

# HEALTHCARE FOR ALL

REPORT OF THE  
INDEPENDENT INQUIRY INTO  
ACCESS TO HEALTHCARE FOR PEOPLE  
WITH LEARNING DISABILITIES

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JULY 2008

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# FOREWORD

As the NHS reaches its 60th anniversary and continues to develop and grow, it is right that we celebrate its many achievements. Standards have risen, investment has grown; quality and delivery have improved. There are however still people in our society who do not receive the service they are entitled to expect. How to ensure that they do, lies at the heart of the challenge to deliver universal, fair, equally accessible and effective healthcare to all those who are entitled to receive it.

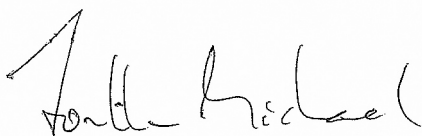
I welcomed Patricia Hewitt's invitation to chair an Inquiry into healthcare for people with learning disabilities, because I was shocked when I read in Mencap's report 'Death by indifference', about the experiences of six families whose relatives died. Being a former consultant physician and acute hospital chief executive, it was not immediately clear to me why I was asked to undertake the Inquiry as I did not have any special expertise in learning disabilities.

I have since recognised that addressing the difficulties faced by people with learning disabilities in accessing general healthcare services does not require specialist knowledge about learning disabilities; the issues they face are relevant to all members of society. What matters is that people with learning disabilities are included as equal citizens, with equal rights of access to equally effective treatment. I have also learnt that 'equal' does not always mean 'the same' and the 'reasonable adjustments' that are needed to make services equally accessible to people with learning disabilities, are not particularly difficult to make.

It was shocking to discover that the experiences of the families described in Mencap's report are by no means isolated, despite a clear framework of legislation against discrimination. I was however, impressed by the many examples of good practice that the Inquiry uncovered and I am clear that we do not need new legislation to make the essential changes that are required from the NHS.

Instead, we need to ensure that good practice is encouraged to spread more widely, and we need to significantly improve the effectiveness of inspection and regulation in this area. By doing this, I believe that it is possible to deliver effective healthcare for people with learning disabilities and reduce what is currently an unacceptable level of avoidable health risk.

I am grateful to all those experts and professionals, as well as those individuals with learning disabilities and their carers, who helped me to understand the issues, and who helped me to make what I hope will be a clear set of practical recommendations for change.



Sir Jonathan Michael

July 2008



# 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.



# THE NATURE OF THE PROBLEM

# 1

THIS CHAPTER contains information about the background to the work of the Inquiry, the prevalence of and type of health risks presented by adults and children with learning disabilities as well as issues for carers.

## 1.1 INTRODUCTION

The Independent Inquiry, chaired by Sir Jonathan Michael MB, BS, FRCP, FRC, formerly the Chief Executive of Guy's and St Thomas' NHS Foundation Trust, was announced on 31 May 2007 following publication of the Mencap report *Death by Indifference*<sup>5</sup>. Building on the Mencap report 'Treat Me Right', 'Death by Indifference' described the circumstances surrounding the deaths of six people with a learning disability whilst they were in the care of the NHS. The year before, the Disability Rights Commission (DRC 2006) Formal Investigation (FI) 'Equal treatment: Closing the Gap'<sup>6</sup> had also highlighted failings in access to, and delivery of appropriate treatment in primary care for people with learning disabilities.

In response to these reports, Sir Jonathan Michael was asked by Patricia Hewitt, the then Secretary of State for Health, to identify the action needed to ensure adults and children with learning disabilities receive appropriate medical treatment in the NHS (not specialised learning disability services or mental health services). A copy of the Terms of Reference (TOR) may be found at Annex 1. An outline of the methodology used by the Inquiry may be found at Annex 2 with details of the two expert panels appointed to support Sir Jonathan.

The Inquiry's findings are based on a public consultation, a review of research, and evidence gathered from witnesses and stakeholders between June 2007 and June 2008. A summary of themes arising out of the public consultation is provided at Annex 3. A list of the people providing evidence, including in face-to-face meetings, is provided at Annex 4. Over 600 respondents supplied information. The Inquiry team is most grateful to them all for their contribution.

The TOR required the Inquiry to 'learn lessons from the six cases highlighted in the Mencap report' (see Annex 1). The Inquiry's report, with permission from the families, takes account of the Health Service Ombudsman's draft reports into the complaints they made, along with their comments. The Inquiry report therefore complements and supplements the work undertaken by the Ombudsman. It identifies the extent to which the experiences of

<sup>5</sup> Death by indifference: following up the Treat me right! report. Mencap. London. 2007.

<sup>6</sup> Equal treatment: closing the gap. Disability Rights Commission. London. 2006.

those families appear to be widespread in the NHS. It sets out the action needed to ensure that all adults and children with learning disabilities receive appropriate (effective, personalised, and safe) general healthcare and treatment.

The following section contains information about the prevalence of learning disability and health risks; the quality of general health treatment and care available, and the views of carers.

## 1.2 BACKGROUND

### 1.2.1 Prevalence

The term learning disability is used throughout this report to ensure distinction from the broad range of learning difficulties that may impede educational attainment in people within the average range of intelligence. The presence of a low Intelligence Quotient (IQ) is not sufficient alone, however, in defining people with learning disability. The Inquiry adopted the definition provided in *Valuing People* (Department of Health, 2001, *op cit*) as meaning 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.

Estimates of the prevalence of learning disability<sup>7</sup> vary reflecting differences in definition. Department of Health figures suggest that about 1.5 million people (around 2.5 per cent of the UK population) has a learning disability. Emerson and Hatton<sup>8</sup> suggest that three per cent of children and two per cent of adults fall into the category overall. Of these, 1.2 million people have mild to moderate learning disability and around 210,000 (about a third of one per cent) have severe and profound learning disabilities. This latter group includes 65,000 children and young people, 120,000 adults of working age and 25,000 older people.

The prevalence of learning disability in the general population is expected to rise by around one per cent per annum for the next 10 years and to grow overall by over ten per cent by 2020. It is also expected that there will be a growth in the complexity of disabilities. This is attributable to improvements in maternal and neonatal care and improvements in general health care for adults which lead to increased life expectancy. Increasing use of alcohol in the UK and rates of unplanned teenage pregnancy are also expected to contribute to increases in the prevalence of foetal alcohol syndrome. In addition, there are increases anticipated in the proportion of younger English adults from South Asian minority ethnic communities<sup>9,10</sup> where the prevalence of learning disability is higher<sup>11</sup>.

Severe learning disability is relatively evenly spread in the population. However, mild to moderate learning disability is linked with poverty and rates are higher in deprived and urban areas. Rates also vary according to service location. In prisons, for example, rates of learning disability are said to lie around 7 per cent depending on the definition of learning disability used (ONS, 1998<sup>12</sup>, HMP Styal, 2007<sup>13</sup>). Rates may also be higher in those parts of the country where a large learning disability hospital previously existed

<sup>7</sup> See Annex 2 for definitions of the terms used in this report.

<sup>8</sup> Emerson E, Hatton C. Estimating the current need/demand for support for people with learning disabilities in England. Lancaster University. 2004.

<sup>9</sup> *Valuing people*: *op cit*.

<sup>10</sup> Estimating future need/demand for support for adults with learning disabilities. *op cit*.

<sup>11</sup> Emerson E et al. Is there an increased prevalence of severe learning disabilities among British Asians? *Ethnicity & Health*. 1997; 2(4): p. 317-321.

<sup>12</sup> Singleton N et al. Psychiatric morbidity among prisoners in England and Wales. ONS. The Stationery Office. 1998.

<sup>13</sup> Mottram P. HMP Liverpool, Styal and Hindley study report. University of Liverpool. 2007.

(e.g. Bristol) since former residents tend to be re-housed locally. Overall, most people with learning disability live in the community most usually with their families.

These figures mean that a GMS doctor with a list of 2,000 patients will have about six patients with severe learning disabilities and about 44 with mild-moderate learning disabilities although the rate will vary widely between different practices.

### 1.2.2 Health and behaviour

There are a number of health issues affecting people with learning disabilities. Hollins et al. (1998)<sup>14</sup> suggest that people with learning disabilities are 58 times more likely to die before the age of 50 than the general population. This is partly because conditions associated with learning disability raise the risk of premature unavoidable death. For example, almost half of all people with Down's syndrome have congenital heart problems, a much higher rate than the general population; they have higher risk of developing Alzheimer's disease (Holland et al., 1998<sup>15</sup>) and a higher risk of gastrointestinal problems and cancer<sup>16</sup>.

Early death may also be associated with difficulties that, to some degree, are preventable. Up to a third of people with learning disabilities, for example, have an associated physical disability, most often cerebral palsy which puts them at risk of postural deformities, hip dislocation, chest infections, eating and swallowing problems (dysphagia), gastro-oesophageal reflux, constipation and incontinence. They tend to have osteoporosis younger than the general population and have more fractures<sup>17</sup>.

Approximately a third of people with learning disabilities have epilepsy (at least twenty times higher than the general population) and more have epilepsy that is hard to control (Branford, 1998<sup>18</sup>). The risks of sudden unexpected death in epilepsy (SUDEP) are highest in children with learning disability<sup>19</sup> and the NICE audit (2002<sup>20</sup>) indicated that almost 60 per cent of child deaths and almost 40 per cent of adult deaths were potentially avoidable. Poor documentation, communication and information sharing were implicated in a large number of these cases.

“I don't like needles” [person with a learning disability]

Mental ill health is also more common amongst people (both adults and children) with learning disabilities (Elliott et al, 2003<sup>21</sup>, RCN, 2007<sup>22</sup>). For example, schizophrenia occurs in around three per cent of people with a learning disability compared to one per cent in the general population<sup>23</sup>.

<sup>14</sup> Hollins S, Attard MT, von Fraunhofer N, Sedgwick P. Mortality in people with learning disability: risks, causes, and death certification findings in London. *Developmental Medicine & Child Neurology*. 1998; (40): 50-6.

<sup>15</sup> Holland A, et al. Population based study of the prevalence and presentation of dementia in adults with Down's syndrome. *British Journal of Psychiatry*. 1998; (172):493-8.

<sup>16</sup> Cooke LB. Cancer and learning disability. *Journal of Intellectual Disability Research*. 1997; 41(4):312-316.

<sup>17</sup> Aspray TJ, et al. Comparison of ultrasound measurements at the heel between adults with mental retardation and control subjects— a prospective study. *Bone*. 1998; (22): 665.

<sup>18</sup> Branford D, Bhaumik S, Duncan F. Epilepsy in adults with learning disabilities. *Seizure*. 1998; (7):473-7.

<sup>19</sup> Epilepsy Bereaved. <http://www.sudep.org>

<sup>20</sup> The epilepsies: diagnosis and management of the epilepsies in adults and children in primary and secondary care. National Institute for Clinical Excellence. London. 2004.

<sup>21</sup> Elliott J, Hatton C, Emerson E. The health of people with learning disabilities in the UK: evidence and implications for the NHS. *Journal of Integrated Care*. 2003; (11): 9-17.

<sup>22</sup> Mental health nursing of adults with learning disabilities. Royal College of Nursing, London. 2007.

<sup>23</sup> Doody GA, et al. 'Ppofschizophrenie' revisited. Schizophrenia in people with mild learning disability. *British Journal of Psychiatry*. 1998; 173(2): 145-153.

Co-morbid conditions such as autism and attention deficit hyperactivity disorder are also more common (Allington-Smith, P 2006<sup>24</sup>). Around 15 per cent of people with learning disabilities display what is commonly called ‘challenging behaviour’ although estimates vary owing to differences in the way that ‘challenging’ is defined<sup>25</sup>.

As well as worse health, people with learning disabilities present a range of common health risks. These include obesity exacerbated by a sedentary lifestyle and a restricted range of opportunities to exercise or eat healthily (Messent et al, 1998<sup>26, 27</sup>). However, smoking and substance misuse are less common. Coupled with sensory impairments (loss of sight and/or hearing<sup>28</sup>) which are common amongst people with learning disability, the cognitive impairment that lies at the heart of learning disability means that health risks are very difficult for individuals to manage by themselves. People with learning disabilities can find it more difficult to identify and describe symptoms of illness, and much harder to navigate the health system to obtain treatment. These problems also make it more difficult for NHS professionals to deliver treatment effectively.

“The doctor wouldn’t look at me. Just talked to my carer.”  
[person with a learning disability]

Overall, it appears that life expectancy is shortest for those with the greatest support needs<sup>29</sup> and the most complex and/or multiple (‘co-morbid’) conditions. In Hollins’ study for example, 52 per cent of those who died also had respiratory disease compared to 15-17 per cent in the general population. Early death in the learning disabilities group was significantly associated with cerebral palsy, incontinence, problems with mobility and residence in hospital. In another controlled study by Halstead et al<sup>30</sup> (2000) behavioural disturbance and disability were better predictors of a low volume and poor quality of primary care than the client’s location (community or residential care). It also seems that ethnicity is a salient factor with morbidity and mortality being higher amongst those with learning disability from a minority ethnic community (Mir et al, 2004)<sup>31</sup>.

Together, the evidence suggests there is unmet health need amongst people with learning disabilities. Research in Wales supports the suggestion that levels of unmet need are, furthermore, relatively high. The ‘Primary care, Evaluation Audit and Research in Learning disabilities’ (PEARL) study (2002) by the Welsh Centre for Learning Disabilities found that of 181 people with learning disabilities who underwent a health review, over half had a new health need identified. The health issues included diabetes, hypertension, high cholesterol, thyroid disorders, dental problems, cardiac difficulties, asthma and mental health difficulties<sup>32</sup>.

The Inquiry believes that the findings on health needs, unmet needs, and variation in health outcome for people with learning disabilities strongly imply that in addition to avoidable morbidity, there are deaths occurring which could be avoided.

<sup>24</sup> Allington-Smith P. Mental health of children with learning disabilities. *Advances in Psychiatric Treatment*. 2007; 12(2): 130-137.

