

# **A NOTE ON COMMISSIONING PRIMARY HEALTH SERVICES THAT ARE INCLUSIVE OF PEOPLE WITH LEARNING DISABILITIES**

## **1. Purpose**

This note provides advice on how Primary Care Trusts (PCTs) can meet their responsibilities for commissioning services that are effective for people with learning disabilities, taking account of the new commissioning framework and the new requirements on addressing inequalities.

It should be emphasised that this note refers to the commissioning of mainstream/generalist primary medical services rather than specialist learning disability services; nor does it address dental or optometry services.

## **2. Introduction**

PCTs can meet the general health care needs of the great majority of people with learning disabilities through mainstream services commissioned for the public as a whole. This note highlights some of the specific issues relating to people with learning disabilities that need to be considered when commissioning mainstream/generalist primary health care services. It also suggests how commissioners can monitor these services to ensure they are being provided effectively and are meeting the health care needs of people with learning disabilities within their local population.

There is clear evidence that the health of the one million people with learning disabilities is much worse than the general population and that current commissioning of mainstream health services fails to address this inequality (Elliott *et al.*, 2003)<sup>1</sup>. The Disability Rights Commission's report 'Equal Treatment: Closing the Gap' (2006)<sup>2</sup> reported international evidence that people with learning disabilities die younger than other citizens. They live with poorer health, which stops them participating in their communities and in the economy. They receive poorer health care.

The Government's agenda for addressing this situation includes policies addressing the lives of people with learning disabilities ('Valuing People'), the obligations of mainstream health services ('Our Health, Our Care, Our Say') and the right of disabled people to equal treatment (the Disability Discrimination Act 2005). Most importantly for commissioners, the 'Public Sector Disability Equality Duty' within the Disability Discrimination Act 2005 places a legal obligation on PCTs to take action.

**Foundation for People  
with Learning Disabilities**

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<sup>1</sup> Elliott, J., Hatton, C. and Emerson, E. (2003). The health of people with learning disabilities in the UK: evidence and implications for the NHS. *Journal of Integrated Care*, **11**, 9-17

<sup>2</sup> Disability Rights Commission (2006). *Equal Treatment: Closing the Gap*. London: Disability Rights Commission

### 3. Commissioning

This note accepts the definition of commissioning as ‘a proactive strategic role in planning, designing and implementing the range of services required rather than a more passive purchasing role’<sup>3</sup>. Effective commissioning makes the best use of allocated resources to achieve the following goals:

- *Improve health and well being and reduce health inequalities and social exclusion*
- *Secure access to a comprehensive range of services*
- *Improve the quality, effectiveness and efficiency of services*
- *Increase choice for patients and ensure a better experience of care through greater responsiveness to people’s needs.*<sup>4</sup>

In a Written Ministerial Statement of 6 November 2006, the Parliamentary Under-Secretary of State for Health, Ivan Lewis, emphasised the need for PCTs to enhance their commissioning capacity in relation to people with learning disabilities.

### 4. Addressing the health needs of people with learning disabilities

#### ***‘Our Health, Our Care, Our Say’ (2006)***

The White Paper insists that this important aspect of health inequality must be addressed:

*People with learning disabilities face particular health inequalities. The NHS has historically not served such people well and the Department of Health has previously committed to introduce regular, comprehensive health checks for learning disabled people. These would help to direct people into the system, from which point onwards they will be better positioned to receive good quality health care. We will review the best way to deliver on this commitment.*

#### ***Disability Rights Commission Formal Investigation Report: ‘Equal Treatment – Closing the Gap’, September 2006***

The Report found that in England and Wales people with learning disabilities are much more likely than other citizens to have significant health risks and major health problems. These particularly include obesity and respiratory disease. People with learning disabilities are likely to die younger than other people.

Despite these findings, the response from primary care services has been patchy. In primary care, these high risk groups are actually less likely to

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<sup>3</sup> Woodin, J. (2006) ‘Health care commissioning and contracting’ in Walshe, K. and Smith, J. [eds], *Healthcare Management*, pp201-223. Maidenhead, Open University Press

<sup>4</sup> From the Department of Health Commissioning Framework Annex (July 2006)

receive some of the expected, evidence-based checks and treatments than other patients and efforts to target their needs specifically are *ad hoc*.

