



briefing

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Commissioning healthcare for people with learning disabilities

Valuing people now

The commissioning of healthcare for people with learning disabilities has traditionally delivered variations between different areas in the accessibility and appropriateness of mainstream healthcare. This *Briefing* is

intended to raise awareness of issues in the commissioning of services for people with learning disabilities that meet their specific needs and enhance the development of mainstream services that are fit for purpose.

Background

There are an estimated 985,000 people with learning disabilities in England (including 769,000 adults) of which 177,000 are known users of learning disabilities services (including 169,000 adults). The approximate cost of providing these services is £2.5 billion. Information on individual needs is not comprehensive and, as a result, services for the range of people with learning disabilities and their family carers may only be scratching the surface of potential need.

A Disability Rights Commission investigation, a Mencap report, *Death by Indifference*, and the report of the Michael inquiry, emphasised a growing concern that people with learning disabilities were effectively invisible to mainstream NHS services. Strategic health authority (SHA) development plans relating to the Next Stage Review (2008) showed a mixed response to the challenges that this could bring for the health service.

Key points for commissioners

Commissioners can:

- Listen to people with learning difficulties and include them in their decision-making process.
- Make getting this right a key objective, because if they do it will benefit all patients. It should mean that they are not only focusing on the patients who are most demanding or eloquent in arguing for what they need.
- Argue the public health case. If patients with learning disabilities are treated early and well it can contribute to other health objectives which they are working towards.
- Make the most of their commissioning clout. PCT's should ensure that they have excellent information about these issues and take a strategic approach to dealing with them.
- Be ruthless about where they have got things wrong in the past. People with learning disabilities often find it difficult to complain. An organisation may think it is doing perfectly well, but managers need to proactively consider if that is actually the case.

'Policy on delivering high-quality services for people with learning disabilities has been in place for several years'

Only two SHA plans supported separate workstreams on learning disability, with one SHA making no mention of it at all.

The NHS Confederation, working with the Foundation for People with Learning Disabilities, held an expert seminar in October 2008 to explore the implications of both the Michael inquiry and the white paper, *Valuing people now*, for the development of commissioning of healthcare for people with learning disabilities within primary care trusts (PCTs), supported through the world-class commissioning framework.

The policy context

The NHS Next Stage Review sets out a vision of an NHS that gives patients and the public more information and choice, works in partnership and has quality of care at its heart. Quality is defined as care that is clinically effective, personal and safe. Delivery of the vision will see the NHS provides high-quality care for all users of services in all aspects of care.

Policy on delivering high-quality services for people with learning disabilities has been in place for several years previously as outlined in the NHS Confederation briefing, *Improving services for people with learning disabilities* (November 2006).

The Department of Health's (DH) papers, *Valuing people* (2001) and *Valuing people now* (2009), have laid out a vision that includes improving choice and control over services; giving better access to housing and

work; and making full and fair access available to good-quality healthcare. The emphasis is on ensuring that legal obligations in relation to human rights and disability discrimination are met and in improving the commissioning of services, so that acute healthcare properly meets the needs of people with learning disabilities, and primary care provides comprehensive health checks and better access to local services.

The operating framework for the NHS in England 2009/10 explicitly includes the delivery of improved access to services as a priority. Alongside this, the new regulators should include access for people with learning disabilities in their regular audit work programme to ensure quality is improved and maintained. Furthermore, *Valuing people now* includes a detailed Government response to the Michael inquiry.

The Michael inquiry

The Michael inquiry stated that there was "convincing evidence that people with learning disabilities have higher levels of unmet need and receive less effective treatment". It found that they had more difficulty accessing assessment and treatment for general health problems unrelated to their disability and in getting reasonable adjustments to support equitable treatment, particularly in the area of communication, which enables understanding and provides support for personal preferences. People with learning disabilities and their family carers also found it hard to be accepted as equal partners in care. This was a particular issue for family carers, especially of children who found their opinions and assessments were ignored, their complaints were not heard

and at times they needed to contribute to the care beyond their personal resources.