<sup>25</sup> Mansell J. Services for people with learning disabilities and challenging behaviour or mental health needs. Department of Health. London. 2007.

<sup>26</sup> Messent PR, Cooke CB, Long J. Physical activity, exercise and health of adults with mild and moderate learning disabilities’. *British Journal of Learning Disabilities*. 1998; 26:17-22 (and *Disability and Rehabilitation*. 20(11):424-7. Cochrane Register).

<sup>27</sup> Emerson E. Underweight, obesity and exercise among adults with intellectual disabilities in supported accommodation in Northern England. *Journal of Intellectual Disability Research*. 2005; 42:134-143.

<sup>28</sup> Carvill S. Sensory impairments, intellectual disability and psychiatry. *Journal of Intellectual Disability Research*. 2001; 45(6):467-483.

<sup>29</sup> Bittles AH, et al. The influence of intellectual disability on life expectancy. *Journal of Gerontology Series A Biological Sciences and Medical Sciences*. 2002; 57(7):470-472.

<sup>30</sup> Halstead S, Milne A, Wright E, Hollins S. Annual primary care contacts by people with intellectual disabilities: a comparison of three matched groups. *Journal of Applied Research in Intellectual Disabilities*. 2000; (13): 100-107.

<sup>31</sup> Mir G, et al. Learning difficulties and ethnicity. Department of Health. London. 2004.

<sup>32</sup> Baxter H, Lowe K, Houston H, Jones G, Felce D, Kerr M. Previously unidentified morbidity in patients with intellectual disability. *British Journal of General Practice*. 2006; (56): 93-98.



### 1.2.3 Treatment and care

There is nonetheless evidence that health interventions when delivered, can make a difference (Chapman et al, 2005<sup>33</sup>; Biswas et al., 2005<sup>34</sup>) and the Inquiry identified many examples of excellent practice in local service provision. This evidence shows how relatively simple changes in services can have a real impact on the health of people with learning disabilities and on their experience. For example, in Sandwell Mental Health NHS and Social Care Trust<sup>35</sup> an investigation<sup>36</sup> of the impact of implementing NICE epilepsy guidelines in an outpatient learning disability service showed significant improvements in seizure assessment, management and documentation. The Inquiry believes that good practice needs to be shared and more widely understood. Further information about good practice is provided in Chapter 3.

“I have attended the expert patient course in Sheffield. It has helped me to cut down my sweets and pop and eat more healthy food.”  
[person with a learning disability]

Research shows that people with learning disabilities have a higher uptake of medical and dental services but a lower uptake of surgical specialties. They have a similar overall rate of admissions but shorter stays<sup>37</sup>. Compared to the general population, people with learning disabilities and diabetes have fewer measurements of their BMI. Those who have had a stroke have fewer blood pressure checks. Cervical screening<sup>38</sup> and mammography are less likely to be undertaken<sup>39</sup>. Researchers argue that this is attributable to low levels of staff awareness regarding the needs of people with learning disabilities and to poor communication, for example, of messages about health promotion.

“Her GP had not seen her for nearly 20 years though he prescribed regularly. Eventually we discovered she had a gastric ulcer. The Health Action Plan is now addressing this.” [LD nurse]

People with learning disabilities are less likely to be given pain relief and less likely to receive palliative care (Tuffrey-Wijne, 2007<sup>40</sup>) especially if they are also from a minority ethnic group (Ahmed et al., 2004)<sup>41</sup>. Several accounts of the consequences of a failure to provide appropriate pain relief were given to the Inquiry team by carers and by the families whose cases were described in the Mencap report ‘Death by indifference’. One parent described vividly how symptoms of severe pain that she could see in her daughter were denied by staff because they mistakenly attributed them to her learning disability. There is also some evidence that staff believe people with learning disabilities have higher pain thresholds and carers, furthermore, allege that<sup>42</sup> that psychotropic (tranquillising) medication is over-prescribed but the Inquiry has not found independent evidence of this.

33 Chapman M, Craven M, Chadwick D. Fighting Fit? An evaluation of health practitioner input to improve healthy living and reduce obesity for adults with learning disabilities. *Journal of Intellectual Disabilities*. 2005; 9(2): 131-144.

34 Biswas M, Whalley H, et al. Women with learning disability and uptake of screening: audit of screening uptake before and after one to one counselling. *Journal of Public Health*. 2005; 27(4): 344-347.

35 Contact: estherwhitten@nhs.net

36 Whitten E, Griffiths A. Implementing epilepsy guidelines within a learning disability service. *Seizure*. 2007; (16): 471-478.

37 Morgan C, Ahmed Z, Kerr M. Health care provision for people with a learning disability: record-linkage study of epidemiology and factors contributing to hospital care uptake. *British Journal of Psychiatry*. 2006; (176): 37-41.

38 Davies N, Duff M. Breast cancer screening for older women with intellectual disability living in community group homes. *Journal of Intellectual Disability Research*. 2001; (45): 253-7.

39 Health needs assessment report: people with learning disabilities in Scotland. NHS Improvement Scotland. 2004.

40 Tuffrey-Wijne I, Hogg J, Curfs L. End of life and palliative care for people with intellectual disabilities who have cancer or other life-limiting illness: a review of the literature and available resources. *Journal of Applied Research in Intellectual Disabilities*. 2007; 20(4): 331-344.

41 Ahmed N, et al. Systematic review of the problems and issues of accessing specialist palliative care by patients, carers and health and social care professionals. *Palliative Medicine*. 2004; (18): 525-542.

42 Injustice in residential care: a joint report by the Local Government Ombudsman and the Health Service Ombudsman for England. The Stationery Office. London. 2008.

“I work with a client with learning disabilities who has a cataract and challenging behaviour. The GP refuses to treat on the basis that ‘He can see out of his other eye.’” [CLDT nurse]

Sometimes, as in the case example given above, treatment is not offered to people with a learning disability because a judgement, albeit an inaccurate one, is made about its value. Such judgements imply that a life lived with learning disability is a life less valued. In other cases, symptoms occurring in patients with a learning disability are misjudged.

“We took P (a man aged 40) to A & E because he had chest pain – as our care protocols say we should. But he was sent home again without any of the usual investigations and he died of a heart attack shortly afterwards. The staff are devastated. Why is it so hard to get basic care?” [Residential support worker]

Diagnostic overshadowing is the term used by the DRC and others to describe the tendency to attribute symptoms and behaviour associated with illness to the learning disability, and for illness to be overlooked. Witnesses reported that the phenomenon is widespread, and is particularly problematic in palliative care or when someone with a learning disability is in pain and can only communicate distress through behaviour (such as screaming or biting) that staff find challenging and/or difficult to interpret. The Inquiry heard many examples of this most disturbing problem and is very concerned that it should be addressed urgently. Further information can be found in Chapters 3 and 4 about the adjustments that are needed to deliver equivalent ‘reasonably adjusted’ services to people with learning disabilities with communication problems.

“Due to appalling treatment and my family’s opinions being ignored and whole trail of events leading up to the death of my sister, we now have very negative views of the NHS and the treatment of people with a learning disability. Had things been done differently, would I still have my sister?”

#### 1.2.4 Children

Growth in the numbers of children surviving with complex disabilities and multiple needs represents a significant challenge to health services. There are a number of issues here. For example, witnesses told the Inquiry that the way in which parents are told that their child has a learning disability is critical to the relationship they develop with future services – a task not always handled positively or sensitively. Witnesses said this was one reason why teaching and training were so important and several commended the teaching programme at St George’s Hospital Medical School. Others also commended the work of the ‘Every Disabled Child Matters’ campaign<sup>43</sup> for their work to support access to an ordinary life and to the services that others receive.

“I now rate people according to whether they see my son as a child with a disability or see the disability first and do not see the child.” [mother]

Several witnesses described how staff often failed to understand how a child with profound disabilities and complex needs could also be a loved, cherished and fully participating family member. They described occasions when staff suggested the child be allowed to ‘slip away’ rather than be resuscitated or treated. In particular, communication with families about treatment and the options was reported to be poor.

<sup>43</sup> Every Disabled Child Matters. A joint campaign by Contact a Family, Council for Disabled Children, Mencap and the Special Educational Consortium (<http://www.edcm.org.uk>)

“No-one ever sat down and discussed what the plan was for D (age 9), no-one ever sat with me and listened or took time to observe her.’ We thought they might talk to us about what had happened and maybe offer us some comfort. Unfortunately, the two nurses that met us did not say a word. They handed us a clinical waste bag marked property of D and made it quite clear we were not welcome. They wanted us to go.” [mother]

There is no accurate information on the numbers of technology-dependent children living at home according to the NPCRDC<sup>44</sup>, but Kirk and Glendinning<sup>45</sup> argue that support in the community has not kept pace with the demands of providing complex care. They say that, above all, families lack a designated key worker to co-ordinate the delivery of services, to be a point of contact between parents and the service system.

Gaps were reported in access to Speech and Language Therapy and to treatment for Attention Deficit Hyperactivity Disorder (ADHD) and autism. There also appears to be a gap in services for children with profound disabilities and complex needs who have musculoskeletal problems. Early interventions are not undertaken to prevent postural deformities from developing. Many families receive no support or advice about how to manage the sleeping position of their child and the Inquiry heard examples of cases where later wheelchair use and/or back surgery could have been avoided if effective early intervention had been provided.

“All the good work fell apart the moment B was admitted to the ward for surgery. Despite the intervention of PALS, care manager, hospital matron and numerous meetings with medical staff B’s physical health deteriorated as she was not supported adequately to take her food/fluid/medication. B had epilepsy which was well controlled until she came into hospital. Very often, her family found her tablets under her bed. Meals/drinks were left by her bedside untouched. Nursing care could best be described as very poor.” [parent of a teenager]

Transitions between primary and secondary care and between health and social care, home and hospital, or adults’ and older adult’s services were reported to be particularly difficult. At age 18, they said, it seemed that support and co-ordination vanished altogether. For example, excellent practice in education ‘statementing’ is commonly lost at this time. Records are not passed on. Staff do not share information.

Many carers spoke about a lack of continuity and co-ordination of care. Failures to pass on information were common in the transition from child (education and paediatric) to adult services. Children typically experienced a loss of progress in treatment or their level of risk rose (for example, in relation to the management of epilepsy medication). In summary, despite some examples of very good practice, many opportunities to provide care in partnership across service boundaries were missed.

Some evidence provided to the Inquiry by the Healthcare Commission from inspections of Youth Offending Teams and from Joint Area Reviews suggests integration and co-ordination of services across health, education and social care for children is improving. However, carers remain concerned about this area and a Commission for Social Care Inspection (CSCI) report on transition planning for young people with complex needs<sup>46</sup> also comments on this problem, arguing for more person-centred planning and co-ordination of assessments to focus holistically on young people.

<sup>44</sup> Supporting families for a technology dependent child in the community, exec summary 16. National Primary Care Research and Development Centre. University of Manchester. 2000.

<sup>45</sup> Kirk S, Glendinning C. Developing services to support parents caring for a technologically dependent child at home. *Child Care, Health and Development*. 2004; 30(3): 209-218.

<sup>46</sup> Growing up matters: better transition planning for young people with complex needs. Commission for Social Care Inspection. London. 2007.

Overall, however, and in contrast with health services for adults, witnesses reported a better quality of general primary and community health care for children with learning disabilities. With some exceptions, paediatric services were generally commended by witnesses for providing ‘all round’ care for children with learning disabilities. But for many children with disabilities, particularly those with complex needs, access to general health care is as problematic as it appears to be for adults.

### 1.2.5 Issues for carers

One in eight people (around 5.2 million altogether in England and Wales according to the 2001 census, of whom nearly 3 million are also in paid work) is a carer and three fifths of these look after someone with a disability (DH, 1999). Most (58 per cent) of carers are women, and some are children. Around 60 per cent of carers look after someone with a disability, 15 per cent care for someone with mental and physical ill health and/or a learning disability and 7 per cent for someone with a mental health problem alone.

“I would like my supporter to be able to come with me to the doctor.”  
[person with a learning disability]

To understand some of the challenges that carers face and to obtain qualitative information about their lives, the Inquiry team held two special consultation meetings for family members providing informal (unpaid) care, and carers supporting people with profound learning disabilities and complex needs. Annex 5 contains a summary of the key themes.

“My daughter needs 24/7 care and when she is in hospital I or another person who knows her well have to stay with her... I often have to sleep in her wheelchair, or the seat by her bed, or a mattress on the floor if I am lucky. I am not offered a drink or food, or access to a toilet for myself...” [mother]

Carers giving evidence to the Inquiry provided many examples like this one, mirroring the descriptions given of families’ experience in ‘Death by indifference. Although they may provide essential support to deliver treatment, nutrition or to help communicate, they receive little or no support themselves. Reluctant to leave a vulnerable and possibly confused patient, they sometimes spent long hours without a drink or food on the ward; indeed, they were sometimes explicitly barred from access to these basics. The Inquiry finds it unacceptable that such simple adjustments to the hospital regime should not be made.

Carers of people lacking capacity, commonly reported lack of attention to or complete rejection of their input. Their offers of help to identify symptoms, obtain consent and/or manage treatment were often rejected or misinterpreted. Staff attitudes were poor. Carers and/or parents of people with learning disabilities often struggled to make themselves heard, despite having the best information. Sometimes, they were expected to do too much or to provide care beyond the limit of their personal resources.

Carers’ most common concerns, however, centred not upon their own needs, but on issues relating to the quality of care for the people with learning disabilities that they support. Gaps in communication and partnership working were a particular focus for concern. In one vivid example given by a family carer, a good quality of supportive primary care was followed by a very poor quality of care in hospital. The hospital failed to communicate with the family about a decision not to provide pain relief or to resuscitate, adding very significantly to the deep distress they already felt at the loss of their child. The hospital failed to work in partnership with the family – thereby failing to address their patient’s interests appropriately at the same time as failing to meet the family’s interests.

