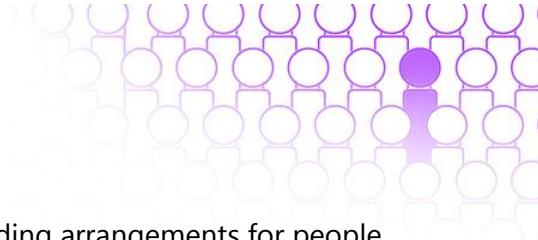
www.kent.ac.uk/tizard/research/research_projects/dh2007mansellreport.pdf

Please also see

- *Developing better commissioning for individuals with behaviour that challenges services: a scoping exercise* at www.challengingbehaviour.org.uk/learning-disability-files/Better-Commissioning-full-report.pdf
- *Well matched and skilled staff* at: <http://www.challengingbehaviour.org.uk/cbf-resources/commissioners-resources.html>
- *Commissioning person-centred, cost-effective, local support for people with learning difficulties* at: www.scie.org.uk/publications/knowledgereviews/kr20.asp

The Challenging Behaviour National Strategy Group developed a Challenging Behaviour Charter which many organisations have signed up to. See: www.challengingbehaviour.org.uk/learning-disability-files/CBF-Charter-for-Website.pdf

⁷⁷ Department of Health (2007). *Services for people with learning disabilities and challenging behaviour or mental health needs.*



'Health and care commissioners need to work together to review funding arrangements for people with behaviour which challenges and develop local action plans to deliver the best support to meet individuals' needs'.⁷⁸ It will be important for CCGs to develop good relationships with innovative and skilled providers of personalised services, not least because provision for people who challenge services needs to be planned on a medium to long term basis. For further information on working with providers see the *guide for commissioners of services for people with learning disabilities who challenge services*:⁷⁹ www.ndti.org.uk/publications/ndti-publications/commissioning-services-for-people-with-learning-disabilities-who-challenge-

Good practice example

The collection of financial data on service costs prior to intervention and/or support from the challenging behaviour support service and then costs of that individual's service over time are a crucial tool in both commissioner decision making and arguing for continued investment in services. In Birmingham the Commissioners have used existing cost analysis systems to ensure there is an ongoing breakdown of costs and potential savings. The information is shared regularly with clinicians and providers and informs commissioning decisions. See:
www.ndti.org.uk/publications/ndti-publications/commissioning-services-for-people-with-learning-disabilities-who-challenge-

Good practice example

The Housing and Support Alliance has published a report called *There is an Alternative*. See: www.housingandsupport.org.uk/site/hasa/templates/searchresults.aspx?pageid=6&search=there%20is%20an%20alternative&cc=gb

The report details the stories of ten people who previously lived in institutions because their behaviour was deemed to be challenging. They are all now living successfully in their own homes as tenants, with a better quality of life, at a lower cost than that paid for institutional care.

⁷⁸ Department of Health (2012). *Department of Health Review: Winterbourne View Hospital. Interim report*.

⁷⁹ National Development Team for Inclusion (2011). *Guide for commissioners of services for people with learning disabilities who challenge services*.

7.6.2 People with learning disabilities and mental health problems

People with learning disabilities have significantly higher rates of mental health problems than the general population. Anxiety and depression are particularly common amongst people with Down syndrome, and there is evidence to suggest that the prevalence rates for schizophrenia in people with learning disabilities may be three times greater than for the general population. Adults with learning disability who have ADHD have been shown to be more severely affected by mental health problems and less likely to improve over time than other people with ADHD.⁸⁰ CCGs should ensure that people with learning disabilities and mental health problems are enabled to access mainstream mental health services with support from specialist learning disability services as appropriate. The Association of Directors of Adult Social Services (ADASS) and the Royal College of Psychiatrists (RCPsych) issued a joint position statement in March 2013, supporting the use of Personal Budgets in social care and Personal Health Budgets (see section 9.10) in the NHS as tools for recovery. See: www.personalhealthbudgets.england.nhs.uk/News/item/?cid=8643

7.6.3 Older people with learning disabilities

Although people with learning disabilities die at a younger age than their non-disabled peers, life expectancy is increasing, particularly for people with Down's syndrome.⁸³ The estimated number of older people with learning disabilities in the population is far greater than the number of older people known to services⁸¹. Some of those not known to services may be living with older family carers, and it will be important to identify these families in order to plan well for the future. Because people with learning disabilities experience health inequalities, older people with learning disabilities are likely to be at a disadvantage when they embark on the ageing process. They may be less mobile, and at greater risk of obesity and age related diseases such as diabetes, arthritis and respiratory disease. However, with personalised support, including the use of personal budgets, older people with learning disabilities can live full and productive lives. CCGs and Local Authorities should know about the needs of older people in their area and work together to ensure there are plans to support them well. For further information see the factsheet on older people with learning disabilities: www.bild.org.uk/information/ageingwell/

7.6.4 People with learning disabilities and dementia

People with learning disabilities have a higher risk of developing dementia compared to the general population, with a significantly increased risk for people with Down syndrome, and at a much earlier age. People with Down syndrome are also more likely to develop epilepsy, which can mark a rapid deterioration in health. Good practice guidance suggests having a register of all

⁸⁰ Emerson, E., et al (2011). *Health Inequalities and People with Learning Disabilities 2011*. Improving Health and Lives learning Disabilities Observatory.

