

# EXECUTIVE SUMMARY

The health and strength of a society can be measured by how well it cares for its most vulnerable members. For a variety of reasons, including the way society behaves towards them, adults and children with learning disabilities, especially those with severe disability and the most complex needs are some of the most vulnerable members of our society today. They also have significantly worse health than others. The Inquiry has found convincing evidence that people with learning disabilities have higher levels of unmet need and receive less effective treatment, despite the fact that the Disability Discrimination Act and Mental Capacity Act set out a clear legal framework for the delivery of equal treatment. Why has the Inquiry concluded this? The research evidence, the responses to our consultation, and the information provided by our witnesses tell us very clearly that:

- ◆ People with learning disabilities find it much harder than other people to access assessment and treatment for general health problems that have nothing directly to do with their disability.
- ◆ There is insufficient attention given to making reasonable adjustments to support the delivery of equal treatment, as required by the Disability Discrimination Act. Adjustments are not always made to allow for communication problems, difficulty in understanding (cognitive impairment), or the anxieties and preferences of individuals concerning their treatment.
- ◆ Parents and carers of adults and children with learning disabilities often find their opinions and assessments ignored by healthcare professionals, even though they often have the best information about, and understanding of, the people they support. They struggle to be accepted as effective partners in care by those involved in providing general healthcare; their complaints are not heard; they are expected to do too much of the care that should be provided by the health system and are often required to provide care beyond their personal resources.
- ◆ Health service staff, particularly those working in general healthcare, have very limited knowledge about learning disability. They are unfamiliar with the legislative framework, and commonly fail to understand that a right to equal treatment does not mean treatment should be the same. The health needs, communication problems, and cognitive impairment characteristic of learning disability in particular are poorly understood. Staff are not familiar with what help they should provide or from whom to get expert advice
- ◆ Partnership working and communication (between different agencies providing care, between services for different age groups, and across NHS primary, secondary and tertiary boundaries) is poor in relation to services for adults with learning disabilities. This problem is not restricted to services used by people with learning disabilities but particularly affects those who may not be able to communicate for themselves, or whose treatment needs careful planning and coordination because they have complex needs.
- ◆ Although there are examples of good practice, which the report highlights, witnesses described some appalling examples of discrimination, abuse and neglect across the range of health services.

The Inquiry believes that there are several reasons for these most disturbing findings which contravene the law as well as the fundamental principles of compassion, caring and the provision of appropriate treatment that lie at the heart of professional standards and of the NHS:

- ◆ People with learning disabilities are not visible or identifiable to health services, and hence the quality of their care is impossible to assess. Data and information on this sub-set of the population and their journeys through the general healthcare system is largely lacking and what exists is inadequately co-ordinated or understood.
- ◆ Lack of awareness of the health needs of people with learning disabilities is striking in primary care and this is particularly important since primary care is the single point of access to health promotion and ill health prevention, as well as most health care and treatment.
- ◆ The health needs of people with learning disabilities do not appear to represent a priority for the NHS. Although the Operating Framework for the NHS in England for 2008/9 refers to the need to ensure that appropriate care is provided, the detailed guidance 'Vital Signs' gives this area only Level 3 priority. This means that it is a matter for local not national decision and is not subject to the same rigorous performance management as a national priority.
- ◆ Compliance with the legislative framework covering disability discrimination and mental capacity is not effectively monitored nor performance managed in primary, community, secondary or specialist care services.
- ◆ Neither healthcare inspectors nor regulators focus specifically on the quality of health services provided for people with learning disability, so they slip through the inspectorial and regulatory net. This is a particular problem in primary care where governance and assurance processes and the levers for managing performance are less well developed and are less clear than in hospital settings.
- ◆ Despite examples of good practice across the country, the lack of knowledge and information means that timely, appropriate and 'reasonable adjustments' as defined by the disability legislation are not easy to make, even when services are keen to adapt their approach for people with learning disabilities.
- ◆ Training and education about learning disability provided to undergraduates and postgraduate clinical staff, in primary care and in hospital services across the NHS is very limited.
- ◆ Together with the ignorance and fear that is often provoked in the absence of training, these factors reinforce negative attitudes and values towards people with learning disabilities and their carers and contribute significantly to a failure to deliver equal treatment, or to treat people with dignity or respect.