It is not surprising that people with learning disabilities and their carers report low levels of satisfaction with the care they receive (Melville et al., 2005<sup>47</sup>; Northway et al. 2006<sup>48</sup>) although there are few systematic accounts of their views as compared to those of other service users. Furthermore, there is good evidence that providing care has a negative impact on carers' health. For example, informal carers of adults with learning disabilities report 40 per cent more limiting health disorders (McGrother et al., 1996<sup>49</sup>) than the general population with depression – a common condition known to have a high co-morbidity with physical ill health. Furthermore, there is some evidence that older carers of people with learning disabilities are not well prepared for the challenges they will face as they get older and continue to provide care (McGlaughlin, 2007<sup>50</sup>) without support.

Overall, it appears that neither policy, practice, nor the legal framework provides a sufficient incentive to deliver appropriate support for carers. Even though the Carers (Recognition and Services) Act 1995 gives people who provide 'substantial care on a regular basis' the right to request an assessment of their needs from social services, results from the general household survey of carers shows that 60 per cent receive no regular visits from service providers. Witnesses giving evidence to the Inquiry are clear that their needs are not being met. For these reasons the Inquiry welcomes the commitment contained in The Carers Strategy<sup>51</sup> and the extra investment to support them.

## SUMMARY

The evidence from the literature, from the consultation and from witnesses suggests very clearly that high levels of health need are not currently being met and that there are risks inherent in the care system. People with learning disabilities appear to receive less effective care than they are entitled to receive, especially as they move from children's to adult services and discrimination is evident in access to and outcomes from services. Many of these problems concern basic shortcomings in the way that treatment is delivered that would be simple to remedy. However, there is also evidence of a significant level of avoidable suffering due to untreated ill health, and a high likelihood that avoidable deaths are occurring. All these areas require urgent attention.

<sup>47</sup> Melville C. Discrimination and health inequalities experienced by disabled people. *Medical Education*. 2005; (39): 122-9.

<sup>48</sup> Northway R, Sardi I, et al. Hopes and fears concerning service developments. A focus group study of parents and family carers of people with learning disabilities. *Journal of Applied Research in Intellectual Disability*. 2006; (19): 240.

<sup>49</sup> McGrother C, Hauck A, et al. Community care for adults with learning disability and their carers. Needs and outcomes from the Leicestershire register. *Journal of Intellectual Disability*. 1996; 40(2): 183-190.

<sup>50</sup> McGlaughlin A, Bowey L. Older carers of adults with a learning disability confront the future: issues and preferences in planning. *British Journal of Social Work*. 2007; 37(1): 39-54.

<sup>51</sup> Carers at the heart of 21st century families and communities: a caring system on your side, a life of your own. Department of Health. London. 2008.



# THE NATIONAL CONTEXT

# 2

THIS CHAPTER summarises the context for the delivery of health care treatment for people with learning disabilities. The legislation, within the overarching framework of the Human Rights Act, includes that relating to the provision of equal treatment (the Disability Discrimination Act); treatment for people who lack capacity (the Mental Capacity Act), and support for carers (the Carers Act). It summarises the framework for delivering healthcare by NHS trusts, NHS foundation trusts and across the spectrum of primary and community health services and describes the general health and learning disability policies that together oblige the NHS to deliver care in an effective, non-discriminatory and personalised manner.

## 2.1 THE LEGAL FRAMEWORK

Health care should be delivered in accordance with the legal framework. The framework is wide-ranging but at the most fundamental level it starts with the Human Rights Act (HRA) 1998. The Joint Committee on Human Rights<sup>52</sup> (JCHR) concludes that, regrettably, it is still necessary to emphasise that adults with learning disability have the same rights as everyone else. Their report (March 2008) says that rights to humanity, dignity, equality, respect and autonomy are not being met.

Several investigations of specialised services undertaken by the Healthcare Commission<sup>53</sup> in partnership with the Commission for Social Care Inspection describe abusive, neglectful and/or degrading treatment breaching Articles 2, 3 and 8 of the European Convention on Human Rights (ECHR). Although the Health Service Ombudsman has undertaken a number of investigations into complaints, there have been no other systematic investigations of this area of general medical services in primary or secondary care. In general, however, the fact that people with learning disabilities may not be able to access health services as others do, is a potential breach of the European Convention on Human Rights (ECHR Articles 2, 3, 8 and 14).

The JCHR report argues that the experiences of people with learning disabilities mirror closely those of older people and, in so doing, fall far short of good practice. The Inquiry welcomes the JCHR report; supports its recommendations and has endeavoured to take an approach that incorporates full awareness of the HRA.

Other legislation governing public bodies such as the Disability Discrimination Act and the Mental Capacity Act also has a direct bearing on care for people with learning disabilities in the NHS and this is summarised in the following sections. Full information about the legislation and the JCHR report is available from <http://www.parliament.uk/jchr>; the web

<sup>52</sup> A life like any other? Human rights of adults with learning disabilities. Joint Committee on Human Rights. London. 2008.

<sup>53</sup> A life like no other: a national audit of inpatient services for people with learning difficulties. Commission for Healthcare Audit and Inspection. London. 2007.

sites for the Department of Health (<http://www.dh.gov.uk>), and the Office for Disability issues (<http://www.officefordisability.gov.uk/>).

### 2.1.1 The Disability Discrimination Act (DDA)

The DDA (1995) describes the entitlement of people regardless of impairment to equal access to healthcare. Since 1995, it has been unlawful to discriminate against people with a disability, including those with a learning disability. The Act requires information to be provided in an accessible format about treatment options, complaints procedures and appointments. There is also a duty to promote equality for disabled people and take steps to take account of disabled persons' disabilities even where that involves treating them more favourably than others.

Since 1999 providers have been required to make 'reasonable adjustments' to the way that services are delivered in order to meet the needs of disabled users. It is now clear in law that a service cannot be deemed equally accessible unless special arrangements or adaptations are made for those with different needs, and unless equality is actively promoted. In 2004, this was extended beyond the physical features of the environment to the way that services are provided across the whole of the public sector.

Many witnesses giving evidence to the Inquiry said that the concept of 'reasonable adjustment' was poorly understood in the NHS. Most services, they said, knew about the need for physical adaptations to buildings (ramps, hearing loops, etc). Few appeared to realise that reasonable adjustment might include easy-to-read pictorial signs for non-readers; adapted automated booking systems; adjustments to waiting times or appointment length. Failures to make reasonable adjustments in respect of communication not only make access to services very difficult for people with learning disabilities, they may breach the DDA and the European Convention on Human Rights (Article 8 ECHR).

A good local example of 'reasonable adjustment' based on sound knowledge of patients' needs can be seen in Derby Hospitals NHS Foundation trust where special arrangements have been made to make outpatient clinics more accessible and easier to manage for patients with learning disabilities. Audiology clinics have longer appointment slots; around 75 per cent of learning disabled patients (as compared to 10 per cent nationally) attend adapted breast screening clinics, and the rehabilitation medicine team offers an adapted service involving community learning disability team (CLDT) members, carers, and physiotherapists.

The legal requirements for public bodies to promote disability equality has two parts – a general duty (Disability Equality Duty) and some specific duties (to establish a Disability Equality Scheme or DES). Guidance on implementing the DED and DES is available from the Equality and Human Rights Commission (EHRC) (incorporating the Disability Rights Commission).

If listed authorities fail to produce a DES, fail to produce a compliant DES or fail to implement it, the EHRC<sup>54</sup> can apply for a Court Order<sup>55</sup>. Breach of any such Order could result in an authority being found in contempt of Court. However, despite the fact that all public sector healthcare organisations were required to publish their DES by December 2006, 10 out of 12 SHAs had not done so a year later according to the DRC (op cit).

Many witnesses were also concerned about the 2005 general election manifesto pledge to introduce a Single Equality Bill for Great Britain during the current Parliament. The aim is to streamline the equality legislation, but witnesses argue that much good work to promote specific disability equality would be lost if public authorities were required to

<sup>54</sup> Unlike other parts of the Disability Discrimination Act relating to individual acts of discrimination such as access to goods and services, only the Commission can instigate legal action regarding non-compliance with the Disability Equality Duty.

<sup>55</sup> Compliance notices can be served in relation to both the general and the specific duty. They can only be served in relation to the general duty if the Commission has already carried out an assessment and the notice relates to its results.



implement single equality schemes covering race, gender, age, sexual orientation and religion as well as disability. The Inquiry urges the government to address these concerns in its response to the consultation on discrimination law review which is expected to be published shortly. Examples to illustrate how compliance with the legislative framework of the HRA and DDA can be assured can be found in Chapter 4.

### 2.1.2 The Mental Capacity Act (MCA)

The MCA was fully implemented in October 2007. It put advance statements to refuse treatment on a statutory basis and provided access to the new Court of Protection in cases of dispute. It introduced a new criminal offence of ill treatment or neglect of a person lacking capacity and it enabled people to create lasting powers of attorney. It put into statute the principle that everything must be done in the best interests of the patient.

The Act states that a person must be assumed to have capacity to make a decision regarding his or her care or treatment unless proved otherwise. The aim is to protect people with learning disabilities and other conditions associated with cognitive impairment, such as Alzheimer's disease, by providing guidelines for carers and professionals about who can take decisions in which situations. The Act requires 'all practicable steps' to present information in a way that is appropriate to the person's circumstances.

The Act also introduces powers (entitlements and a duty) to establish Independent Mental Capacity Advocacy (IMCA) to help vulnerable people who lack capacity when they have to make a major decision, for example about serious medical treatment or a change of residence. NHS bodies and Local Authorities have a duty to consult the IMCA when decisions are needed by people lacking capacity who have no family, friends or others to advocate for them.

According to witnesses, the statutory footing provided by the Mental Capacity Act has been of great significance in strengthening the role of IMCAs compared to generic advocacy services. Although most are currently providing support for older people to make decisions about residential care, the Inquiry heard only a few examples of work with people with learning disabilities.

The Independent Complaints Advocacy Service (ICAS) has been working to strengthen the profile for advocacy to and for people with learning disabilities in prison and forensic services in the South West, but very few advocates currently work in general acute medical or primary care settings supporting people to make decisions about medical treatment. This is a gap that should be filled. Advocacy was poorly understood and little used by the carers providing evidence to the Inquiry. Some witnesses were also concerned about the survival of small advocacy organisations if NHS resources were all used to deliver their statutory obligations to the larger client groups such as older people.

### 2.1.3 The Carers Act

The Carers (Recognition and Services) Act 1995 gives people who provide 'substantial care on a regular basis' the right to request an assessment of their needs from social services. However, the Prime Minister's Carers Strategy 1999 acknowledged that this was patchily provided. 'Our health our care our say' (2006) and the White Paper 'Modernising social services' (1998) contained proposals for improvement. A 'New Deal for Carers' was announced in 2007. This included additional monies for councils to provide emergency cover for carers; the development of a helpline; an expert carers programme and a review of the 1999 Strategy. The Inquiry welcomes this, and the new investment associated with the recently published Carers Strategy (op cit) but believes information for carers about their rights and entitlements is still very limited. Recommendations relating to carers can be found in Chapters 3 and 4.

## 2.2 THE FRAMEWORK FOR HEALTHCARE IN THE NHS

The Secretary of State for Health carries responsibility for health services but uses a range of statutory powers to delegate functions to NHS organisations. Ten strategic health authorities (SHAs) are accountable to the Secretary of State and carry responsibility for strategic planning; for ensuring the successful commissioning and delivery of services through performance management of primary care trusts (PCTs) and NHS Trusts.

SHAs also performance-manage the local NHS public health function, working closely with Regional Directors of Public Health in the government offices of the regions. NHS foundation trusts are not accountable to SHAs but have contracts with PCTs to deliver services to an agreed standard and general obligations and responsibilities to meet NHS service standards and of partnership under their licence to operate issued by Monitor, the Independent Regulator for Foundation Trusts.

The Inquiry welcomes the clear focus provided by the Department of Health in ‘Developing the NHS Performance Regime’<sup>56</sup> on the role of strategic health authorities (SHAs) in managing the performance of PCTs as commissioners of services. SHAs will now need to direct organisations to enforce better standards of care for all those with disabilities, including learning disabilities in order to demonstrate that they are compliant with their Disability Equality Duty under the legislation.

‘Standards for Better Health’ is a common set of requirements applying across all NHS health care organisations to ensure that health services are safe and of an acceptable quality. They provide a framework for continuous improvement in the overall quality of care; they help Trust Boards assure themselves that their services satisfy the requirements of the Healthcare Commission’s annual health check of NHS Trusts, and, in the case of NHS foundation trusts, meet the terms of their authorisation by Monitor.

Core standards C07e (‘challenge discrimination, promote equality and respect human rights’) and C18 (‘enable all members of the population to access services equally and offer choice in access and treatment equitably’) are the basis for the assessment of NHS organisations undertaken by the Healthcare Commission in relation to equality. The Inquiry believes that, by themselves, these standards are not sufficient to enable a judgement to be made about whether NHS organisations are meeting their obligations under the disability legislation. Although the Healthcare Commission works with Monitor and, to some extent in partnership with the Commission for Equality and Human Rights, the Inquiry believes that their methods of inspection need strengthening. The Inquiry’s recommendations in this area may be found in Chapter 4.

### 2.2.1 Healthcare providers

NHS services are delivered by a range of different providers, public sector private sector and voluntary. In England<sup>57</sup> there are 152 PCTs (including one care trust/PCT); 73 acute foundation trusts (including 2 trusts delivering children’s care); 30 mental health foundation trusts; 97 non-foundation acute trusts (including 3 solely delivering children’s care); 42 non-foundation mental health trusts (including 10 care trusts covering social care as well) and two specialised LDs trusts. In addition, there are 12 NHS ambulance trusts.

Foundation trusts (FTs) are established as ‘freestanding’ legal entities under the provisions of the Health and Social Care (Community Health and Standards) Act 2003 (consolidated in the National Health Service Act 2006). They operate outside of the direction of the Secretary of State for Health. Instead of direct line management by the DH, FTs are accountable to their membership and to commissioners through performance

<sup>56</sup> Developing the NHS performance regime. Department of Health. London. 2008.