This inquiry also raised more systemic issues, including limited knowledge of learning disabilities by those professionals working in general healthcare. This was associated with unfamiliarity within professional groups with what help should be provided or who should be contacted for expert advice. The inquiry found poor partnership working between agencies, between services for different age groups and across NHS primary, secondary and tertiary boundaries, with evidence of discrimination, abuse and neglect across the range of health services.

The inquiry highlighted a number of conditions which had brought this about and which are of note when considering the commissioning of services.

- People with learning disabilities are not visible or identifiable to the NHS, and data and information on their care pathways is largely lacking, inadequately co-ordinated and not well understood.
- The health needs of people with learning disabilities are not understood in primary care with a knock-on impact on access to health promotion and ill health prevention, as well as treatment.
- The health needs of people with learning disabilities do not seem to be a priority for the NHS – while mentioned in the operating framework for the NHS in England 2008/09 (and again in 2009/10), they are a level 3 priority in the *Vital signs* and hence not subject to robust national performance management.
- Compliance with the legislative framework is not monitored or performance-managed.

- Healthcare regulators and inspectors do not focus specifically on the quality of health services provided for people with learning disabilities. This is a particular problem in primary care where governance and assurance processes are less well developed.
- Lack of knowledge and information means that timely, appropriate and reasonable adjustments are not easy to make, even where services are keen to adapt their approach.
- Training about learning disability in undergraduate and postgraduate education is very limited.
- In the absence of training, the “ignorance and fear provoked” reinforces negative attitudes and values which contribute to a failure to deliver equal treatment or treat people with dignity and respect.

While problems in services for people with learning disabilities have been well rehearsed, in practice, services are still not meeting their needs despite the clear policy direction. Participants in the NHS Confederation’s expert seminar articulated the position very clearly – good commissioning of services, including the reasonable adjustments necessary for those with learning disabilities, will deliver high-quality services which are accessible and appropriate for all. Getting it right for those with learning disabilities gets it right for everyone.

Improving commissioning

Local strategic approaches to learning disability services are vital

Seminar participants were clear that there should be a strategic, co-ordinated approach to commissioning healthcare for people

‘In practice, services are still not meeting needs despite the clear policy direction’

with learning disabilities within any local system. This includes the reasonable adjustments necessary

in mainstream services, as well as specialist services for those with more complex conditions. For some specialist services, joint commissioning across several PCTs is necessary and needs to be encouraged at regional or

Current legislative and support framework

Human Rights Act 1998

This includes the monitoring of compliance by the Commission for Equality and Human Rights.

Disability Discrimination Act 2005

All NHS bodies must draw up a disability equality scheme setting out how they will promote equality of opportunity for disabled people.

Mental Capacity Act 2005

This includes the Code of Practice which provides guidance and information for those working with or caring for those who cannot make decisions for themselves. It sets out good practice in caring for those in need.

Inclusion in the Quality and Outcomes Framework (QOF)

GPs are rewarded for establishing a register of their patients over 18 years with a learning disability.

Operating Framework requirement for PCTs

There is a requirement to develop local action to improve services for people with learning disabilities through reasonable adjustments and through the directed enhanced service (DES) for annual health checks. PCTs must ensure effective communication and partnership working is in place between healthcare providers and primary care to improve the overall quality of healthcare.

Support for local services from Valuing People Support Team – with support for local enhanced services schemes based on a primary care framework for managing the health of people with learning disabilities

The framework, produced by Primary Care Contracting for the DH, gives guidance on health facilitation, health action planning, the role of community learning disabilities teams and DES. Linked materials on introducing health checks were produced in association with the Foundation for People with Learning Disabilities.

Regional self-assessment and performance framework

This is being piloted in Yorkshire and Humber SHA and covers four main areas: completing resettlement and campus re-provision, addressing health inequalities, making sure people are safe, and continuing to achieve *Valuing people* objectives.

Valuing people now: a new three-year strategy for people with learning disabilities (2009)

This sets out the cross-government strategy for people with a learning disability, and includes the Government’s response to the ten main recommendations in the report *Healthcare for All*.

sub-regional levels. However, with this comes the requirement to ensure that local visions work synergistically and that health scrutiny and health impact assessments take into account the cross-PCT nature of services.