- For people with learning disabilities, some checks are given less often; those who have diabetes have fewer measurements of their body mass index than others with diabetes and those with stroke have fewer blood pressure checks. Women have very low cervical and breast cancer screening rates. It was found that health checks identify significant unmet health needs amongst people with learning disabilities; when a second health check is given one year later, further significant unmet need is identified, some of it serious.
- People with learning disabilities experience 'diagnostic overshadowing': that is, reports of physical ill health being viewed as part of their learning disability and so not investigated or treated. This could mean that levels of ill health are even higher than the figures suggest.
- There is little or no evidence that information on the physical health needs of people with learning disabilities is either regularly collated or used locally by commissioners to develop improved services.
- There are some impressive examples of positive practice in primary care. There is also extensive evidence that primary care services are not generally making 'reasonable adjustments' – simple things like offering double appointments, providing treatment information in alternative formats, or sending text or phone appointment reminders. Such adjustments have been required by the Disability Discrimination Act since 1999.

The Investigation Report states that commissioners of services should:

- Identify groups who may need outreach or new service models to ensure they get primary care to the same standard required for everyone.
- Ensure the views of people with learning disabilities are used to drive actual improvements.
- Commission new service models between primary care and the voluntary sector or specialist services.
- Ensure healthy living support is targeted at people with learning disabilities and their families and they are involved in designing their individual health promotion programmes.
- Build robust disability access and quality standards into all contracts with providers.
- Track GP allocation requests to spot any potential discrimination on grounds of disability or race.

It also recommends that primary care providers should improve equity of access and treatment for people with learning disabilities by:

- Providing the option of recording access needs on a patient's records and meeting these needs.

- Offering regular health checks.
- Taking extra care to ensure these groups receive health promotion, screening and physical treatment.
- Making direct contact with local disability groups and involving them in advising on improvements.
- Giving anyone removed from a GP list or refused access written reasons why.

### ***Disability Discrimination Act 2005***

The 'Public Sector Disability Equality Duty' within the Disability Discrimination Act 2005 requires all public authorities (including PCTs) to look actively at ways of ensuring that disabled people are treated equally. There is a general duty that applies to all public authorities, plus additional specific duties to support the majority of public authorities in achieving the outcomes required by the general duty.

The basic requirement for a public authority when carrying out their functions is to have due regard to do the following:

- Promote equality of opportunity between disabled people and other people.
- Eliminate discrimination that is unlawful under the Disability Discrimination Act.
- Eliminate harassment of disabled people that is related to their disability.
- Promote positive attitudes towards disabled people.
- Encourage participation by disabled people in public life.
- Take steps to meet disabled people's needs, even if this requires more favourable treatment.

### ***'Valuing People' White Paper, 2001***

'Valuing People' set out plans for specific developments to address these health inequalities:

- Health facilitators, to help health services become more inclusive, and to support people with learning disabilities to obtain Health Action Plans.
- Health action plans, to ensure that health needs of individuals are identified and action taken to meet them.
- Changing roles for health professionals in community learning disability teams, to focus more on educating and supporting mainstream health services.

## 5. How to make progress locally

The PCT needs to secure appropriate expertise and advice on learning disability issues. We recommend that this is done by retaining, or appointing, a **Strategic Health Facilitator** within the PCT: this appointment should be a person from a learning disability clinical background. The key purpose of the Strategic Health Facilitator would be to ensure that access for people with learning disabilities to all mainstream health care services is equitable with that for the rest of the local population, with appropriate support from specialist learning disability practitioners. Such a role can also support the PCT's public health role by ensuring that information about the health of people with learning disabilities is fed into action on health inequalities. There is important potential here for obtaining health gains and therefore saving later expenditure on providing health services. The post-holder should also lead collaboration with the local authority on general health and wellbeing matters, including involvement with the Local Area Agreement.