<sup>57</sup> Figures correct at July 2008.

contracts negotiated with primary care trusts. They are subject to independent inspection from the Healthcare Commission and to regulation by Monitor.

Governance, corporate and clinical, provides the ‘framework through which the Boards of NHS organisations fulfil their accountability for the performance of the organisation. Boards and management teams use an assurance cycle to steadily improve the quality of their services and safeguard high standards of patient care by creating an environment in which excellence will flourish’.<sup>58</sup> The clinical governance framework covers systems such as patient and public engagement and feedback, continuing professional development, monitoring of clinical outcomes, performance management of clinical and other staff, records, risk management, communication, and team working.

Accountability for the delivery of care and compliance with NHS standards, legislative and regulatory requirements at an organisational level at hospital trust level rests with the Trust Board. It is the Board’s responsibility to ensure that appropriate systems of clinical and corporate governance<sup>58</sup> (*op cit.*) and systems for assurance are in place. Trust Boards are required to make an annual return to the Healthcare Commission confirming the Trust’s compliance with the requirements of ‘Standards for Better Health’<sup>59</sup> or explain their non-compliance. They are also required to produce and sign off an annual clinical governance report<sup>60 61</sup>. For example, NHS Trusts, including FTs, carry responsibility to ensure that staff training is appropriate and they obtain continuing professional development (CPD).

Data and information systems are critically important. Without data – about patients, activity, outputs, costs or outcomes – it is difficult for systems (patient administration systems, clinical governance systems) to operate effectively. The absence of data and information currently constrain the capacity of Trust Boards to assure themselves that they are compliant with the legislation or to check that they are providing effective, non-discriminatory care to people who happen to have learning difficulties. Data and information are almost entirely missing about people with learning disabilities entering hospital care. Recommendations for strengthening information at national and local level are set out in Chapters 3 and 4.

The Inquiry welcomes plans to extend provision of individual budgets from social care to health to enable the families of children, and adults with complex needs to commission their own support with whatever help from professionals they need. However, it will be important to elaborate the implications for people with learning disabilities and provide any necessary additional support to help them take advantage of this opportunity.

The Inquiry also believes there would be value in strengthening knowledge about and scope for local services to overcome potential financial obstacles inherent in the Payment by Results (PbR) tariff for the delivery of treatment for people with complex conditions. Witnesses argued that there were financial disincentives to delivering services and arguments about responsibility for funding. The Inquiry urges the Department of Health to address this, as suggested in ‘High Quality Care for All’<sup>62</sup>. It may be possible, for example, to develop a framework of banding for health treatments for people with severe learning disability and more complex needs, similar to that which exists for the treatment of people with cystic fibrosis.

### 2.2.2 Primary care

Primary care service delivery is the responsibility of GPs and other primary care staff such as community nurses, audiologists, podiatrists, and dentists. Access to services for most people is achieved through primary care services in the first instance, so it is crucially

<sup>58</sup> Cited in Integrated governance handbook. Department of Health. London. 2006.

<sup>59</sup> Standards for better health. Department of Health. London. 2006.

<sup>60</sup> A practical handbook for clinical audit. Department of Health. London. 2005.

<sup>61</sup> Board assurance prompts. Department of Health. London. 2004.

<sup>62</sup> High quality care for all: NHS next stage review final report. Department of Health. London. 2008.

important that such services are sensitive to communication and other special needs presented by people with learning disabilities. However, the multiplicity of potential providers, their employment arrangements and systems for regulation complicate the process of monitoring and performance management of the quality and effectiveness of care provided to patients.

Some primary care and community staff are salaried, employed by GP practices, Primary Care or Community Trusts, voluntary organisations or private providers. Most GPs, dentists and opticians are self-employed and work under contract to the NHS – an arrangement that provoked particular comment from witnesses in relation to the difficulty of assuring that services are delivered to a good standard. Individual General Practices are not currently required to report nor are they subject to inspection by the Healthcare Commission, although the possibility of direct inspection of primary care providers by the new Care Quality Commission is the subject of current consultation.

The Quality and Outcomes Framework (QOF) is part of the GMS contract. It rewards GPs for implementing good practice according to criteria grouped into four domains: clinical, organisational, patient experience and additional services. Participation in the QOF is voluntary but most practices participate and secure additional income by participation. In England in 2006 a Learning Disabilities Indicator was included as an element of the QOF. It is earned by those Practices able to report the number of patients aged 18 years and over with a learning disability as a proportion of total list size. The aim (there are also other registers including mental illness and diabetes) is to support accurate determination of the population of patients for which health services are provided and to which future health indicators might relate.

The first report from the Department of Health containing summary data relating to learning disabilities registers (September 2007) shows that over 98 per cent of GPs are currently capturing data in this area. However, the overall number of people with learning disabilities recorded is around 0.3 per cent, corresponding to the number with profound and multiple disabilities in the population as a whole. GPs therefore seem to be recording only those at the most severe end of the spectrum who are easiest to identify and people with mild and moderate learning disabilities do not appear to be being included. The Inquiry believes it is important to improve the quality of information recorded by GPs and more information about this is given in Chapters 3 and 4.

### 2.2.3 Health policy

In addition to an extensive framework of legislation, NHS provision is shaped by policy, targets, guidance and a range of evidence-based advice such as that provided by the National Institute for Health and Clinical Excellence (NICE). NICE publishes guidance on treatments and new technologies and compliance varies from mandatory in the case of NICE technology appraisals, to extremely strongly advised in the case of treatment guidelines.

The Department of Health (DH) publishes policy statements and guidance on health conditions. For example, there are National Service Frameworks for cancer, mental ill health, and long term (neurological) conditions, although there is no framework for services for people with learning disabilities<sup>63</sup>, which many witnesses regretted. Like NICE guidance, DH targets and guidelines vary in the degree to which compliance with their direction is obligatory. Overall, there is a trend towards lessening the volume of central directives in the context of 'shifting the balance of power'<sup>64</sup> and there are more freedoms for local services to decide their own priorities.

Coupled with the extent to which they are publicised and their political profile, the sanctions imposed for failing to comply with targets and guidance are a core feature of

<sup>63</sup> NSF's include: Mental Health; Children, Young People and Maternity Services; Coronary Heart Disease; Long term (Neurological) Conditions; Diabetes; and Renal Services. An NSF for Chronic Obstructive Pulmonary Disease is in development.

<sup>64</sup> Shifting the balance of power: the next steps. Department of Health. London. 2002.

their power to drive change. To some degree, this variation reflects the best and the worst consequences of strong political involvement in health care. For example, targets set for waiting times in Accident and Emergency Departments and for Hospital Acquired Infection were widely publicised and regarded as mandatory for Trust Boards. As a result, these targets had a high profile and they were largely met. In the case of learning disabilities policy and compliance with the legislation relating to discrimination, there are not only very few national targets, they have a low profile; they are not prioritised, there is no systematic assessment of performance and there are few sanctions for failing to meet them. Poor monitoring and inadequate data are among the disincentives to progress (Ghazala et al.,<sup>65</sup> 2007).

This is illustrated clearly in relation to 'The NHS Plan' (DH 2000) which highlighted the importance of preventing as well as treating ill health. It set a target for England:

*'to reduce inequalities in health outcomes by 10% by 2010 as measured by infant mortality and life expectancy at birth.'*

To achieve this, 'Tackling Health Inequalities: a programme for action' (DH 2003) emphasised the importance of effective treatment; reducing risk, improving prevention, early detection and access to effective care. Thus far, the focus for equalities policy has been upon interventions most likely to have a major impact on population health such as smoking, treatment for cardiovascular disease, prevention of teenage pregnancy and, more recently, obesity. 'Our health, our care, our say' (DH 2006) further committed the NHS to giving people more control over their health. It promoted action to support health, independence and wellbeing and improve access.

'Our health our care our say' identified people with learning disabilities as a group facing particular health inequalities and it contained a commitment to review the action outlined in 'Building on the Best' (Dec 2003) to introduce regular, comprehensive health checks. In fact, very little progress has been made in introducing health checks. Furthermore, the cognitive impairment that characterises learning disability inhibits recognition of ill health, the identification of health risks and the effectiveness of help-seeking. This means that simply expecting all people with learning disabilities to self-manage their health is not a realistic option.

Overall, it is difficult to assess the impact of general Public Service Agreements (PSAs) and equality targets, for people with learning disabilities – a point made by the Disability Rights Commission in their report 'Equal treatment' (op cit). This is partly a function of the limited priority afforded to the client group as a whole, and partly, once again, because of gaps in data and information. It is extremely difficult to know whether the inequalities gap for this group is narrowing or getting wider.

'Health Inequalities: Progress and Next Steps'<sup>66</sup> (Department of Health, 2008) contains a number of helpful commitments to improve progress. It says 'Progress on health inequalities will be judged against how public services treat especially vulnerable groups.' The Inquiry welcomes these commitments. It urges the Department to develop a workable, practical way to achieve this nationally and locally, and also to deliver the commitments contained in 'High Quality Care for All' (op cit) to reward the service for delivering good outcomes.

Some witnesses giving evidence to the Inquiry argued that policy should be written around the needs of people with learning disabilities (among the most vulnerable members of the population) as opposed to the needs of the least vulnerable. The Inquiry believes that this is best achieved through policy initiatives that strengthen services for people with learning disabilities and other vulnerable groups – otherwise their needs will fail to be identified or addressed.

<sup>65</sup> Ghazala M, Allgar V, Cottrell D, Heywood P, Evans J, Marshall J. Health facilitation and learning disability (research commissioned by the Department of Health). University of Leeds. 2007.

<sup>66</sup> Health inequalities: progress and next steps. Department of Health. London. 2008.

Nowhere is this truer than in relation to prison health and the criminal justice system, where adults and young people with learning disabilities are represented in relatively high numbers (see Chapter 1) and where social vulnerability and multiple stigma combine to impede access to effective treatment<sup>67</sup>. For example, prisoners must complete a form to access primary care – a barrier to those who cannot read or write. There are also very few specially trained learning disability nurses working in mental health in-reach teams or primary care services – often the main point of contact for people with learning disabilities.

In April 2006 responsibility for prison health care was transferred to the NHS with the aim of ensuring that prisoners ‘have access to the same range and quality of services appropriate to their needs as are available to the general population through the NHS.’ Commissioning for prison health is now the responsibility of PCTs. The Inquiry welcomes this, and the proposals set out in the new offender health strategy ‘Improving Health – Supporting Justice’ (DH 2007). The Inquiry urges the Department to extend its work on delivery of health services for people with learning disability to ensure that the problems identified in the wider NHS for this group are managed effectively in prison where the Disability Discrimination Act also applies<sup>68</sup> and throughout the criminal justice system.

#### 2.2.4 The Operating Framework

The Operating Framework for the NHS describes each year how priorities should be addressed and measured. The New Performance Framework for Local Authorities and Local Authority Partnerships<sup>69</sup> (2007) builds on the local government White Paper ‘Strong and Prosperous Communities’ (2006) which promised greater freedoms for local government to set their own priorities. The Operating Framework for 2008-09 (op cit) aims to support this by moving towards local target setting and focussing on shared local priorities for improving health and wellbeing.

A specific target relating to learning disabilities was included for 2008/09 in the ‘tier 2’ list: a target with national priority for local action. However, when ‘The Vital Signs’<sup>70</sup> was published describing the indicators to be used, it was only classified as ‘tier 3’; that is, it was not identified as a national priority; this means PCTs can choose to ignore it and our witnesses anticipate that, as a consequence, they will.

The Inquiry believes that the Department of Health should ensure that policies on equality, choice, access and self-management are adapted effectively for vulnerable groups. This means taking a more proactive approach for people with learning disabilities to ensure they can obtain a level of service that is at least equivalent to that available for other people.

There is also a need to strengthen investment in research to inform our understanding of the impact, including upon health outcomes, of health policy and health interventions for disadvantaged groups, especially as it is also argued that they are less well served in research terms. Bell and Wise (2007<sup>71</sup>) argue that ‘Best Research for Best Health’ will lead to reductions in the volume of local research funding and they anticipate a particular impact on research in mental health, learning disabilities and forensic services.

#### 2.2.5 Learning disabilities policy

The Department of Health has taken some significant steps towards directing the NHS to deliver better care for people with learning disabilities. For example, all long stay institutions for people with learning disability were targeted for closure by 2004 (Valuing

<sup>67</sup> No one knows. Prison Reform Trust. London. 2007

<sup>68</sup> Prison Service Order 2855: Prisoners with disabilities. HM Prison Service. 2008.

<sup>69</sup> The new performance framework for local authorities and local authority partnerships: single set of national indicators. Department for Communities and Local Government. London. 2007.

<sup>70</sup> Operational plans 2008/09-2010/11: the vital signs. Department of Health. London. 2008.

<sup>71</sup> Bell S, Wise J. The impact of the NHS R&D strategy on mental health services and research. Report to the Department of Health. 2007.

People 2001) and there is now only one hospital left. People with learning disabilities are expected to access general health services as others do and general health targets apply to them as to others. New leadership in the form of a National Director and a support team are in place to support implementation.

DH also published a range of guidance to support the move towards 'mainstreaming' or 'normalising' general health care for people with learning disabilities. 'Once A Day' (1999) for example, outlined good practice for primary health care teams in respect of people with learning disabilities<sup>72</sup>. Statements were made in the Valuing People White Paper (DH, 2001); in subsequent health guidance 'Our health our care our say' (DH 2006) and in the DH response<sup>73</sup> to the DRC report 'Equal Treatment'. For example, Valuing People said every person with a learning disability should:

- ◆ Be offered a named health facilitator by summer 2003
- ◆ Be registered with a GP by June 2004
- ◆ Have a health action plan (based on a health check) by June 2005

Six years on, Valuing People Now (DH, 2007) says progress is limited for the majority of people with learning disabilities, particularly in relation to general primary health care. Our own consultation indicated that a lack of data and information impedes progress. In addition, there is still confusion about what the terms health check, health facilitation and Health Action Plan mean.