Positioning of local services within a public health context improves visibility

Where people with learning disabilities are part of public health approaches and the local health inequalities agenda, their visibility within commissioning is increased. Placing their needs in a public health context also enables greater access to a variety of funding streams. Many of the mainstream service issues for people with learning disabilities were felt by seminar participants to fall within the context of improving the accessibility of healthcare services and in health promotion and ill health prevention.

Good information supports development

The inclusion of people with learning disabilities specifically as part of the overall joint strategic needs assessment is central. Recent estimates show a likely increase in the number of people with learning disabilities of around 8 per cent by 2011 and 14 per cent by 2021. Such projections can help to make the case for this being core commissioning business, but better and more comparative local data is important to form a good basis for decisions. This includes the gathering of data to ensure that the reach of services meets need. For sub-regional specialist services, data needs to be capable of aggregation across PCTs. The development of the minimum data set across health and social care needs to happen alongside a reconsideration of learning disabilities indicators in *Vital signs*.

Better data is also needed on outcomes and the impact of healthcare. The international Pomona project has been working to develop a set of indicators that can be linked to health indicators for the whole population.

Commissioning capacity needs developing

The development of regional plans in response to the Next Stage Review has highlighted the differences in approach to commissioning both mainstream and specialist services in

Case study: NHS Westminster

The development of a local enhanced service (LES) in Westminster PCT has been part of a whole system approach to increase access to the NHS and other services for people with learning disabilities. This is co-ordinated through the Westminster Learning Disability Partnership. The partnership includes the city council, voluntary sector representatives, service users and carers. Specific working groups are happening with Imperial College Healthcare Trust and Central and North West London Mental Health Foundation Trust. The LES includes annual health checks and health action plans for people with learning disabilities, more training for staff, longer appointment slots and more accessible health promotion advice. Alongside this, public health data has been collected enabling more responsive and evidence-based services to be commissioned by the PCT and other local partners.

One of the key success factors has been the extent of collaboration with local practices and feedback from service users. The project which has been running for three years has taken an incremental approach, focusing on processes in the first year, outputs and outcomes in the second and value for money and balanced scorecard approaches in the third. LES outcomes have been striking. Numbers of patients with a recorded body mass index have risen from 35 per cent in 2005 to 80 per cent in 2007/08 with similar rises in blood pressure checks (from 41 per cent in 2005 to 82.5 per cent in 2007/08). Health action plans are now available for around 75 per cent of patients.

Case study: NHS Lincolnshire

The East Midlands SHA has included learning disabilities as one of its themes in its regional NHS Next Stage Review. This has been reflected in the commissioning intentions for NHS Lincolnshire, which has included it as one of its 14 priorities in its five-year strategic plan. Its work programme includes a redesign of its services, focusing particularly on health inequalities and access to mainstream services by creating liaison roles across mental health, primary care and acute settings; the use of the DES to deliver annual health checks; and the development of community multi-disciplinary teams with a focus on health facilitation.

Alongside this, the commissioning of specialist health services includes reviews of the assessment and treatment capacity, redesign of community services and development of active case management for complex and forensic cases. The commissioning of an assertive outreach and crisis intervention service are also part of the redesign process.

'Promoting good health is everyone's business, so social care providers also need to pay attention to health and access to healthcare'

different parts of the country. They have also shown the need to ensure that robust linkages are made between different workstreams within individual SHA regions.

There must be an impetus to keep health improvement high on the agenda, following the transfer of social care funding to local authorities and as the re-provision of campuses draws to a close. The commissioning of health services will remain the responsibility of PCTs, but there is concern that this will not be seen as core business even following the report of the Michael inquiry.

Commissioning capacity to deal with specialist services could be further developed. Seminar participants felt that, on occasion, some PCTs had focused too much on the commissioning of specialist services and now needed to widen their horizons considerably.

Finally, practice-based commissioning as it develops should include specific attention to the growing number of vulnerable adults, to ensure that they are not disadvantaged, if they need additional or longer-term support.