Arrangements for commissioning primary health care services that are inclusive of people with learning disabilities could be agreed between individual GP practices or Practice Based Commissioning (PBC) groups and the PCT, building on the Quality Outcomes Framework indicator on learning disability registers. As the implementation of PBC develops, it will be vital to give specific attention to ensuring that the needs of people with learning disabilities for mainstream services are properly considered.

Where a Local Enhanced Service (LES) contract is in place that describes specialist service provision, a separate agreement will be necessary to ensure equal access to primary care services for people with learning disabilities.

It is recommended that the agreement for primary care services include the following **Key Messages**:

- People with learning disabilities need access to all mainstream services, drawing upon the support and advice of specialist services where necessary.
- People with learning disabilities should be treated as individuals in the assessment of their health needs and the commissioning of services to meet those needs.
- People with learning disabilities should benefit equally from the targets and standards set out in the National Service Frameworks and other mainstream plans.
- Workforce development is central to the improvement of health services for people with learning disabilities. Training should ensure that all health professionals gain a greater awareness of the health issues for people with learning disabilities and the 'reasonable adjustments' to services that may be required.

## 6. Monitoring – standards and targets

Commissioners should monitor the provision of mainstream primary health care services for people with learning disabilities against the relevant standards described in 'Better Metrics'<sup>5</sup>, section 8:

- 8.01 - All GP practices have a system in place for identifying patients who have learning disabilities.  
Data on the number of people with learning disabilities known to GP practices but not yet coded using a locally agreed and appropriate Read code.  
Note: this links to the QOF indicator on learning disability registers
- 8.02 - All patients with learning disabilities to have a health action plan that has been initiated or checked by a primary care professional and is based on a comprehensive health check.  
Data on the number of people with learning disabilities with or offered a health check, prior to a health action plan (per 10,000 of PCT population) in the last 3 years.  
Data on the number of people with a health action plan (per number offered).
- 8.03 - PCTs have a system in place to identify 1:1 health facilitators to primary care for people with learning disabilities and their families.  
Each PCT should have a system for identified local health facilitators.
- 8.04 - All GPs have a system for ensuring patients with learning disabilities are invited to attend for health screening if they have not visited the surgery in the last three years.  
Data on the number of people with learning disabilities who have been invited, in the past year, for a comprehensive health check if they have not visited the surgery in the last 3 years.
- 8.08 – A system is in place to ensure that patients at risk of dysphagia are screened and assessed to determine vulnerability and that a care plan is in place and reviewed regularly.  
Data on how many people with learning disabilities have been screened in the last three years.  
Data on how many people have a plan in place for dysphagia that has been regularly reviewed.
- 8.09 – Patients with learning disabilities and their families will be offered easy to understand information about their health.

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<sup>5</sup> The full list of metrics is available on the Healthcare Commission website <http://www.healthcarecommission.org.uk/serviceproviderinformation/bettermetrics/suggestedmetrics.cfm>

Regularly survey to ascertain how easy to understand information provided about their health and treatment was for people with learning disabilities and their family carers.

- 8.10 – Increase the strength of the ‘voice’ of people with learning disabilities and their families through membership of patient forums, advocacy and annual surveys.  
Data on the number of people with learning disabilities on any patient forums.
- 8.12 - To ensure that a system is in place to ensure people with learning disabilities benefit from the local implementation and progress on the targets within the National Service Frameworks – CHD, cancer plan, etc.  
PCTs have a system in place to ensure access and take up rates are monitored by the PCT executive board quarterly for people with learning disabilities to check and promote equal access to mainstream services, NSFs and plans.

Commissioners should also consider the use of other locally relevant metrics that could assist the development of better health services for people with learning disabilities.

The Foundation for People with Learning Disabilities led a national pilot project to test the effectiveness of the metrics shown above and to support their implementation. The project demonstrated that it was possible to make some real improvements. These required co-ordinated action between various local participants and required time to implement. Details are available on the Foundation’s website, together with contact details for possible support to PCTs in taking this work forward.

[www.learningdisabilities.org.uk](http://www.learningdisabilities.org.uk)

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09.02.07