A variety of guidance has been published about health checks and the role of PCTs and Community Learning Disability Teams (CLDTs). 'Questions to Ask'<sup>74</sup>, for example, is a short leaflet containing tips and advice for patients about getting the best out of medical appointments. This was distributed to most GP surgeries and pharmacies in autumn 2007 – including in 'easy read' format.

Health checks are routine checks (a form of screening) for ill health or health risk. In Wales, the check includes a physical examination and takes about an hour. A different, largely history-based check is available in Birmingham<sup>75</sup> and takes about 45 minutes. The check used in Glasgow includes a detailed 70 page semi-structured interview and a physical examination and takes around 4 hours.

Health facilitation<sup>76</sup> is the process whereby people with learning disabilities and their families and carers obtain help to access health services. It is expected to work on two levels:

- ◆ Service development work, informing, planning and commissioning (strategic health facilitation)
- ◆ Person-to-person work with people with learning disabilities to support access to services and improve the care pathway (liaison nursing).

Health Action Plans (HAPs) are person-centred plans for adults and children designed to support health checks and the delivery of effective care and treatment<sup>77</sup>. Valuing People says that responsibility for the HAP lies with the Strategic Learning Disability Health Facilitator, commissioned by the PCT to work in partnership with primary care nurses and GPs. A HAP contains information about what a person with learning disabilities needs to do to stay healthy. It lists any treatment needed, and any help needed to support individuals to get it. Valuing People argued that HAPs should be offered and reviewed at transition points and/or at points when health needs change. However, it is difficult to get

<sup>72</sup> Once a day: a primary care handbook for people with learning disabilities. Health Service Circular/Local Authority Circular. 1999/103: LAC (99) 17

<sup>73</sup> Promoting equality: response from the Department of Health to the Disability Rights Commission report: Equal treatment – closing the gap. Department of Health. London. 2007

<sup>74</sup> Questions to ask: getting the most out of your medical appointment. Department of Health. London. 2007.

<sup>75</sup> Health screening template for people with learning disabilities. South Birmingham Primary Care Trust. Birmingham. 2003. Available from: <http://www.rcgp.org.uk/>

<sup>76</sup> Action for health: good practice guidance for partnership boards. Department of Health. London. 2002.

<sup>77</sup> Action for health: health action plans and health facilitation. Department of Health. London. 2002.

an impression of progress on the appointment of Health Facilitators or the success of HAPs because no central data are collected.

Last year (2007) the Department of Health commissioned NHS Primary Care Contracting (op cit) to produce a specialised service specification for learning disabilities services in primary care covering strategic development, working in partnership, leadership, provision of health checks and screening, care planning and support for self-care. Unfortunately, there is no central information on how many PCTs have taken this up and witnesses giving evidence to the Inquiry suggest that very few have.

## SUMMARY

Although the policy and legislative frameworks are clear, there are challenges presented by insufficient data and poor information. The evidence shows a significant gap between policy, the law and the delivery of effective health services for people with learning disabilities. There is guidance on the delivery of effective general health care for people with learning disabilities but it is poorly understood, health care services are poorly co-ordinated in relation to the needs of people with learning disabilities and few providers are taking the essential steps to improve practice.



# OVERCOMING THE BARRIERS

# 3

IF THE POLICY and legislative frameworks are clear and yet services are not being provided to an adequate standard, it is important to understand the remedial action that is needed. This chapter contains information about how some local services have managed to overcome the barriers to delivering effective health care for people with learning disabilities. Examples are given where research and our witnesses agree that there are lessons for the wider NHS to learn.

## 3.1 PRIORITY AND PROFILE

Time and again in our discussions with patients, carers and service providers, the crucial importance of leadership was emphasised. Leadership is crucial to the change in attitudes and behaviours, without which it is so hard to improve performance. The joint National Directors for Learning Disability have led very significant improvements in policy and service delivery for specialised services for people with learning disabilities. Sadly, this has not been matched by improvements in the quality of general health services where clear leadership is equally important to provide.

Leadership starts at the top of an organisation but is the responsibility of staff at all levels. As was shown in Chapter 2, the political priority afforded to the health needs of people with learning disabilities appears to be low in comparison to that afforded to other areas of health care. People with learning disabilities have little or no visibility. Our witnesses suggest there are several reasons why this might be:

- ◆ First, there is poor understanding of the health problems and risks presented by people with learning disabilities. General staff training is very limited; health risks are complicated, and the behaviour of clients may be challenging and difficult to interpret. Uncertainty and ignorance can provoke fear and reluctance on the part of staff to engage. Too many still fail to understand the law relating to disability equality.
- ◆ Secondly, the decision to close long stay institutions is relatively recent in policy terms. Even though the majority of people with learning disabilities live at home, the health service, our witnesses say, has not caught up with what this means, particularly in primary care. Often staff involved in general healthcare and social care seem to think that support for people with learning disabilities to access health services is 'somebody else's responsibility'.
- ◆ Thirdly, many healthcare staff have limited personal experience of people with learning disability; their numbers in the population are relatively small. This places staff and their learning disabled patients at greater social distance from one another and distinguishes care for this group from that provided for, say, vulnerable older people.

Together, these factors distinguish care for people with learning disabilities from that provided for vulnerable older people or people with other disabilities, although there is a significant degree of overlap, as the JCHR report suggests. They also help to explain why good practice in England is thinly spread. In fact, Inquiry witnesses went so far as to say that no good practice exists in this area without strenuous effort from energetic, passionate local staff prepared to fight continuously against the odds. The Inquiry team believes it should not be so hard to achieve change but there are, nevertheless, lessons to learn from the good practice that does exist.

### 3.2 EDUCATION AND TRAINING

All healthcare practitioners have a duty in common law to exercise reasonable care and skill in providing medical treatment and services that comply with their respective professional codes of conduct. For doctors, the General Medical Council, the British Medical Association and the medical Royal Colleges set out clear guidance<sup>78</sup> on what constitutes appropriate treatment. Professional bodies covering nursing, midwifery<sup>79</sup>, psychology<sup>80</sup> and the other healthcare professionals have a similar role and issue equivalent guidance for their members. Individual patients who are unhappy with the services they have received can take this up with the professional bodies for registered practitioners. The Inquiry welcomes steps being taken by the Department of Health to strengthen professional regulation for non-medical staff under the auspices of the Health Professions Council.

Witnesses giving evidence to the Inquiry agreed that there are serious shortcomings in education and training for staff. Work with people with learning disabilities per se is not a compulsory part of training, other than clinical psychology pre-registration training. Relevant information in pre-registration courses for doctors, nurses, and others varies in its quality, volume and content. Researchers (e.g. Sowney and Barr, 2004<sup>81</sup>; McKenzie et al., 1999<sup>82</sup>) describe how staff without training tend to stereotype people with learning disabilities. They are less likely to listen, or believe that a life lived with learning disability could be a life worth living.

“I have had clients with cancer and Parkinson’s whose physical ill health has been dismissed as ‘behaviour problems’. . .we often have to battle for the possibility of physical illness to be considered and for access to the sort of diagnostics that the rest of us take for granted.” [CLDT member]

‘Diagnostic overshadowing’ (see Chapter 1) may occur in relation to other groups (such as older people, people with mental health problems), but witnesses speaking to the Inquiry argued that learning disability, in many ways, represents a special case. This is largely because of the ignorance that still surrounds learning disability. There is a strong argument, for this reason, in favour of including basic teaching about learning disabilities in all pre-registration courses and involving people with learning disabilities in providing it.

“When L passed away the doctor came to certify her death; the doctor took one look at her then looked at my mother and asked ‘. . .mongoloid?’ As if losing my precious sister wasn’t bad enough a member of the NHS then insulted her. . .” [sister]

<sup>78</sup> Good medical practice. General Medical Council. London. 2006.

<sup>79</sup> Code of professional conduct: standards for conduct, performance and ethics. Nursing and Midwifery Council. London. 2004.

<sup>80</sup> The code of conduct. British Psychological Society. London. 2006.

<sup>81</sup> Sowney M, Barr O. Equity of access to health care for people with learning disabilities: a concept analysis. *Journal of Learning Disabilities*. 2004; 8(3): 147-165.

<sup>82</sup> McKenzie K, et al. What is learning disability? Do people need to be reminded? *Learning Disability Practice*. 1999; 2(1) 8-11.

The research shows that knowledge, skills, attitudes and values are all capable of improvement through training (Slevin and Sines 1996<sup>83</sup>). In Glasgow, for example, Melville et al. (2007)<sup>84</sup> assessed the training needs of 210 practice nurses and delivered a bespoke training package that had a significant impact on knowledge and practice. There are also several examples in the literature showing the beneficial effect on teaching of involving people with learning disabilities themselves, perhaps best exemplified by the teaching at St Georges Hospital Medical School (Thacker et al., 2007<sup>85</sup>).

A helpful guide published 2007 (A National Framework for Disability Equality Etiquette Learning – DEEL – for health and social care services) is available from the DRC. In addition, the DRC has published helpful materials for primary care practitioners<sup>86</sup> illustrating how ‘reasonable adjustments’ can be made. Mencap<sup>87</sup> also publishes valuable guidance on profound and multiple learning disabilities for staff and service users. It includes material on independent living, health, education and rights in the context of the legislation.

“Why did the trust take no notice when the family warned of what might happen when M was distressed?”

But ...

“One nurse in particular told us she had taken some books out of the library to find out more about Down’s syndrome. This was very reassuring.” [father]

The relationship between training and subsequent change in attitudes and behaviour is difficult to measure. Pre-registration training is unlikely to be sufficient by itself in the long term and in-service training or continuing professional development are also very important. Good examples can be found in Shropshire of training on the use of patient passports and communication tools, and in Bromley Hospitals NHS Trust, Kent where the multi-professional CPD programme incorporates a half day for everyone on the Mental Capacity Act.

The Inquiry team believes there may be scope to incorporate work along these lines into that being undertaken on medical regulation and revalidation<sup>88</sup> and encourages the Department of Health to work with the Royal College of General Practitioners to develop appropriate teaching materials.

Specialist learning disability service providers in Northumberland Tyne and Wear Trust (Northgate Hospital) have been working collaboratively with Northumbria Police to provide Mental Health Awareness Training for new recruits in their probationary period which is positively reinforced by the facilitation of placements within learning disabilities service. The training is based on values and attitudes and offers scenario based learning. A workbook is currently being developed to enhance the learning and encourage officers to make contact with their local services once assigned to an area<sup>89</sup>.

Excellent suggestions for the strengthening of general medical training are provided in the report by the BMA equal opportunities committee and patient liaison group<sup>90</sup>. The Inquiry commends the recommendations it contains. Although training by itself will not be sufficient to deliver the much needed changes in practice in the NHS, the Inquiry

<sup>83</sup> Slevin E, Sines D. Attitudes of nurses in a general hospital towards people with learning disabilities: influences of contact and graduate, non-graduate status, a comparative study. *Journal of Advanced Nursing*. 1996; (24): 1116-1126.

<sup>84</sup> Melville C, Finlayson J, et al. Enhancing primary health care services for adults with intellectual disabilities. *Journal of Intellectual Disability Research*. 2005; (49): 190-198

<sup>85</sup> Thacker A, Crabb N, et al. How (and why) to employ simulated patients with intellectual disabilities. *The Clinical Teacher*. 2007; (4):15-20.

<sup>86</sup> Closing the gap: important recommendations for primary care practitioners. A documentary depicting the real life experiences of four people with learning disabilities and/or mental health problems in primary care. Disability Rights Commission. London. 2006.

<sup>87</sup> www.mencap.org.uk

<sup>88</sup> Good doctors, safer patients. Department of Health. London. 2007.

<sup>89</sup> Contact: allison.armstrong@nap.nhs.uk

<sup>90</sup> Disability equality within healthcare: the role of healthcare professionals. British Medical Association Equal Opportunities Committee and Patient Liaison Group. London. 2007.

recommends that those with responsibility for regulation (including the GMC, NMC and other professional regulators) must give urgent attention to strengthening training.

The Inquiry believes that this is an essential step towards improving the quality of treatment for people with learning disabilities. Work currently being undertaken to modernise careers in medicine, nursing and in other areas should therefore consider these recommendations in full.

## RECOMMENDATION 1

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.

### 3.3 INFORMATION ABOUT PEOPLE WITH LEARNING DISABILITIES

Chief among the obstacles to delivering and evaluating the effectiveness of health services for people with learning disabilities is a lack of information about them. As we saw in previous chapters, it is difficult for services to prepare properly or make the necessary ‘reasonable adjustments’ if patients’ communication and other special needs are unknown. Mistakes can lead to failures of treatment, risks for the patient, and a failure to engage other partners, including carers, in the treatment plan. Such mistakes are described vividly in the NICE (2002, *op cit*) audit of sudden unexpected but potentially avoidable deaths in children and adults with epilepsy where shortcomings in information exchange were highlighted as a major problem.

In primary care, GP registers are now part of the QOF, but current registers, as described in Chapter 2, appear to include only people with severe learning disabilities rather than the wider group. One explanation may be that GPs are still new to the task of identifying learning disability and have not yet established the local partnerships with providers that would help them to improve data quality. Some also argue (Gates 2003<sup>91</sup>) that people at the milder end of the spectrum of learning disability prefer not to be identified as having a learning disability, but witnesses speaking to the Inquiry suggest that these are relatively few in number. Best practice suggests that it is appropriate to discuss the pros and cons and offer a choice and in these circumstances, they say, very few people opt out.

The Foundation for People with Learning Disabilities publishes helpful good practice guidance to support primary care services and their partners to get the best out of their local data sets and records<sup>92</sup>. It includes examples of excellent practice in Teeside, Barnet and Peterborough. Areas where Local Enhanced primary care services have been developed (e.g. Westminster, South Birmingham and Surrey) also have particularly good stories to tell. Good practice is not restricted to the statutory sector either. For example, Helen & Douglas House is a registered charity providing respite and end of life care for children and young adults with life-shortening conditions that received very positive feedback.