Directed enhanced and local enhanced services were seen as an appropriate first priority

While the DES was seen as a step forward some concerns were raised about both its implementation across the country and its coverage of people with mild learning disabilities. Some LES arrangements were more

comprehensive and the emphasis must be on getting the process and outcomes right rather than a rigid centralised approach. People already registered with social care were seen as a first priority for improved health promotion services.

All commissioned services need to pay attention to health

Promoting good health is everyone's business, so social care providers also need to pay attention to health and access to healthcare. Each person with a learning disability should have a health action plan.

Market readiness should be assessed

Some issues remain about the readiness of the market to deliver the agenda, particularly where the combination of personalised and more traditional services are required. As the market of providers is diverse, including third sector, independent and statutory services, help for both commissioners and providers will be necessary to develop and deliver services of a high quality that meet the needs of people with learning disabilities. The assessment of market readiness is a first step in this and should be a central part in the commissioning process.

Investment in family carers is needed as well as investment in professional capabilities

Much of the support for people with learning disabilities is delivered by family carers. The development of the Carers' Strategy and the delivery of services that meet the needs of family carers require attention to the health of family carers themselves (for example, through health checks). In addition health services need to recognise and work with the expertise of family carers who are supporting a disabled person.

PCT Network viewpoint

The development of world-class commissioning for PCTs is a key driver in the current health reform process. Partly, this will involve the development of new alliances with service users and providers, the delivery of choice, and the increasing personalisation of services. However, for the care of some groups of individuals to improve, a mix of strongly commissioned and personally tailored services will be necessary. This is particularly the case for people with learning disabilities where the NHS performance has been variable despite the range of central guidance already in place. There are several challenges that arise as a result of this.

The care of people with learning disabilities is one area where local partnerships have a major role to plan in the shaping, commissioning and delivery of good quality and accessible services. The importance of profile both within individual organisations and across partnerships locally was frequently mentioned in our seminar and was clear in the strategic plans produced by the PCTs outlined in the case studies on page 4.

Information gathering and stronger outcome measures are also essential to provide ongoing monitoring of how services are developing and delivering against the challenges set through the Michael inquiry's recommendations. Improvements in information and information sharing are needed to get the most out of local services and ensure good co-ordination of individual care plans. This will be a challenge for both commissioners and providers in the short term. The development

'Improvements in information and information sharing are needed to get the most out of local services'

of good local protocols will be necessary to help deliver this within the framework of local authority information systems and the NHS National Programme for IT.

The final challenge set out in the Michael inquiry, and indeed previous government reports, is to ensure that priority is given, not just to specialist services but, in particular, to delivering mainstream services in such a way that the reasonable adjustments which should be made for people with learning disabilities are always considered in the way services are designed. Our seminar participants were clear that good commissioning for this group will produce a template that could deliver improved services for other disadvantaged groups. This, more than anything, is a pointer for commissioners that delivering against the Michael's inquiry findings will not only improve outcomes for this group, but should improve commissioning performance overall. For more information on the issues covered in this *Briefing*, contact yvonne.cox@nhsconfed.org or jo.webber@nhsconfed.org

Improvement tips for commissioners

- Support a group of people with learning disabilities to look at your disability equality scheme and suggest how it could include learning disabilities.
- Review your Darzi workstreams and see where the health of people with learning disabilities could be included.
- Ensure that the specification for the community learning disability team includes wider support for health action planning and health facilitation, using the new guidance when it comes out.
- Explore how you can get involved and contribute to the development of the self-assessment and performance framework.
- Find out about and get involved in support networks within your region and make use of the national good practice networks.

Provided by the Foundation for People with Learning Disabilities.

Further information

Michael, Jonathan and Richardson, Anne. 2008: *Healthcare for all: the independent inquiry into access to healthcare for people with learning disabilities*.

Valuing people; a new strategy for learning disability for the 21st century. Department of Health, 2001.

Valuing people now: from progress to transformation. Department of Health, 2009.

The Primary Care Trust Network

The PCT Network was established as part of the NHS Confederation to provide a distinct voice for PCTs. We aim to improve the system for the public, patients and staff by raising the profile of the issues affecting PCTs and strengthening the influence of PCT members.

For more information on the work of the PCT Network, visit www.nhsconfed.org/Networks/primarycaretrust

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