⁸¹ Emerson, E. et al (2011). *People with learning disabilities in England 2011*. Improving Health and Lives Learning Disabilities Public Health Observatory.

adults with Down syndrome, and carrying out baseline screening from the age of 30 years.⁸² CCGs should ensure that people with learning disabilities and dementia have access to the full range of assessment and interventions as others with dementia including appropriate use of dementia medications. For further information see: www.rcpsych.ac.uk/files/pdfversion/cr155.pdf A Quality Outcome Measure for Individuals with Dementia (QOMID) is available at: http://dcp-ld.bps.org.uk/dcp-ld/useful-links-and-info/useful-links-and-info_home.cfm

7.6.5 People with learning disabilities and epilepsy

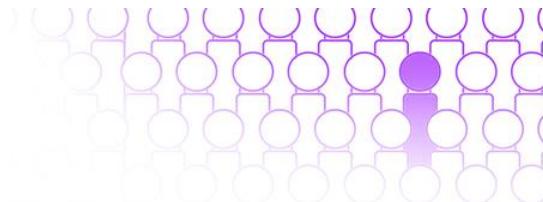
Evidence suggests that there is quite a strong relationship between difficult to control epilepsy and learning disabilities and that the proportion of people with epilepsy with learning disabilities who achieved seizure control is significantly below the proportion of the general population with epilepsy⁸³. There are also higher risks of mortality for children, young people and adults with learning disabilities and epilepsy. NICE guidance on the management of epilepsy makes clear that people with learning disabilities should be offered the same services, investigations and therapies as the general population. Good epilepsy services are likely to reduce the risk of seizures, the number of unplanned hospital admissions and thus save money. It is important for CCGs to carry out a formal review of the implementation of NICE epilepsy guidelines and develop plans to ensure these are met. See: <http://guidance.nice.org.uk/CG137>

SAF indicators relating to specialist learning disability services

- There is evidence that health and social care commissioned services for people with learning disability have full scheduled annual contract and service reviews, demonstrate a diverse range of indicators and outcomes supporting quality assurance, and there is evidence that the number regularly reviewed is reported at executive board level in both health & social care.
- Commissioners review Monitor Compliance Framework returns and Equality Delivery System compliance including evidence used to agree ratings, and work with non-Foundation Trusts to gather similar evidence.
- There is evidence that services are involving people with learning disability and families in recruitment/ training and monitoring of staff including advocates.
- Commissioners know of all funded individual health and social care packages for people with learning disability, and have mechanisms in place for on-going monitoring and review.
- Local Authority Strategies in relation to the provision of support, care and housing are the subject of Equality Impact Assessments and are clear about how they will address the needs and support requirements of people with learning disabilities.
- There are well functioning formal partnership agreements and arrangements between health and social care organisations, and clear evidence of pooled budgets or pooled budget arrangements, joint commissioning structures, intentions, monitoring and reporting arrangements.

⁸² Royal College of Psychiatry (2009). *Dementia and People with Learning Disabilities. Guidance on the assessment, diagnosis, treatment and support of people with learning disabilities who develop dementia.*

⁸³ Wasted Money Wasted Lives: the Human and economic cost of epilepsy in England, All Party Parliamentary Group on Epilepsy (2007)



Expected outcomes (NHS Outcomes Framework)

Reducing health inequalities by:

- Reducing premature death in people with learning disabilities;
- Enhancing the quality of life for people with long term conditions;
- Ensuring that people have a positive experience of care;
- Treating and caring for people in a safe environment and protecting them from harm.

(Public Health Outcomes Framework)

- Domain 1 objective - Improvements against wider factors that affect health and wellbeing, and health inequalities.
- Domain 2 objective – People are helped to live healthier lifestyles, make healthy choices and reduce health inequalities.
- Domain 4 objective – Reduced numbers of people living with preventable ill health and people dying prematurely, while reducing the gap between communities.

8. Wider health and wellbeing and public health issues

CCGs need to work with Local Authorities and public health to tackle the social determinants of poorer health, such as housing, discrimination, unemployment and social exclusion, although commissioning responsibility for these issues sits with Local Authorities.

Good practice example

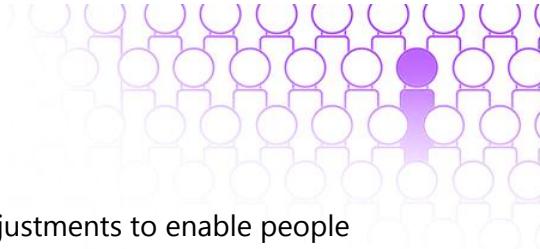
A number of London Boroughs took part in an initiative to increase the number of people with learning disabilities in settled accommodation. The initiative incorporated:

- placement analysis, using the care funding calculator (CFC);
- person-centred reviewing to support adults with a learning disability to achieve their aspirations;
- engagement and negotiation with providers to reduce costs;
- moves to different types of accommodation such as supported living under a tenancy, where appropriate.

The initiative delivered:

- significant efficiency savings in expenditure on learning disability services;
- quality outcomes for adults with learning disabilities;
- improvements in the balance between supported living and residential care;
- an increase in the number of adults living in settled accommodation.

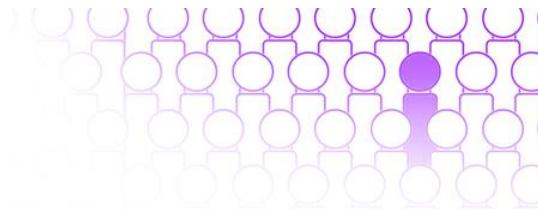
For further information please see www.evidence.nhs.uk/qipp



Health promotion and screening services should make reasonable adjustments to enable people with learning disabilities to access their services. People with learning disabilities are more likely to be obese or underweight, and less likely to exercise than the general population. Reasonable adjustments should be put in place to ensure they have equal access to services to support healthy eating, weight loss and physical exercise/mobility.

People with learning disabilities should be able to access sexual health services and smoking cessation services should also be accessible. Although fewer adults with severe learning disabilities smoke tobacco compared to the general population, rates of smoking among people with mild learning disabilities are higher than among their peers.⁸⁴

⁸⁴ Emerson et al. (2011). *Health Inequalities and People with Learning Disabilities 2011*. Improving Health and Lives Learning Disabilities Observatory.