Westminster PCT in partnership with the Imperial College Healthcare NHS Trust has introduced a vulnerable patient form which now accompanies each patient with a learning disability on admission to an acute ward. Staff work in partnership with the local Patient Advice and Liaison services and advocates to support patients when they are admitted<sup>93</sup>. Central Lancashire PCT with Lancashire Teaching NHS Foundation trust also has a policy

<sup>91</sup> Gates B. Planning for health: a contrary reflection on health action plans and health facilitators. *Journal of Learning Disabilities*. 2003;7(1):5-7.

<sup>92</sup> Contact: [agiraud-saunders@fpld.org.uk](mailto:agiraud-saunders@fpld.org.uk) or view material at [www.learningdisabilities.org.uk/](http://www.learningdisabilities.org.uk/)

<sup>93</sup> Contact: [stephan.bruschi@westminster-pct.nhs.uk](mailto:stephan.bruschi@westminster-pct.nhs.uk)

and a protocol for admission to the acute hospital services. The Royal Berkshire NHS Foundation Trust now operates a similar scheme and uses a booklet 'Information about me' containing information about patients' special needs. Kingston Hospital NHS Trust has also worked with the local Learning Disability service to develop a Patient Passport containing information about health needs for people with learning disabilities.

Torbay Hospital has a system (Patient Profiles) for people with learning disabilities in the catchment area of the hospital. Emphasis is placed on those who find communication difficult because of cognitive impairment, speech difficulties or hearing problems (regardless of diagnosis). A profile for the patient notes is completed and sent to medical records. A copy is kept in the Accident and Emergency department and the computer flags a special need when the patient is booked in<sup>94</sup>. Similar arrangements in the form of Communication Passports and Health Action Plans are available in North Yorkshire and York PCT where information is highlighted in medical records using 'Risk Alert Cards'.

Humber Mental Health Teaching NHS trust<sup>95</sup> has worked closely with Hull and East Yorkshire hospitals NHS trust to improve the patient journey using a 'Patient Passport'. This is also available on a CD and can be downloaded onto paper or shared electronically. Decision making and best interests pathways have also been developed to support decision making for other people who may be vulnerable in the acute hospital setting such as older people with dementia.

“The traffic light system for admission into hospital in Gloucestershire is really good. Bed names have a colour symbol that indicates if a person has communication needs or LD.” [Support worker]

'2gether NHS Foundation Trust'<sup>96</sup> (formerly Gloucestershire Partnership NHS trust), Oldham PCT and Sheffield Teaching Hospital Foundation Trust<sup>97</sup> all use Patient Passports based on a traffic lights system. These give staff important information about people with learning disabilities and, in Gloucestershire, they have been incorporated into a trust-wide policy for all vulnerable patients who require emotional and physical support. In Oldham<sup>98</sup>, the Passport is supplemented by a Hospital Liaison Nurse Care Pathway, including a Traffic Light Hospital Assessment tool to give staff information about people with learning disabilities. It also includes a Discharge Information Plan to ensure that people receive appropriate follow up support from community services.

“In East Lancashire the children's learning disability team liaises with the acute sector to plan admissions proactively for children going into hospital.” [CLDT nurse]

## RECOMMENDATION 2

All health care 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.

<sup>94</sup> Contact: katy.welsh@nhs.net or tanya.drew@nhs.net

<sup>95</sup> Contact: allyson.kent@humber.nhs.uk

<sup>96</sup> Contact: simon.shorrick@glos.nhs.uk

<sup>97</sup> Contact: rosemary.bolland@sth.nhs.uk

<sup>98</sup> Contact: ruth.bell@oldham.gov.uk

### 3.4 INFORMATION ABOUT SERVICES

Hospital Episode Statistics about secondary services (for example, data on admissions, emergency re-admission and data on outcomes, length of stay, complaints) also fail to permit any systematic analysis of services for people with learning disabilities. Local commissioners, planners and managers cannot derive meaningful information about the quality of their secondary services. They cannot assess performance, explore outcomes from treatment, or assess the impact of service improvement. They may not even be able to judge whether their services are compliant with legislation.

In time, the Electronic Patient Record will provide ready access to a range of information about care and treatment for individuals. It will include information about treatment across a range of different domains (acute, specialised, general medical, etc). For now, it remains true that local services have no standard way to assess whether they are meeting their legal obligations to provide equal, equivalent healthcare.

Some services are taking steps to overcome these obstacles. Yorkshire and Humber<sup>99</sup>, for example, have introduced a learning disabilities performance and self-assessment framework containing standards, key objectives and progress criteria for health services for people with learning disabilities. This covers issues relating to specialised provision such as resettlement and hospital campus closure. It also incorporates elements relating to commissioning, primary care, screening, health promotion, data and information, safety, hospital admission, and complaints. Locally, Learning Disability Partnership Boards can play a key role in monitoring services and working alongside Local Involvement Networks (LiNKs).

### 3.5 INFORMATION FOR PEOPLE WITH LEARNING DISABILITIES AND THEIR CARERS

Information is important not just for service providers but for service users and carers themselves. A range of useful self-help information in Easy Read pictorial format is already available for people with learning disabilities themselves (e.g. Hollins 1999, 2000<sup>100, 101</sup>). The Foundation for People with Learning Disabilities<sup>102</sup> produces a range of helpful information, as does the Royal College of Nursing<sup>103</sup>. In Walsall<sup>104</sup>, a Partnership Board web site has been established ([www.walsalltogether.net](http://www.walsalltogether.net)) to enable service users, carers, and health care professionals to access information about services and the support available to them. A newly established web site ([www.easyhealth.org.uk](http://www.easyhealth.org.uk)) contains a range of accessible jargon-free and pictorial health information, including videos about visiting the GP and other health care providers.

NHS Direct (NHSD) has strengthened means of access for people with learning disabilities by accepting calls from third parties such as parents or carers of people with a learning disability. NHS Direct stocks over 80 Easy Read health information leaflets for people with learning disabilities ranging from alcohol and smoking cessation advice to condition specific information such as diabetes<sup>105</sup>. NHS Direct also has a reciprocal training agreement in place with Mencap (East Midlands) whereby NHSD staff deliver training to Mencap staff and vice versa.

Nurse advisors in NHSD are also able to use 'special patient notes' for some frequent callers. These specify any hereditary conditions, significant diagnoses, characteristics or care plans including information on emergency referral arrangements that they can share

<sup>99</sup> Contact: [colin.mcilwain@yorksandhumber.nhs.uk](mailto:colin.mcilwain@yorksandhumber.nhs.uk)

<sup>100</sup> Hollins S, et al. Books beyond words series. Royal College of Psychiatrists. London. 1999, 2000 et seq.

<sup>101</sup> 50 or over? Breast screening is for you. NHS Cancer Screening Programmes. 2000.

An Easy Guide to Cervical Screening. NHS Cancer Screening Programmes. 2006. Accessible materials are also available at: <http://www.easyhealth.org.uk/> and <http://www.rcpsych.ac.uk/>

<sup>102</sup> Foundation for People with Learning Disabilities (<http://www.learningdisabilities.org.uk>)

<sup>103</sup> Royal College of Nursing (<http://www.rcn.org.uk>)

<sup>104</sup> Contact: [greenisilj@walsall.gov.uk](mailto:greenisilj@walsall.gov.uk) or [daviessam@walsall.gov.uk](mailto:daviessam@walsall.gov.uk)

<sup>105</sup> Contact: [jacqui.jedrzejewski@nhsdirect.nhs.uk](mailto:jacqui.jedrzejewski@nhsdirect.nhs.uk)

with other agencies such as A&E departments. The Inquiry believes there may be scope to extend these arrangements for people with learning disabilities who may wish to share information on their 'health passports' when they use NHSD.

“I recently attended the eye hospital. I asked the receptionist to be mindful of my son's difficulty with waiting and not understanding. The receptionist's response was that he needed to wait liked everyone else. I suggested she needed to understand 'reasonable adjustment'” [mother]

In general, the Inquiry believes there would be value in further strengthening the information available for people who provide care on a regular basis to help them to know their rights and entitlements under the legislation, including carers' statutory entitlements. The National Council of Voluntary Organisations and Mencap could help here, and perhaps also the Foundation for People with Learning Disabilities.

The Inquiry therefore also supports the recommendation made by the Joint Committee on Human Rights report 'A life like any other' (March 2008) that the relevant government departments should develop a strategy to help vulnerable people understand what the statutory duties in the HRA and DDA mean for them.

## RECOMMENDATION 3

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 and support carers to do this effectively. This will include the provision of information, but may also involve practical support and service co-ordination.

### 3.6 COMMISSIONING

Information about population needs lies at the heart of effective commissioning. PCTs in England carry responsibility for needs assessment and for commissioning an appropriate level of evidence-based services to deliver health care for their population, including people with learning disabilities. Joint Strategic Needs Assessments (JSNAs) – part of the new duty in the Local Government and Public Involvement in Health Act – are the means by which PCTs and local authorities do this. JSNAs form the basis for three-year Local Area Agreements (LAAs) and decisions about local outcome and performance measures.

A core data set to support JSNAs was published by the Department of Health in December 2007<sup>106</sup> with guidance on the JSNA process. The data set, which is still in development with support from Yorkshire and Humber Public Health Observatory, contains items relating to adults with learning disabilities in employment, in settled accommodation and/or receiving (social) services in the community, but none currently relating directly to health care or health outcomes.

Witnesses speaking to the Inquiry commented on shortcomings in the approach taken by PCTs who, they alleged, were more focused on contracting and procurement than commissioning in its widest sense. The Department of Health acknowledges that there are weaknesses in commissioning and the 'World Class Commissioning' programme<sup>107</sup> is designed to strengthen it. Two learning disabilities-specific pilot sites established by the Department of Health to support the programme will, hopefully, support the development of knowledge about how to improve commissioning quality.

<sup>106</sup> Core dataset for joint strategic needs assessment. Yorkshire and Humber Public Health Observatory. 2007.

<sup>107</sup> World class commissioning. Department of Health. London. 2007.

Local Area Agreements (LAAs) are the practical, semi-contractual face of the local agreements between the NHS and local government and their partners. They are three-year agreements with central government about joint work to improve services and the quality of life in local areas. LAAs covering the period 2008-2011 are now required to be in place. Good partnership working is essential to the process of effective commissioning and is fundamental to the process of securing local agreements for service delivery. The Inquiry believes that Local Strategic Partnerships, currently of variable quality according to witnesses, should be strengthened in relation to commissioning, provision and evaluation of services.

The Healthcare Commission intends to review the quality of commissioning services for people with learning disabilities and complex needs by PCTs in partnership with local authorities. The Inquiry believes it will be important to involve people with learning disabilities and to consult Learning Disabilities Partnership Boards.

## RECOMMENDATION 4

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.

### 3.7 HEALTH CHECKS

There have been three controlled trials of health checks. The 'Primary care, Evaluation Audit and Research in Learning disabilities' (PEARL) study (2002) by the Welsh Centre for Learning Disabilities which found health checks to be effective, identifying untreated diabetes, hypertension, high cholesterol, thyroid disorders, dental problems, cardiac difficulties, asthma and mental health difficulties<sup>108</sup>. In another controlled trial by Cooper et al. (2006)<sup>109</sup> 100 People with learning disabilities were followed up for a year; half received health checks, half did not. An average of 4.8 new conditions in the health check group compared to 2.4 conditions amongst controls were identified (240 conditions versus 113 in total).

A randomised controlled trial (Lennox et al, 2007<sup>110</sup>) in Australia compared the impact of a comprehensive health assessment over twelve months. It showed a six-fold increase in the detection of visual impairments; a thirty-fold increase in hearing testing (by a GP, audiologist or ENT); an increase in immunisation updates (tetanus/diphtheria boosters) and improvement in women's health screening. Unfortunately, the sample sizes were too small (453 participants with intellectual disability in 34 clusters) to demonstrate any overall impact on morbidity or mortality.

The evidence therefore suggests that whilst health checks are useful for people with learning disabilities they are not undertaken systematically and are not currently part of routine primary care practice in England. The overwhelming majority of our witnesses, the research evidence, and those responding to our public consultation agree that health checks should be provided for people with learning disabilities.

They also believe that more central direction is the only way forward and argue that

<sup>108</sup> Baxter H, Lowe K, Houston H, Jones G, Felce D, Kerr M. Previously unidentified morbidity in patients with intellectual disability. *British Journal of General Practice*. 2006; (56): 93-98.

<sup>109</sup> Cooper SA, Morrison J, Melville C, Finlayson J, Allan L, Martin G, Robinson N. Improving the health of people with intellectual disabilities: outcomes of a health screening programme after one year. *Journal of Intellectual Disability Research*. 2006; (50): 667-677.

<sup>110</sup> Lennox N, et al. Effects of a comprehensive health assessment programme for Australian adults with intellectual disability: a cluster randomized trial. *International Journal of Epidemiology*. 2007; 36(1): 139-146.



neither publication by the Department of Health of commissioning guidance for PCTs in 2007, nor reference to health issues for people with learning disabilities in the 2008/09 Operating Framework, will be sufficient to deliver change. Chapter 4 contains a more detailed discussion of how change might be achieved in this important area.

### 3.8 ACUTE LIAISON NURSES

There is preliminary qualitative support for the value of appointing staff, commonly called ‘acute liaison nurses’ to provide health facilitation or link working (Caan W et al., 2005<sup>111</sup> and Taylor, A., 2007<sup>112</sup>) between and across primary and secondary specialised (acute hospital) care. To help services develop these roles locally, professional bodies have issued guidance (RCN<sup>113</sup>). Robson, the founder member of the service in Shropshire has also established ‘Access to Acute Care’ (A2A)<sup>114</sup>, a special interest group of the National Network for Learning Disability Nurses to provide support, teaching, assessment tools, training and good practice. Such staff can help to support data collection and the provision of information; they can develop and support the use of communication tools and ‘health passports.’