The Government through the Department of Health, the Department for Children, Schools and Families and the Department for Innovation, Universities and Skills (formerly DfES) and the Department for Communities and Local Government have taken steps to ensure that there is a comprehensive legislative and advisory framework to prevent discrimination. However, the evidence suggests that there is a lack of awareness and understanding in the wider NHS concerning the action that this legislation and guidance should prompt and hence, behaviour is slow to change. The legislative and advisory framework includes:

- ◆ Legislation (the Disability Discrimination Act 2005, Mental Capacity Act 2005, Care Standards Act 2000 and carers' legislation.<sup>1</sup>)

<sup>1</sup> More information about the legislative framework may be found at <http://www.officefordisability.gov.uk> and <http://www.equalityhumanrights.com>

- ◆ New arrangements to monitor compliance by the Commission for Equality and Human Rights.
- ◆ Reform of the General Medical Services (GMS) contract so that general medical practitioners (GPs) can earn points through the Quality and Outcome Framework by establishing a register of their patients over eighteen years old with a learning disability.
- ◆ A primary care service framework for managing the health of people with learning disabilities from Primary Care Contracting.<sup>2</sup>
- ◆ A requirement in the Operating Framework for 2008/09<sup>3</sup> for all PCTs to develop local action to improve services, including general health services for people with learning disabilities.
- ◆ A focus on health issues in 'Valuing People'<sup>4</sup> and support for local services from the Valuing People Support Team and a series of regional events to promote the primary care framework and support services to develop Local Enhanced Schemes.
- ◆ A range of guidance including on health checks, health facilitation, health action planning, the role of community learning disabilities teams (CLDTs), and how to develop Disability Equality Schemes.

Individual local health service commissioners and providers have also taken steps to improve healthcare for people with learning disabilities. These examples help to demonstrate what it is possible to achieve, but good practice is very patchy and far from common. For the most part, innovation and good practice owes more to the enthusiasm of energetic individuals than to any structured and systematic engagement by health services. The following providers exemplify some of the best practice and are to be commended:

- ◆ Improved primary care services in Westminster, South Birmingham, Surrey and other parts of the country where Local Enhanced Schemes have been, or are being, developed.
- ◆ A learning disabilities specialist providing input to public health teams in Bristol Primary Care Trust.
- ◆ Effective liaison between acute general and specialised services and health facilitation in South Staffordshire and Shropshire Healthcare NHS Foundation Trust, and Humber Mental Health Teaching NHS Trust.
- ◆ Patient records systems in Gloucestershire Partnership Trust, Oldham PCT and Sheffield Teaching Hospital Foundation NHS Trust that signal special needs using a traffic lights scheme.
- ◆ A medical records system in Torbay Hospital that signals when someone has a communication need.
- ◆ Effective self-assessment and performance management through a framework of standards, key objectives in Yorkshire and Humber SHA.
- ◆ A high quality of teaching for medical students at St. George's, University of London with a direct contribution from people with learning disabilities.
- ◆ Local scrutiny of access to health care for people with learning disabilities by Haringey local authority's Overview and Scrutiny Committee.

The Inquiry is of the view that much stronger action is required at all levels to deliver equal access to routine health care services including ill health prevention, health

<sup>2</sup> Management of health for people with learning disability in primary care. Department of Health. London. 2007.

<sup>3</sup> The NHS in England: the operating framework for 2008/09, Department of Health. London. 2007.

<sup>4</sup> Valuing people: a new strategy for learning disability for the 21st century. Department of Health. London. 2001.

promotion, and timely action to address general health problems across the English NHS for people with learning disabilities. Action is needed to ensure that all service providers meet their obligations under existing legislation and provide effective treatment and care without discrimination.

There is no simple or single solution. The requirement is to make the health system across the country work as effectively for this group of the population as it does for any other. Much more effective leadership at all levels of the health service is essential. Systems of inspection and regulation must be strengthened.