SAF indicators relating to wider health and wellbeing

- Local Commissioners have good data about the numbers of people with a learning disability in the criminal justice system along with information about their health needs.
- People with learning disabilities have access to reasonably adjusted local amenities and transport facilities and services that enable them to participate fully and build / maintain social networks.
- People with learning disabilities have access to reasonably adjusted arts and culture facilities and services that enable them to participate fully.
- People with learning disabilities have access to reasonably adjusted sports and leisure facilities and services that enable them to participate fully.
- People with learning disabilities are supported into employment.
- Young people with learning disabilities have a single education, health and care plan (April 2014), and there are good transition pathways and support.
- Commissioning intentions support people with learning disabilities to be part of their community.
- There is a co-produced family carer strategy based on assessed need.

Expected outcomes (Public Health Outcomes Framework)

- Domain 1 objective – Improvements against wider factors that affect health and wellbeing, and health inequalities.
- Domain 2 objective – People are helped to live healthy lifestyles, make healthy choices and reduce health inequalities.
- Domain 4 objective – Reduced numbers of people living with preventable ill health and people dying prematurely, while reducing the gap between communities.

9. Cross cutting commissioning considerations

Please note – this section is organised alphabetically.

9.1 Assistive technology and telecare/telehealth

Effective commissioning of Assistive Technology (AT) and telecare/telehealth has the potential to reduce hospital admissions, contribute to faster discharge and support people and their families in the community. Please see: *New Approaches to Supporting Carers' Health and Well-being: Evidence from the National Carers Strategy Demonstration Sites programme*:

www.sociology.leeds.ac.uk/circle/news/new-approaches.php . AT can be defined as any piece of equipment that helps people to perform everyday activities. The definition incorporates a large number of devices, ranging from 'low-tech' mobility devices such as Zimmer frames to 'high-tech' speech synthesizers or stair-climbing wheelchairs. Telecare and telehealth technology help people live more independently at home. They include personal alarms and health-monitoring devices. For further information please see: www.nhs.uk/Planners/Yourhealth/Pages/Telecare.aspx . CCGs need to work in partnership with other agencies to commission this equipment as commissioning is complex and requires coordination with other agencies such as social care, housing, education and the voluntary and private sector. Many users of AT have multiple needs, require a holistic assessment and may need AT throughout their lives. For further information see:

http://archive.audit-commission.gov.uk/auditcommission/sitecollectiondocuments/AuditCommissionReports/NationalStudies/NationalReport_FINAL.pdf

9.2 Services for children and young people with learning disabilities

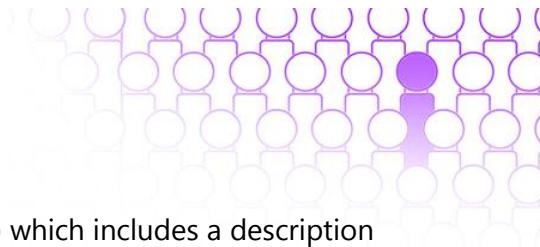
9.2.1 General commissioning issues

Children and young people with complex health needs are likely to have a multitude of services involved in their care and support (including health, education and social services). They may not come into contact with primary care until they are adults, which can create problems with transition and information sharing. Commissioners should ensure that joint agency planning and commissioning takes place to enable the development of person centred, co-ordinated and integrated packages of care and support for children and young people, to enable smooth transition to adult services and avoid crises.⁸⁵ *Support and aspiration: A new approach to special educational needs and disability. Progress and Next Steps*⁸⁶ sets out the government's intention to legislate through the proposed Children and Families Bill to ensure that services for children and young people with special educational needs are planned and commissioned jointly between local

⁸⁵ Department of Health (2013). *Transforming care: A national response to Winterbourne View Hospital. Department of Health Review: Final Report.*

⁸⁶ Department for Education (2012). *Support and aspiration: a new approach to special educational needs and disability. Progress and next steps.*

<https://www.education.gov.uk/publications/standard/publicationDetail/Page1/DFE-00046-2012>



authorities and clinical commissioning groups. See also Wright (2008) which includes a description of what good services should look like: <http://pb.rcpsych.org/content/32/3/81.full>

Guidance on the care and support of young people with cerebral palsy is available from NICE: <http://publications.nice.org.uk/spasticity-in-children-and-young-people-with-non-progressive-brain-disorders-cg145>

9.2.2 Young people with learning disabilities and mental health problems

For young people with learning disabilities and mental health problems, services may be commissioned as part of the general Child and Adolescent Mental Health Service (CAMHS) specification.

CAMHS are provided for children and young people with mental health needs up to their 19th birthday. The aim should be to commission a single service integrating Tier 2 (Targeted) and Tier 3 (Specialist) into a Community CAMHS model with a single point of access. The tiers are:

- Tier 1 Universal services and primary care, early identification and prevention (GPs, health visitors, teachers, youth workers etc.);
- Tier 2 Services provided by professionals relating to workers in primary care, uni-disciplinary working, consultation, assessment, training (mental health workers, psychologists, paediatric clinics);
- Tier 3 Specialised services for young people with more severe, complex or persistent disorders, multi-disciplinary team, child psychiatry out patient, specialized mental health working;
- Tier 4 Essential tertiary level services providing in-patient, day-patient and outreach units for children and adolescents with learning disabilities and severe and complex neuro-psychiatric symptomatology.

The Royal College of Psychiatrists Quality Improvement Network for Multi-Agency CAMHS (QINMAC) have developed:

- A set of standards for measuring the delivery of Tier 3 Learning Disability CAMH services.
See:
www.rcpsych.ac.uk/quality/qualityandaccreditation/childandadolescent/communitycamhsqncc/ourstandards.aspx
- A Toolkit for Clinicians developing Mental Health Services for Children and Adolescents with Learning Disabilities in collaboration with the National CAMHS Support Service (2009).
See: www.rcpsych.ac.uk/PDF/DevMHservCALDbk.pdf



Commissioners should ensure that a full range of services similar to generic CAMHS including assessment, diagnosis, and a comprehensive array of interventions at all tiers is available. Specialist knowledge will be necessary for physical comorbidities, epilepsy, autistic spectrum disorders, neurodegenerative and metabolic disorders, and teams will need specialist skills in dealing with challenging behaviour and child protection.