Witnesses speaking to the Inquiry were unanimous in their support for this model of working and there are a number of examples of good practice (e.g. Cheshire and Wirral Partnership NHS Trust<sup>115</sup>, Oldham PCT<sup>116</sup>, Shropshire Healthcare NHS Foundation Trust<sup>117</sup>). However, there is little or no systematic research (Foster, 2005<sup>118</sup>) and the impact on health or service quality of appointing liaison staff is difficult to measure. Although A2A has over 150 members, an informal survey<sup>119</sup> identified only 20 securely funded staff in England with the liaison role as an explicit part of their job description. Provision is stronger in Scotland with 11 out of 14 health boards having a liaison nurse and research is currently under way to explore the impact on outcomes<sup>120</sup>.

“We need a champion in each acute hospital to ensure that they are getting the same treatment as everyone else.”  
[Consultant Psychiatrist in learning disability]

Most specialised staff currently working in a liaison capacity are nurses. However, there is also one GP in England with a Special Interest in learning disability. The Department of Health is currently working with the Royal College of General Practitioners to develop competency based specialty specific guidance for GPs and Pharmacists with a Special Interest in learning disabilities to support the national accreditation process published in April<sup>121</sup>.

Social care staff are also often involved in supporting access to health care, even though they have no special training in this area. Indeed, National Minimum Standards for Care Homes for Adults (standard 19) requires service users to be offered annual health checks. Witnesses speaking to the Inquiry said that there were often difficulties in delivering this commitment because some social care staff do not see it as part of their role to support people to access health services. Furthermore, health services often fail to take account of the views expressed or the help offered by staff. However, the

<sup>111</sup> Caan W, et al. Health facilitation in primary care. *Primary Health Care Research and Development*. 2005; 6(4): 348-355.

<sup>112</sup> Unpublished qualitative research project undertaken in Chelmsford.

<sup>113</sup> Meeting the health needs of people with learning disabilities: guidance for staff. Royal College of Nursing, London. 2006.

<sup>114</sup> Access to Acute: a network for staff working with people with learning disabilities to support access to acute medical treatment (<http://www.nnldn.org.uk/a2a/>.)

<sup>115</sup> Contact: diane.royle@cwprnt.nhs.uk

<sup>116</sup> Contact: helen.oconnor@oldham.gov.uk

<sup>117</sup> Contact: rick.robson@sssft.nhs.uk

<sup>118</sup> Foster J. Learning disability liaison nurses in acute hospitals: if there evidence to support the development of this role? *Learning Disability Practice*. 2005; 8(4):33-38.

<sup>119</sup> Informal evidence from surveys undertaken by Robson for the Access to Acute network in 2007 (<http://www.nnldn.org.uk/a2a/>)

<sup>120</sup> Personal communication with Dr Michael Brown, NHS Lothian, Edinburgh.

<sup>121</sup> Guidance for GPs and other professionals with a special interest. Department of Health. London. 2007.

Commission for Social Care Inspection's results show that only 12 per cent of residential homes for younger adults in 2005-06<sup>122</sup> and 11 per cent in 2006-7<sup>123</sup>, including those with learning disabilities, failed to meet the standard.

Best practice and the views of witnesses suggest that the most effective partnerships across service boundaries are forged when someone in the locality takes clear responsibility for their development. This is important across all service boundaries, but may be particularly important where highly specialised services such as Accident and Emergency are involved. At York hospital<sup>124</sup>, a consultant neurologist and an epilepsy specialist nurse run designated learning disability clinics jointly with the local learning disability team. Dorset PCT<sup>125</sup> has also undertaken work to identify the additional needs of people with learning disabilities in HMP Guys Marsh and HMPYOI Portland to establish how access to health services is affected.

The Care Services Improvement Partnership<sup>126</sup> has published helpful guidance for staff working with offenders with learning disabilities. Here, there may be synergies between specialised services that make it more economical for them to work together. At HMP Wymott, for example, prisoners with a learning disability are managed within the framework for 'Older Vulnerable Prisoners'<sup>127</sup>.

Surrey and Borders Partnership NHS Foundation Trust<sup>128</sup> and Surrey LD Partnership Board have developed an 'Acute Hospitals Learning Disability Training Pack' which contains information on working with people with learning disabilities, challenging behaviour, communication, consent, the legislation, and 'best interests' decisions. It contains protocols for the outpatients department and information to show how to make contact with the community learning disability teams who provide support.

The Inquiry believes there would be value in strengthening the workforce resource in general in this area through a Directed Enhanced Service incorporating health checks and general health liaison provided by acute liaison nurses. More detail about this is provided in Chapter 4. There may also be ways to strengthen partnerships and cross-boundary working by including explicit reference to this in staff job descriptions.

## SUMMARY

This chapter argues that positive action is needed to strengthen the workforce, local information, education, training and primary care services for people with learning disabilities. This is because people with learning disabilities fare less well than other vulnerable groups in what can seem like a competition for political and local attention. Despite guidance published by the Department of Health and others, good practice has been slow to develop and spread. Although there are examples in a number of key areas, good practice is patchy. Where it does occur, it is attributable to the energies of individual enthusiasts battling against the odds, rather than to systems designed with people with learning disabilities in mind. Understanding this provides important clues to the most effective way of strengthening health care for people with learning disabilities.

<sup>122</sup> The state of social care in England 2005-06. Commission for Social Care Inspection. London. 2007.

<sup>123</sup> The state of social care in England 2006-07. Commission for Social Care Inspection. London. 2008.

<sup>124</sup> Contact: mary.clarke@york.nhs.uk or pamela.crawford@york.nhs.uk

<sup>125</sup> Contact: simon.coombes@dorset-pct.nhs.uk

<sup>126</sup> Positive practice: a handbook for professionals in the criminal justice system working with offenders with learning disabilities. Care Services Improvement Partnership. 2007.

<sup>127</sup> Positive practice, positive outcomes. Department of Health. London. 2007.

<sup>128</sup> Contact: phil.boulter@sabp.nhs.uk

# ASSURING GOOD QUALITY SERVICES

# 4

IN PREVIOUS CHAPTERS, evidence is summarised concerning the priority, profile, and legislative framework for services for people with learning disabilities and the reasons why services need to improve. The Inquiry believes that the arguments are compelling. It is also important to consider the sanctions for failing to deliver equally effective, safe services. Responsibility and accountability lie at different points within the health care system for ensuring that the NHS environment is supportive and its performance effective. The Department of Health, regional representatives (SHAs), and the Boards of NHS organisations are all involved. This chapter argues that systematic checks are needed at all levels to ensure that people with learning disabilities, like anyone else, can access an equivalent volume and quality of health care.

## 4.1 DATA AND INFORMATION

The lack of information about people with learning disabilities and their care is a major obstacle, as previous chapters show. The Inquiry believes (as suggested by Hatton et al.,<sup>129</sup> 2005) that public health experts have a crucial role to play in helping to strengthen data and information. 'Our expertise lies in turning information and data into meaningful health intelligence' (Association of Public Health Observatories). At present, there are 12 public health observatories (PHOs) in the UK producing data and intelligence on health and health care for practitioners, policy makers and the wider community. There is no PHO to cover health of adults and children with learning disabilities.

In other areas of health care (older people, mental health), PHOs provide information about the social context for, and prevention of ill health. The Inquiry believes that:

- ◆ The evidence indicates there is enough data about variation in avoidable death to warrant establishment of a PHO for learning disabilities;
- ◆ There is a wide potential audience for the information; and
- ◆ There is a wide potential impact on the relevant audiences in the context of current legislation on discrimination and policy to reduce inequality and promote better health.

A PHO could advise PCTs on the use of existing local databases in health and social care to assist in the development of Joint Strategic Needs Assessments and to inform commissioning through Local Area Agreements. There is a need to develop a consistent information framework including a coding framework which, if it were developed in SNOMED-CT would ensure consistency between primary and secondary care.

<sup>129</sup> Hatton C, Emerson E and Lobb C. Evaluating the impact of Valuing People: a review of existing national databases. Institute for Health Research, Lancaster University, 2005.

In addition, local services could be helped to identify patients with learning disability registered with a GP as a proportion of the total number expected in the population. Comparisons could be made between primary care QOF data and local authority education and social services records to try to ensure a uniform and accurate database of the at risk population. This would provide an indication of the degree of local shortfall in GP registrations (people served) and could support uptake of the advice contained in the framework published by Primary Care Contracting (op cit) to improve data and information in national contracts

A PHO could also develop intelligence and advise on cross-boundary information, not just about health and medical treatments but about health facilitation and social care, and advise national inspectors and regulators and DH on equalities and access indicators. It could also support the development of better functionality and use of ICT and the NHS IT Programme to support exchange of information about people with learning disabilities as they move through the education, social service and health services where there are currently quite separate databases.

In addition, but for different reasons, the Inquiry believes there would be value in establishing a time-limited Confidential Inquiry (CI) into premature avoidable deaths amongst people with learning disabilities. Confidential Inquiries provide information primarily to clinical and medical staff. Through a series of retrospective reviews of incidents, they aim to detect errors or omissions that show a clear causal association with death. This would be valuable for clinical professionals providing general health care for people with learning disabilities. There may also be scope to explore the value of an indicator relating to premature avoidable death due to physical illness.

The Inquiry therefore supports the general argument, if not the detail, set out in 2006 by the National Patient Safety Agency (NPSA) in their report to the Department of Health. At this time, the NPSA argued for a review of one thousand incident cases of death using the tools of root cause analysis and significant event audit to augment the classical core confidential enquiry methodology. The Inquiry believes it would be important to update the business case, and believes that the mainly clinical work of the CI should be closely linked with the work on information managed by the PHO to ensure that local services are supported properly to develop JSNAs, LAAs and to manage and evaluate the performance of their services.

## RECOMMENDATION 5

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 difficulties to provide evidence for clinical and professional staff of the extent of the problem and guidance on prevention.

### 4.2 NATIONAL INSPECTION AND REGULATION

The system of inspection and regulation is complex: national inspectorates and regulators such as the Healthcare Commission, Commission for Social Care Inspection and Monitor, the independent regulator of foundation trusts must work in consultation with each other and with other agencies. These include the Health and Safety Executive, the Disability Rights Commission (now the Commission for Equality and Human Rights), the Mental Health Act Commission, the Office of the Public Guardian, the Information Commissioner's Office, and the Audit Commission.

In addition, a large number of clinical and professional regulators provide support for the development and maintenance of a high quality of professional and clinical practice, most, with some notable exceptions including the British Psychological Society, under the jurisdiction of the Council for Healthcare Regulatory Excellence – an independent statutory body answerable to Parliament.

Witnesses agree that it is essential that inspectors and regulators work together effectively, but say they do not always do so at present; a point also made by the Department of Health in response to the consultation on reform<sup>130</sup> of regulation in health and adult social care. The Healthcare Commission is undertaking useful work in partnership with other regulators on commissioning specialised services for people with learning disabilities following their audit of inpatient care. However, it is also important to consider general health care where special needs can easily slip through the inspectorial and regulatory net.

It is essential that the systems for regulation and inspection of healthcare are responsive – not blind to – the needs of people with learning disabilities when they receive treatment in mainstream primary and secondary care. At present, the CEHR (and only the CEHR) can apply to the court for an order requiring compliance with the Disability Equality Duty (DED) but most work in practice by the CEHR takes place at an earlier stage. It is designed to raise awareness and support organisations to develop competence in relation to disability equality.

The Inquiry team believes that, whilst this is important work, it is essential that the CEHR strengthen its systems for inspection of services in respect of their ongoing compliance with the Disability Discrimination Act. Work in partnership with Monitor, for example, could help to strengthen awareness of risks in the acute sector at the point when applications, for authorisation to become a foundation trust are made, as well as later when compliance with the terms of authorisation are reviewed.

Proposals for reform of regulation in health and social care in the Health and Social Care Bill 2008 offer an opportunity to strengthen inspection and regulation of services and improve communication between the different agencies involved. Core standards are scheduled to be replaced by April 2010 with a new registration scheme covering health and social care providers managed by the Care Quality Commission (CQC).

The Inquiry welcomes the proposals to strengthen regulation in primary care provision by the CQC because, at present for people with learning disabilities, inspection seems less effective in these services than in secondary care. This is particularly important when care is provided across a diverse range of providers; across primary and secondary care and when vulnerable patients with long-term conditions such as many with learning disabilities are supported at home and primary care is in the lead.

There are clear risks for some vulnerable groups, as indicated by the JCHR report into older adults, and particular risks referred to in this report (Chapter 2) for people with learning disabilities, that seem unlikely to be mitigated by the establishment of a single regulator without special attention. As a first step, the Inquiry believes that the Department of Health should amend Core Standards for Better Health to reflect the requirement in legislation to make ‘reasonable adjustments’ to services to ensure they are accessible to people with disabilities. This should help to focus the work of inspectors and regulators and ensure effective examination of services for their compliance with disability legislation.

<sup>130</sup> The future regulation of health and adult social care – response to consultation. Department of Health. London. 2007.

## RECOMMENDATION 6

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.

Many witnesses commented on the fact that there are no indicators specific to the healthcare of people with learning difficulties in current assessment procedures and no national targets or a national service framework. In addition, very few PCTs have adopted guidance from Primary Care Unlimited, the Valuing People Support Team and the Foundation for People with Learning Disabilities that they should monitor delivery at Practice level using the Better Metrics Indicators 8.01, 8.02, 8.03 and 8.04 (learning disability registers, health checks, health facilitation, and health action plans)<sup>131</sup>.

The Healthcare Commission reported in 2007<sup>132</sup> that they had plans to introduce ‘an indicator on learning disability health services’ as part of the 2008/09 annual health check – an intention also stated in the Operating Framework for 2008-09. The Inquiry welcomes this, although the indicators published in June 2008<sup>133</sup> based on the analysis of consultation responses refer only to specialised learning disability and mental health trusts. Further work by the PHO would help to identify a range of indicators that might also be appropriate for use in primary care and specialised acute settings for people with special needs to support compliance with the disability discrimination legislation.

## RECOMMENDATION 7

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.