To achieve an effective, fair system of general health care for people with learning disabilities, who also happen to have health problems, the Inquiry makes ten principal recommendations. Other recommendations to strengthen the service further are included in the body of the report.

## RECOMMENDATIONS

- ◆ The Department of Health should immediately amend Core Standards for Better Health, to include an explicit reference to the requirement to make 'reasonable adjustments' to the provision and delivery of services for vulnerable groups, in accordance with the disability equality legislation. The framework that is planned to replace these core standards in 2010 should also include a specific reference to this requirement.

RECOMMENDATION 6

- ◆ The Department of Health should direct primary care trusts (PCTs) to secure general health services that make 'reasonable adjustments' for people with learning disabilities through a Directed Enhanced Service. In particular, the Department should direct PCTs to commission enhanced primary care services which include regular health checks provided by GP practices and improve data, communication and cross-boundary partnership working. This should include liaison staff who work with primary care services to improve the overall quality of health care for people with learning disabilities across the spectrum of care.

RECOMMENDATION 8

- ◆ To raise awareness in the health service of the risk of premature avoidable death, and to promote sustainable good practice in local assessment, management and evaluation of services, the Department of Health should establish a learning disabilities Public Health Observatory. This should be supplemented by a time-limited Confidential Inquiry into premature deaths in people with learning disabilities to provide evidence for clinical and professional staff of the extent of the problem and guidance on prevention.

RECOMMENDATION 5

- ◆ Those with responsibility for the provision and regulation of undergraduate and postgraduate clinical training, must ensure that curricula include mandatory training in learning disabilities. It should be competence-based and involve people with learning disabilities and their carers in providing training.

RECOMMENDATION 1

- ◆ Inspectors and regulators of the health service should develop and extend their monitoring of the standard of general health services provided for people with learning disabilities, in both the hospital sector and in the community where

primary care providers are located. The aim is to support appropriate, reasonable adjustments to general health services for adults and children with learning disabilities and their families and to ensure compliance with and enforcement of all aspects of the Disability Discrimination Act. Healthcare regulators and inspectors (and the Care Quality Commission, once established) should strengthen their work in partnership with each other and with the Commission for Equality and Human Rights, the National Patient Safety Agency and Office for Disability Issues).

#### RECOMMENDATION 7

- ◆ All healthcare organisations, including the Department of Health should ensure that they collect the data and information necessary to allow people with learning disability to be identified by the health service and their pathways of care tracked.

#### RECOMMENDATION 2

- ◆ All Trust Boards should demonstrate in routine public reports that they have effective systems in place to deliver effective, 'reasonably adjusted' health services for those people who happen to have a learning disability. This 'adjustment' should include arrangements to provide advocacy for all those who need it, and arrangements to secure effective representation on PALS from all client groups including people with learning disabilities.

#### RECOMMENDATION 10

- ◆ Section 242 of the National Health Service Act 2006 requires NHS bodies to involve and consult patients and the public in the planning and development of services, and in decisions affecting the operation of services. All Trust Boards should ensure that the views and interests of people with learning disabilities and their carers are included.

#### RECOMMENDATION 9

- ◆ Family and other carers should be involved as a matter of course as partners in the provision of treatment and care, unless good reason is given, and Trust Boards should ensure that reasonable adjustments are made to enable them to do this effectively. This will include the provision of information, but may also involve practical support and service co-ordination.

#### RECOMMENDATION 3

- ◆ Primary care trusts should identify and assess the needs of people with learning disabilities and their carers as part of their Joint Strategic Needs Assessment. They should consult with their Local Strategic Partnership, their Learning Disability Partnership Boards and relevant voluntary user-led learning disability organisations and use the information to inform the development of Local Area Agreements.

#### RECOMMENDATION 4

These recommendations concern the 'reasonable adjustments' that are needed to make health care services as accessible to people with learning disabilities as they are to other people. An annual health check; support when a visit to hospital is needed; help to communicate; better information, and tighter inspection and regulation will all work to reduce inequalities in access to and outcomes from healthcare services.