For information on children and young people with autism see section 1.4 which includes a link to appropriate NICE guidance.

The national Child and Maternal Health Observatory (ChiMat) produces a monthly Learning Disabilities & CAMHS network e-Bulletin summarising the latest policy and practice. It highlights and links to news, events, research, guidance, reports and other resources relating to CAMHS and learning disabilities. See: www.chimat.org.uk/ldcamhs

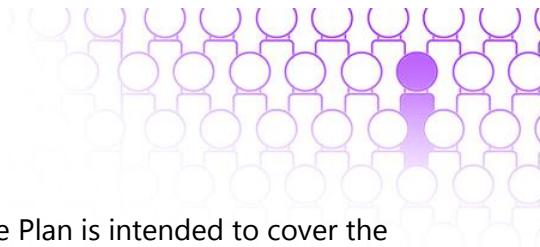
9.2.3 Young people with a learning disability and epilepsy

Commissioners need to ensure rapid access to specialist epilepsy services, including those dedicated to young people and transition clinics. Each child should have an individual management plan agreed with the family and primary care team. As young people begin the move into adulthood, it is critical that there is an agreed transition period during which their continuing epilepsy care is reviewed jointly by paediatric and adult services. For further information see: <http://publications.nice.org.uk/quality-standard-for-the-epilepsies-in-children-and-young-people-qss27/list-of-quality-statements>

9.2.4 Transition

Preparation for transition is often not started early enough and some areas still don't have good information on the needs of young people so are unable to plan services to meet their needs. Statutory transition planning starts at the year 9 review (age 13/14), should be person centred, and should include health, independent living, employment and social inclusion. If somebody has complex health needs they may need an in-depth health plan, but the plan needs to ensure that the young person's aspirations are known and taken account of, along with information on the management of identified issues, and details of which professional/agency is leading on each aspect of management. *Support and aspiration: A new approach to special educational needs and disability. Progress and next steps*⁸⁷ proposes a new single assessment process and Education, Health and Care Plan by 2014. This will replace the current system of statementing, bringing

⁸⁷ Department of Education (2012). *Support and aspiration: A new approach to special educational needs. Progress and next steps*



together all services across education, health and social care. The Care Plan is intended to cover the full age range from 0 to 25 and support a more child-centred assessment process, with greater focus on long-term planning that will help to achieve the outcomes that matter most to children, young people and their families.

Well planned, person centred transition is important not least because poor transition can lead to serious health outcomes following disengagement with health services and subsequent costs to health services. Identifying a care coordinator or navigator is important, and is valued by families and young people. The navigator works with the young person, their family and the multi-disciplinary team (including the GP) to coordinate the plan. *Pathways to Getting a Life*⁸⁸ <http://gettingalife.org.uk/downloads/2011-Pathways-to-getting-a-life.pdf> includes a health pathway but sets it in the context of holistic transition planning, personalisation and support planning.

For young people with learning disabilities and mental health needs, *No health without mental health*⁸⁹, says that "Care and support should be appropriate for the age and developmental stage of children and young people, adults of all ages and all protected groups. Careful planning of the transfer of care between services will prevent arbitrary discontinuities in care as people reach key transition ages. Services can improve transitions, including from CAMHS into adult mental health services, or back to primary care, by:

- Planning for transition early, listening to young people and improving their self-efficacy;
- Providing appropriate and accessible information and advice so that young people can exercise choice effectively and participate in decisions about which adult and other services they receive; and
- Focusing on outcomes and improving joint commissioning, to promote flexible services based on developmental needs."

Useful guidance is also available at: www.ldtransitionguide.bham.ac.uk/chap5_4.pdf

SAF indicators relating to transition

- Young people with learning disabilities have a single education, health and care plan (April 2014), and there are good transition pathways and support.

⁸⁸ Department of Health (2011). *Pathways to Getting a Life: transition planning for full lives*.

⁸⁹ HM Government (2011). *No Health without Mental Health: a cross government mental health outcomes strategy for people of all ages*.

www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_123766

9.3 Continence

Incontinence is a common health problem for people with learning disabilities. Good practice guidance suggests that commissioners should commission integrated (urinary and faecal) continence services. People with learning disabilities should be able to access continence services in the same way as everyone else. Referral to a dietician should also be considered. Supply of continence products should be governed by clinical need. NICE guidance on the commissioning of faecal continence services is available at:

www.nice.org.uk/usingguidance/commissioningguides/faecalcontinenceservice/FaecalContinenceService.jsp?domedia=1&mid=87F6E7ED-19B9-E0B5-D410389926647780

9.4 Continuing Health Care (NHS)

CIPOLD⁹⁰ found that problems with accessing NHS Continuing Health Care (NHS CHC) funding made people with learning disabilities vulnerable to a poor-quality death. They found evidence of confusion about access to funding and delays in approval. People with learning disabilities who meet NHS CHC criteria should be supported in a person centred way in the least restrictive environment possible. Individuals with a social care direct payment lose the direct payment when they become eligible for NHS CHC unless they live in a Personal Health Budget (PHB) pilot area (see below), when it may be possible to award NHS CHC as a PHB direct payment. Wherever they live, their NHS CHC award can already be personalised (using the other PHB options) and every effort should be made to continue existing support arrangements where these are working well. From April 2014, all people receiving NHS Continuing Health Care will have the right to ask for a PHB, and from October 2014 will be entitled to a PHB (subject to clinical and financial considerations).

The NHS may still have a responsibility to contribute towards a person's health needs if they do not qualify for NHS Continuing Health Care, either by directly commissioning services or by part-funding the package of support. Where a package of support is commissioned or funded by both an LA and a CCG, this is known as a 'joint package'. All support packages should be regularly monitored. The revised National Framework for NHS Continuing Healthcare and NHS Funded Nursing Care, checklist, decision support tool and fast track pathway tool is available from:

www.gov.uk/government/publications/national-framework-for-nhs-continuing-healthcare-and-nhs-funded-nursing-care

See also: www.learningdisabilities.org.uk/publications/continuing-healthcare/

⁹⁰ Heslop et al (2013). *Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD) Final report.*

9.5 Dysphagia

Research indicates that dysphagia affects around 8% of adults with learning disabilities known to services, approximately 40% of whom experience recurrent respiratory tract infections.⁹¹

Individuals with dysphagia have difficulty in eating, drinking or swallowing, and are in danger of becoming malnourished and dehydrated.⁹² Asphyxia and respiratory-related mortality are known to be disproportionately high in people with learning disabilities (see section 4.2).

For guidance on the management of dysphagia, please see:

www.nrls.npsa.nhs.uk/resources/?EntryId45=59823

The guidance suggests that organisations providing for people with learning disabilities and dysphagia should have a lead clinician (probably a speech and language therapist) with overall responsibility for dysphagia services. Care and support from trained practitioners should also be available. CIPOLD further recommends that CCGs ensure they are commissioning expert and sufficient preventative services for people with learning disabilities at high risk of respiratory illness, including ready availability of speech and language therapists or other suitably qualified practitioners able to undertake swallowing assessments, aggressive treatment of gastro-oesophageal reflux, clear clinical pathways for gastrostomy insertion, and frequent reviews of patients waiting for a gastrostomy procedure.

9.6 End of life care

People with learning disabilities should be able to access the same palliative care services as everyone else – but often this is not the case. CIPOLD found that 43% of those whose deaths they reviewed had some evidence of end-of-life care planning, and that where plans were in place, they contributed to effective care. However, a number of people had uncoordinated end of life care, which contributed to them being at risk of not having a good death. *The Route to Success in end of life care*⁹³ is a practical guide to improving end of life care for people with learning disabilities that CCGs should be aware of. See: www.endoflifecare.nhs.uk/download.ashx?mid=3302&nid=3304

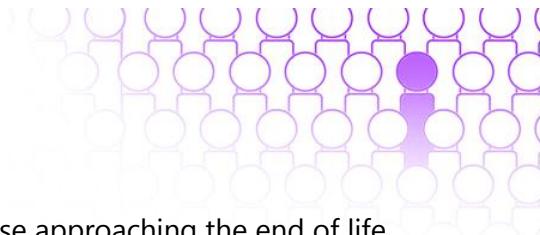
Route to success refers to the Department of Health's quality markers for end of life care. The following are of particular relevance to commissioning:

- Have mechanisms in place to ensure that care for individuals is coordinated across organisational boundaries 24/7.

⁹¹ Emerson et al. (2011). *Health Inequalities and People with Learning Disabilities 2011*. Improving Health and Lives Learning Disabilities Public Health Observatory

⁹² National Patient Safety Agency (2007). *Problems swallowing? Ensuring safer practice for adults with learning disabilities who have dysphagia*.

⁹³ NHS National End of Life Care Programme (2011). *The route to success in end of life care – achieving quality for people with learning disabilities*.



- Have essential services available and accessible 24/7 to all those approaching the end of life who need them.
- Monitor the quality and outputs of end of life care and submit relevant information for local and national audits.

CCGs should also be aware that NICE has published a Quality Standard for end of life care for adults. The accompanying support document for commissioners states at Quality Statement 2 (communication and information) that "Commissioners should ensure that providers can demonstrate that all information provided to people with end of life care needs and carers is available in a variety of accessible formats. Information should be culturally appropriate and accessible to people with additional needs such as physical, sensory or learning disabilities and for people who do not speak or read English."

<http://guidance.nice.org.uk/QS13/CommissionerSupport/pdf/English>

9.7 Medicines management

People with learning disabilities are often on a large amount of medication, and a high proportion receive prescribed psychotropic medication, most often anti-psychotic drugs to control challenging behaviour. This is despite a lack of evidence for their effectiveness in treating challenging behaviour and evidence of considerable harmful side effects.⁹⁴

CCGs should ensure there are effective mechanisms in place to undertake regular medication reviews, which can also result in cost savings.

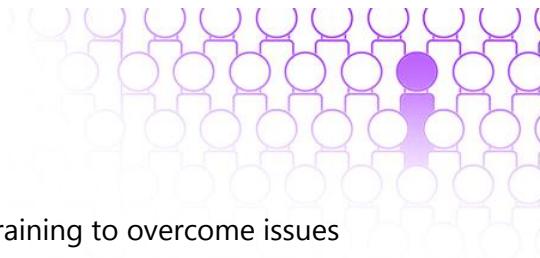
9.8 Pain recognition and management

People with learning disabilities may not be able to express pain in a way that others easily recognise. Support staff are often the first to notice changes which may indicate a health problem if the individual lives in supported living or residential care. However, research indicates that support staff may feel they are lacking in skills, knowledge and training to identify health needs.⁹⁵ Social and health care commissioners can jointly commission community learning disability teams to support providers, enabling support workers to recognise potential problems and take action. The way in which individuals express pain or discomfort should be documented, and support staff trained to use this information and react appropriately.

The Disability Distress Assessment Tool can assist staff in assessing pain when patients cannot communicate verbally. See: www.disdat.co.uk/ *Death by Indifference; 74 deaths and counting*

⁹⁴ Deb, S., Clarke, D. and Unwin, G. (2006). *Using medication to manage behaviour problems among adults with learning disability. A quick reference guide*.

⁹⁵ Emerson et al. (2011). *Health Inequalities and People with Learning Disabilities 2011*. Improving Health and Lives Learning Disabilities Public Health Observatory



recommends that all staff involved in pain treatment should receive training to overcome issues around communication, as well as drawing on the knowledge and skills of those who know the person best, in order to tackle pain effectively.

9.9 Parents with learning disabilities

People with learning disabilities need appropriate contraceptive advice to avoid unwanted pregnancies. People with learning disabilities who do want to become parents, often receive little support, and frequently have their children taken away. Good practice guidance ⁹⁶ is available for agencies working with parents with learning disabilities: <http://dera.ioe.ac.uk/6709/>

Commissioners should check that services provide accessible information for parents and potential parents with learning disabilities, clear, co-ordinated referral and assessment procedures and care pathways at an early stage, support designed to meet the needs of parents and children based on assessments of their needs and strengths, long-term support where necessary and access to independent advocacy.

9.10 Personal Health Budgets (PHBs)

PHBs give people more choice over the services they receive by giving them a transparent resource to plan how to meet their health needs in a way that is more personal to them and agreed in a care plan. The resource can be delivered as a notional budget, a third party budget or a direct payment. PHBs have the potential to engage groups not traditionally well served by health services and enable people to take more control of their lives. People receiving NHS Continuing Health Care will have the right to ask for a PHB from April 2014, and be entitled to a PHB from October 2014 (subject to clinical and financial considerations). For further information see:

www.personalhealthbudgets.england.nhs.uk/

The RCGP has also published a practical guide to PHBs for GPs. See:

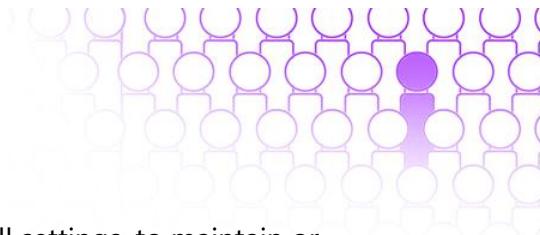
www.rcgp.org.uk/news/2013/january/personal-health-budgets-a-guide-for-gps.aspx

Effective CCGs will work in partnership to build on the learning from social care personal budget implementation as well as the PHB evaluation when implementing PHBs locally.

9.11 Postural care

Postural care is a way of preserving and re-establishing body shape for people with movement difficulties. The principles of posture care are about ensuring that everybody with movement

⁹⁶ Department of Health and Department for Education and Skills (2007). *Good practice guidance on working with parents with a learning disability*.



difficulties has their body shape protected over a 24 hour period, in all settings, to maintain or regain good body shape and reduce the risk of further deterioration and secondary complications. This approach challenges the assumption that changes in body shape are inevitable for people who have movement difficulties. In meeting this need there is a requirement for people to have access to services, equipment and training to support the long term management of their body shape.

Changes in body shape, particularly chest distortion, result in a poor quality of life, including problems with breathing and eating, and can lead to premature death. Body distortion is also costly in terms of equipment and increasingly complicated medical intervention.⁹⁷

CCGs should consider investing in postural care interventions to improve quality of life and save money.

9.12 Wheelchair services

Wheelchair services can be slow to provide wheelchairs for those that need them, and chairs that are provided are often not suitable. Some wheelchair services do not provide 'smart' wheelchairs or powered wheelchairs if these are needed by carers to move the individual. Some wheelchair services are now being tendered out to Any Qualified Provider. Mansell⁹⁸ recommends that:

- Powered wheelchairs should be provided where carers need them in order to move the disabled person;
- People with complex needs who have used powered wheelchairs (e.g. 'smart' wheelchairs) during childhood should have the option of continuing to have them provided in adult life, where this sustains or enhances their quality of life;
- Other people with complex needs should be provided with powered wheelchairs suitably adapted with 'smart' technology, where this sustains or enhances their quality of life.

⁹⁷ Hill, S. (2011). *A One Year Postural Care Training Programme for the Workforce Supporting the Needs of those with Complex and Continuing Healthcare Needs: Project Evaluation*. Skills for Health.

⁹⁸ Mansell, J. (2010). *Raising our sights: services for adults with profound intellectual and multiple disabilities*.

Appendix I

The Commissioning Cycle

Although the commissioning cycle will be familiar to many, details of each phase of the cycle are included as a reminder for CCGs, along with specific issues for learning disability services, and signposts to further information.

Public and patient involvement – No decision about me without me

In order to commission effectively, patients, carers and the public need to be engaged in every aspect of the commissioning cycle. This is not just about listening to people's views, but about actively engaging them in making commissioning decisions so that services meet local needs. Partnership Boards can be a helpful resource for CCGs and HealthWatch, who have a role in supporting this process.

CCGs need to have robust mechanisms for collecting, understanding and making public patients' and carers' views, particularly in areas of known inequality so that health inequalities can be addressed. Patient-Reported Outcome Measures (PROMS) and other tools will need to be accessible to people with learning disabilities so that their views are included. Patient Participation groups should also be accessible to people with learning disabilities. This information will contribute to a better picture of service quality and will support patient choice.

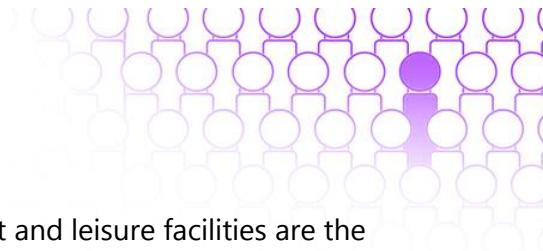
CCGs also need to seek evidence that service providers have systematic ways of listening to and engaging with patients and carers including people with learning disabilities, acting on their views and providing evidence of the improvements made in line with domain 4 (*Ensuring people have a positive experience of care*) of the NHS Outcomes Framework.

Assessing need

The first stage in any commissioning cycle is a thorough assessment of local population health needs via the Joint Strategic Needs Assessment (JSNA), which provides the framework within which more detailed commissioning plans can be developed. CCGs and local authorities including the Directors of Public Health will prepare the JSNA through arrangements made by the health and wellbeing board.

Learning Disability Partnership Boards have a considerable amount of knowledge regarding the health needs of people with learning disabilities locally and are a useful resource for health and wellbeing boards and CCGs when assessing local need. They are also an excellent way of engaging with people with learning disabilities and family carers.

Health and wellbeing boards have the power to promote joined up services which could be of benefit to people with learning disabilities as many of the wider social and environmental



determinants of health and wellbeing such as jobs, housing, transport and leisure facilities are the prime responsibility of other partners.

The JSNA should include information on the current and future prevalence of people with learning disabilities in the local population. Estimates of local need are available at:

www.ihal.org.uk/numbers/howmany/laestimates/

Review of current service provision

The second stage in the commissioning cycle requires a good understanding of existing services and their ability to meet desired outcomes, including any gaps in service provision. There should be particular emphasis on access to services (compared with that of the general population) in order to address health inequalities.

Some areas have undertaken a needs assessment specifically for people with learning disabilities, identifying gaps in services and health issues. See:

www.ihal.org.uk/areas/cornwall/tacklinghealthinequalities/

The South West undertook a review of all its acute hospital services regarding service provision for people with learning disabilities. Please see: www.swacutehospitalreview4ld.org.uk/

Service reviews need to include assessing capacity against current and future population needs. A good needs assessment relating to children and young people who will need services will enable CCGs to compare the availability and appropriateness of services with projected needs.

The self-assessment framework already provides good information on local services. Information is available at: www.improvinghealthandlives.org.uk/projects/hscldsaf

Learning Disability Partnership Board reports also provide valuable information and are available on the IHaL website along with an analysis of contents:

www.ihal.org.uk/projects/partnershipboardreports

Deciding priorities

Once the needs assessment and the analysis of current pattern of provision are complete, the two need to be compared along with the agreed outcomes framework in order to identify key priorities for development.

It is also important to take into account the current evidence available regarding health inequalities and people with learning disabilities. Please see:

www.ihal.org.uk/projects/particularhealthproblems

The Learning Disability Partnership Board has much to offer in this process and can help ensure that priorities are developed with people with learning disabilities and their carers.

Specifying services

The next stage involves setting out a clear vision of what local health services for people with learning disabilities should look like in future. All commissioned services should offer safe care and support that is 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. When procuring services, and monitoring and renewing contracts, commissioners are responsible for ensuring providers have processes in place to facilitate recruitment into approved research studies.

Shaping the structure of supply

As well as ensuring that mainstream health services are responsive to the needs of people with learning disabilities, CCGs need to commission services for health funded people with complex needs, including those with mental health needs. It is important to work with partners to shape markets and ensure that services are innovative, flexible, and able to support people with complex and challenging needs locally. Market development may also involve decommissioning services that are shown to be ineffective, or are no longer based on best evidence.

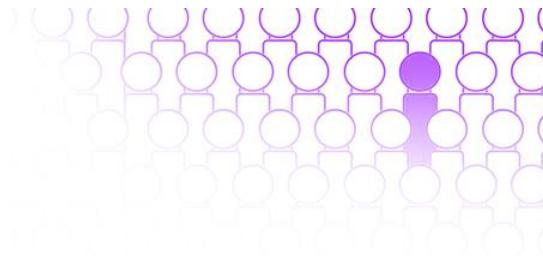
People with complex needs usually require individual support packages bringing together a range of different services from different sectors (e.g. health, social care, education and housing). People with learning disabilities may increasingly have personal health budgets and will need good information in order to exercise choice and get the best services for their money.

Some of these services are costly, however a recent report by the Social and Health Evaluation Unit of the University of Chester⁹⁹, which looked at the experiences of the last 39 Sutton residents of Orchard Hill Hospital who moved out of long stay care into new supported accommodation in the community found that that people receiving a personalised model of care are happier, fitter and have greater independence, dignity and control over their lives. The report also showed that significant financial savings can be made, and is the first of its kind to show nothing but positive outcomes for people making the move into the community - as long as the care model is based upon individual assessment of need.

Planning local services should take account of the needs of any people with learning disabilities who are out of area, so that they can be repatriated as soon as possible.

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

⁹⁹ University of Chester Social and Health Evaluation Unit (2011). *Into the community from Orchard Hill Hospital*. www.sutton.gov.uk/CHtpHandler.ashx?id=15296&p=0



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

Managing demand and ensuring appropriate access to care

CCGs should work closely 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 that health services 'should ensure momentum is maintained in improving care and outcomes for people with learning disabilities' and that particular emphasis should be given to ensuring staff are trained to make reasonable adjustments, communicate effectively and follow the Mental Capacity Act (2005) Code of Practice in all their interactions with patients with learning disabilities to ensure full compliance with the law in respect of capacity, consent and best interest decision making. Annual health checks for people with learning disabilities remain an important means of ensuring improved access to health services. As well as annual health checks, there should be good liaison systems in place to make sure that people with learning disabilities can access a range of services to help maintain good health, such as dental services, podiatry and sight testing.

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 choice. 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 at:

www.learningdisabilities.org.uk/our-news/2011-09-07/ and at: www.ihal.org.uk/adjustments/

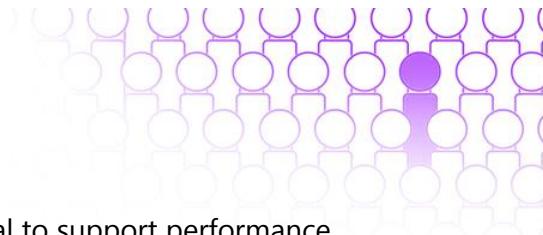
Guidance on using reasonable adjustments can be found at:

www.ihal.org.uk/projects/reasonableadjustments

Managing performance (quality, performance, outcomes)

This involves regular monitoring of performance and early intervention when performance suggests that quality standards 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.

Where there is no alternative to an out of area placement, systems for monitoring the quality and appropriateness of care must be robust and open to scrutiny.



CCGs 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;
- payment by results;
- page 56 of 53 of the Commissioning For Quality and Innovation payment framework (CQUIN).

CQUIN is a commissioning tool which makes a proportion of the providers income conditional on delivering quality and Innovation. It has been used successfully in some parts of the country to improve services for people with learning disabilities.

The Health Equalities Framework can provide good information on outcomes. See:

www.ndti.org.uk/publications/other-publications/the-health-equality-framework-and-commissioning-guide1/

Appendix II

Clinical Lead Learning Disabilities

Draft Role Description

| | |
|----------------------------|---|
| Title: | Clinical Lead Learning Disabilities |
| Responsible to: | Commissioning Lead Director |
| Sessions: | 1 session per week |
| Tenure: | 2 years initially, subject to satisfactory appraisal at 12 Months |
| Strategic Group(s): | Professional Executive Committee Learning Disability Partnership Board |
| Payment: | £300 per session (3 Hours per session) |

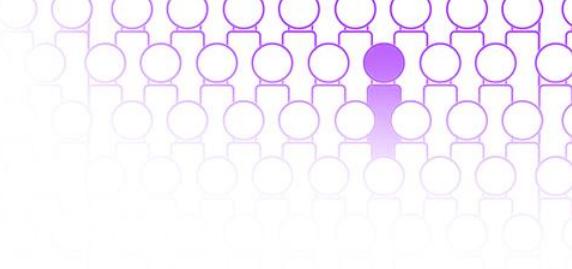
JOB RATIONALE:

This post is designed to give clinical leadership in relation the commissioning of health needs of people with Learning Disabilities from birth to death. You will work closely with people with learning disabilities, their families and carers, GPs, Community Learning Disability Teams, Acute trusts and other health care professionals to ensure that high quality, accessible health care services are delivered in area.

An important part of the role is to ensure that there is an effective interface between primary care and secondary care health services for people with learning disabilities.

You will play a key role in:

- The development of relevant integrated care pathway protocols.
- The development of strategic leadership both within the Commissioning Group and externally.
- The development and monitoring of enhanced services including annual health checks.
- Supporting the development of commissioning.
- Identification of gaps in services for people with learning disabilities and health inequalities.



KEY OBJECTIVES:

- Identify the key priorities for health services in relation to people with learning disabilities and their carers
- Utilising health performance indicators, and working closely with the lead public health strategists, identify areas for improvement and instigate and oversee work plans in these areas.
- Work across the area to help develop local responses to identified gaps in (access to) health services for people with learning disabilities.
- Contribute to the development of new models and deliveries of services that meet patient and carers needs and reach out and ensure access to marginalised groups.
- Develop effective primary care and secondary care interface agreements for people with learning disabilities.
- Work with relevant Trusts, LBN Adults and Children's services and PCT provider services to improve equity of access to services for all residents.
- Work with primary care and other stakeholders and act as a lead in relation to safeguarding policy and practice for people with learning disabilities.
- Reduce bureaucracy, duplication and waste.

CLINICAL LEADERSHIP:

- To proactively develop relationships with all providers of health care services in the area.
- To work closely with the Medical Directors and Nursing Directors of all trusts
- Contribute towards the development of commissioning and helping to ensure the Commissioning Group delivers its key strategic objectives and performance targets.
- Play a key part at the relevant Partnership Board / Health Task Group.

- To take a lead role in the learning disability Performance and Self-Assessment Framework

ADVICE AND SUPPORT TO THE COMMISSIONING GROUP:

- To support the implementation of annual health checks and health action planning for people with a learning disability.
- To work with practices on specific referral or interface issues with the support of the relevant Director.
- To provide advice to other staff in terms of people with learning disabilities and commissioning.
- To provide a 6-monthly written report and presentation to the Commissioning group Committee.

REPRESENTING THE COMMISSIONING GROUP EXTERNALLY:

- To build strong links with other Commissioning groups to ensure sharing of best practice.
- To represent the Commissioning group at relevant external meetings.
- To represent the Commissioning group within relevant clinical networks.

GENERAL

The nature of this post is one of continual development and the duties and responsibilities outlined above may change from time to time to reflect the changing needs of the organisation. The post holder will be expected to comply with commissioning group quality standards at all times. Therefore the above job description is not intended to be restrictive and may change as a result of service requirements in consultation with the post holder

CONFIDENTIALITY

The confidential nature of the work means that employees working within the function must maintain the strictest security in relation to documentation and ensure that confidentiality is maintained at all times in accordance with relevant Data Protection and associated legislation.

Person specification

Commissioning Lead for Learning Disabilities

| | Essential | Desirable | How Tested |
|--------------------------------------|--|---|---|
| Education/ Qualifications | Full GMC Registration or extensive experience of working with people with learning disabilities and families. | 5 years after completing GP Training. | <i>Application/ Originals required prior to interview</i> |
| Skills/Abilities | <p>Excellent communication skills – very high level persuasive, influencing and negotiation skills are essential to this post.</p> <p>The ability to make decisions and implement them in complex healthcare environments.</p> <p>Ability to work as part of a multi-disciplinary team</p> <p>Ability to work with other agencies involved in the development of new integrated services</p> <p>Adult Educational skills Evaluation</p> <p>Strategic planning skills</p> | <i>Flexibility</i> | <i>Application/ Interview</i> |
| Experience | <p>Teaching, training, and planning for continuous professional development</p> <p>Service development</p> | <i>Audit in General Practice</i> <i>Professional appraisal</i> | <i>Application/ Interview</i> <i>Lessons learnt from successful and unsuccessful</i> |

| | | | |
|---|--|--|-----------------------------------|
| | | <i>Service improvements implemented.</i> | <i>services changes</i> |
| Knowledge/ Understanding <input type="checkbox"/> | <p>An in depth understanding of the relevance of Learning Disabilities to primary and secondary care</p> <p>An understanding of the implementation of evidence based medicine in service development</p> <p>An understanding of key stakeholders in learning disabilities</p> <p>Clinical Governance agenda in general practice and secondary care</p> | <i>A sound clinical knowledge of the health needs of people with a learning disability and the current services available to them and their carers</i> | <i>Application/ Interview</i> |
| | The ability to act as a change agent, contributing to the development and implementation of the vision & strategy of the Commissioning Group | <i>Desire to work on continuous improvement</i> | <i>Application/ Interview</i> |