There would also be value in strengthening reporting of Serious Untoward Incidents (SUIs) which cannot, at present, be analysed with respect to the numbers reported in general health settings about people with learning disabilities. As part of their evidence to the Inquiry, the National Patient Safety Agency (NPSA) made a special search of the National Learning and Reporting System (NLRS) using keywords to identify incidents affecting people with learning disability receiving care outside specialised settings.

<sup>131</sup> The better metrics project. Commission for Healthcare Audit and Inspection. London. 2007.

<sup>132</sup> Developing the annual health check in 2008/09: have your say. Commission for Healthcare Audit and Inspection. London. 2007.

<sup>133</sup> Analysis of the consultation responses received for developing the annual health check in 2008/09: have your say. Commission for Healthcare Audit and Inspection. London. 2008.

Unfortunately, the data set was too small to allow analysis of any trends or patterns, but it did reveal some vivid individual case examples very similar to the cases described by Mencap and the Ombudsman. The Inquiry believes the NPSA should work closely with Monitor, the Healthcare Commission and the CEHR to share information about health risks that may be relevant to inspection and regulation in general medical settings. This should improve the quality of care and inspection.

## 4.3 ASSURING THE QUALITY OF LOCAL SERVICES

### 4.3.1 Commissioning

Commissioning lies at the heart of effective services and, together, the evidence implies that a ‘reasonable adjustment’ is needed to the policy set out in the Operating Framework (op cit) of leaving decisions about health care for people with learning disabilities to local commissioners. For example, very few commissioners have used the framework published by Primary Care Contracting (op cit) for local enhanced primary care services for people with learning disabilities. Witnesses argue there is little evidence that ‘The Vital Signs’ (op cit) will drive improvement further.

There are, broadly, two options to consider. Health checks – already a component of published policy for the development of primary care – could continue to be pursued in negotiation with the BMA and others as part of the Quality Outcomes Framework. Alternatively, and the Inquiry argues more appropriately, the Secretary of State for Health could direct PCTs to commission an enhanced service (a ‘Directed Enhanced Service’ or DES)<sup>134</sup> for people with learning disabilities incorporating health checks and the necessary additional steps to make ‘reasonable adjustments’ to services. The reasons for this recommendation include the following.

The research and witnesses giving evidence to the Inquiry suggests that GPs who lack training in learning disability are unlikely to deliver health checks to a good standard without support. At present, they are uncertain where to go for help with health checks (Hames and Carlson, 2006<sup>135</sup>) and some witnesses argue that GPs would resist the burden of sole responsibility for their delivery. Community Learning Disability Teams also have concerns that when they provide the health check instead (an activity for which they may also have little or no training) primary care teams tend to disengage.

There are debates about whether health checks should be annual and/or at points of transition; what to include; who should be included (adults and/or children; all people with learning disabilities or just those with severe disabilities) and whether checks should be done by GPs, practice nurses, specialists or in partnership. The evidence suggests that annual health checks would benefit people with moderate and severe learning disabilities but in all cases an individualised approach is important. Guidance on these points of clinical practice could usefully be provided by an Observatory and Confidential Inquiry working in consultation with each other.

There is also evidence from debates amongst professionals and in the literature about the value of a health check alone, that is, without additional support provided for patients to have their health needs assessed and met through ‘reasonably adjusted’ services. For these reasons, and because the research shows that health checks have been most effective when delivered as part of a wider service (as in Wales<sup>136</sup> or in Local Enhanced Services in Westminster, South Birmingham and Surrey) including health facilitation and Health Action Planning, the Inquiry believes their pursuit through the QOF alone is insufficient.

<sup>134</sup> There are currently six Directed Enhanced Services in England: the childhood immunisation scheme, violent patient scheme, influenza and pneumococcal immunisation, improved access scheme, choice and booking, and minor surgery.

<sup>135</sup> Hames A, Carlson T. Are primary health care staff aware of the role of community learning disability teams in relation to health promotion and health facilitation? *British Journal of Learning Disabilities*. 2006; (34): 6-10.

<sup>136</sup> Cardiff health check for people with a learning disability. Available at: <http://www.rcgp.org.uk>

Directed Enhanced Services, on the other hand, traditionally used to target areas of health care or practice until alternative arrangements are in place or until good practice beds down, offer the potential to strengthen arrangements on a broader basis. A DES for health care for people with learning disabilities would ensure that responsibilities at local level were clear in relation to primary as well as secondary care services and would establish a single point of contact for all those seeking information and support.

A DES for people with learning disabilities should incorporate health checks by GPs. It should incorporate the appointment of liaison staff (acute liaison nurses, for example) to support the development of equivalent, 'reasonably adjusted' general health care, improvements in the quality of GP registers, and health facilitation. Liaison staff should also facilitate links between primary care, specialised services and the general health sector, and between social care and health or local authority education services and health.

If local circumstances suggested it would add value, a DES could provide the framework for commissioners to secure more effective service partnerships by establishing vertical integration between primary and secondary providers. This is particularly important for those with the most complex needs, as described in Mansell's (2007 op cit) report whose care crosses many boundaries and for whom the communication challenge is particularly significant.

A DES would also offer the potential to strengthen engagement by PCT Boards. Witnesses have argued that, although PCT Boards are already responsible for ensuring compliance with legislative and regulatory requirements and oversight of contracts, the existence of the national general medical services contract represents a constraint on their influence over individual general practitioners. A DES would help to ensure stronger connections for the PCT between the inspections they already undertake for the QOF and their local service commissioning.

## RECOMMENDATION 8

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.

### 4.3.2 Provision

Accountability for delivering and managing care at trust level rests with the Board of Directors and the Chief Executive as Accountable Officer. In foundation trusts, the Board of Governors appoints the Chairman and non-executive directors and approves the appointment of the Chief Executive. The majority of the members of boards of governors of foundation trusts are elected. Those eligible for election include patients and staff of the trust, and members of the local community. These constituencies and local stakeholder representation on the board of governors (from PCTs and local Authorities inter alia) are a natural route for trust management to monitor inter-agency partnerships to support effective access to health care for people with learning disabilities.



The Health and Social Care Act 2001 (Section 242) placed a duty on the NHS to involve and consult patients and the public are involved at all stages of the planning and delivery of services, and in decisions affecting their operation. From April 2008, Patient and Public Involvement (PPI) Forums were replaced by Local Involvement Networks (LINKs) and the Commission for Patient and Public Involvement in Health ceased to exist. LINKs are designed to provide everyone in the community with the chance to say what they think about local health and social care services and to influence how they are run.

Our witnesses suggest there is growing representation of people with learning disabilities in PPI forums (LINKs) connected to specialised services. However, we have found only one example of a representative with learning disabilities working in acute services. To some extent, this is not surprising; patient numbers are very small, but there are ways to strengthen their involvement. In March 2007, for example, Peterborough and Stamford NHS Foundation Trust invested in the Change Health Picture Bank, which is now used to produce all agendas and minutes for the Trust Disability Involvement Forum in anticipation of recruiting a member with a learning disability. In addition, all Trust Board agendas and Governor's Agendas are now produced in Easy Read.

Peterborough and Stamford Hospitals NHS Foundation Trust also drew up a 26 point action plan following work with the Learning Disability Partnership Board, which involved listening to the needs and experiences of local people with learning disabilities and their carers. An 'Access to Mainstream Healthcare Group' has now been established to deliver service improvement.

## RECOMMENDATION 9

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.

There may be scope for further development of partnerships ('twinning') between governors of specialised trusts where user representation is good, and acute trusts. This would help acute trusts to strengthen their capability to provide safe, effective care for people with learning disabilities and reduce risks on admission, especially in an emergency, for people with learning disabilities who have limited communication and depend upon their carers for support.

## RECOMMENDATION 10

All Trust Boards should demonstrate in routine public reports that they have effective systems in place to deliver effective, 'reasonably adjusted' health services. This 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.

### 4.33 Complaints

Complaints are an important way for health care services to understand and remedy shortcomings in their services; they provide an important assurance of quality, and a means to judge whether lessons from mistakes are being learnt.

Complaints are initially investigated locally. If the complainant is unhappy with the outcome, s/he can go to the Healthcare Commission within six months (stage two) for an independent review. If the complainant is unhappy with the formal response from the Healthcare Commission, the case may be taken to the Health Service Ombudsman.

The Inquiry heard many examples from people with learning disabilities and their carers, including those families whose stories featured in the Mencap report, about poor management of their complaints. Not only did complaints take a long time to be responded to, the information and explanations they received were perceived to be inadequate.

It was difficult for the Inquiry to obtain systematic information about complaints at national level; however, it was notable in itself that the absence of information about people with learning disabilities receiving care in other than specialised settings, limits the scope for investigation. Neither PCTs nor Acute Trusts nor NHS Direct is able to say how many complaints they receive from people with learning disabilities, or describe any action taken as a result.

'Our health, our care, our say' (2006) contained a commitment to develop a comprehensive complaints system across health and social care by 2009 and the Department published its formal response to the consultation 'Making Experiences Count' in February 2008<sup>137</sup>. The Inquiry welcomes this development and urges the Department of Health to ensure that information is provided in an accessible format to help people with learning disabilities understand it.

For individuals who have difficulty in understanding and/or reading and writing, the complaints procedure is very complex. The Inquiry believes that it will be important to strengthen the availability of appropriate information for service users, their carers and supporters, and the availability of advocacy support.

#### 4.34 Advocacy

As we saw in Chapter 2, there is a duty (Health and Social Care Act 2001) to provide Independent Advocacy Services to assist individuals making complaints against the NHS and the Independent Complaints Advocacy Service (ICAS), launched September 2003, provides a national service delivered to agreed quality standards. In addition, Mental Capacity Act Advocacy (IMCA) is provided on a statutory footing for those who lack capacity to help them make important decisions relating to health and residential care.

For other people, self-advocacy or supported advocacy may be provided by Patient Advocacy and Liaison (PALs) groups; through Patient and Public Involvement (PPI) Forums (now Local Involvement Networks or LINks); or via health facilitation provided by other NHS staff (including liaison nurses). Charitable, voluntary and user-led organisations also have a hugely important role to play. The leading providers of advocacy (including Independent Mental Capacity Act advocacy – see Chapter 2) report that restrictions on resources limit their activities. They also argue that, in addition to that provided by local authorities, more support for advocacy should be provided by the NHS. The Inquiry supports this view.

The Inquiry believes there would be value in strengthening the availability of independent advocacy for people with learning disabilities in relation to their experience of general health care. PALs and LINks should, for example, always include people with learning disabilities to ensure that they have access to the knowledge and the skills needed to make effective input to services. At present, there are very few examples of work being undertaken in the learning disabilities area. There is also widespread confusion about the roles of the different players in the advocacy field and, in acute general health care, much scope for improving the partnerships with specialised services to strengthen it.

<sup>137</sup> Making experiences count: the proposed new arrangements for handling health and social care complaints– response to consultation. Department of Health. London. 2008.

#### 4.4 LOCAL OVERVIEW AND SCRUTINY

Following the introduction of local authority Overview and Scrutiny Committees under the Local Government Act 2000, the Health and Social Care Act 2001 formally enables authorities with responsibility for social services to review and scrutinise health service matters, and make recommendations to NHS bodies, secure hospital and community services. There is a particularly good example of the use of a review by a local scrutiny committee in Haringey<sup>138</sup>, focused on the health needs of people with learning disabilities<sup>139</sup>. The Centre for Public Scrutiny (CfPS) in partnership with the Foundation for People with Learning Disabilities recently published guidance based on this for others wanting to do the same<sup>140</sup>.

The Inquiry believes there would be value for local scrutiny committees helping to support and strengthen services for people with learning disabilities in Local Area Agreements; particularly as these relate to their combined health, social care, leisure and education needs. There should also be scope for Overview and Scrutiny Committees to draw on information held by Learning Disability Partnership Boards and review, for example, information sharing (e.g. between health and education, primary and secondary, health and health service users, etc.) in the interests of better health care and more effective partnership working.

## SUMMARY

In this chapter, the Inquiry argues that the systems for assuring equity and quality of health services for people with learning disabilities as well as compliance with existing legislation must be significantly strengthened. This requires better data and information at all levels. It also requires more effective systems for inspection and regulation of health care services, and stronger partnerships at local level between commissioners, providers and the public. In this way, commissioners and the public can be assured that services are being delivered equitably, in accordance with the legislation. The aim is to ensure services are effective, safe, fair, personalised, transparent and measurable rather than invisible.

<sup>138</sup> Healthy and equal: improving the health of people with profound and multiple learning disabilities. Haringey Health Overview and Scrutiny Committee. London. 2007.

<sup>139</sup> Contact: rob.mack@haringey.gov.uk

<sup>140</sup> 10 questions to ask if you are scrutinising mainstream health services for people with learning disabilities. Centre for Public Scrutiny. London. 2008.



# CONCLUSIONS AND RECOMMENDATIONS

# 5

‘PUBLIC AUTHORITIES should never be allowed to treat their duties towards adults with learning disabilities under the Human Rights Act 1998 and the Disability Discrimination Act (including their positive duties under the Disability Equality Duty) as optional.’  
(A Life like any other, Joint Committee on Human Rights, 2008).

The evidence from the literature, from the consultation and from witnesses suggests very clearly that high levels of health need are not currently being met and that there are risks inherent in the care system. People with learning disabilities appear to receive less effective care than they are entitled to receive. There is evidence of a significant level of avoidable suffering and a high likelihood that there are deaths occurring which could be avoided.

The evidence shows a significant gap between policy, the law and the delivery of effective health services for people with learning disabilities. Although the policy and legislative frameworks are clear, there is insufficient data, poor information about people with learning disabilities and shortcomings in training. Despite guidance on the delivery of effective health care, few primary care and acute services are aware that the guidance exists, and few are aware of best practice. People with learning disabilities fare less well than other vulnerable groups in what can seem like a competition for political and local attention.

Despite this, there are examples of excellent practice in a number of key areas. However good practice is patchy and, where it does occur, it is attributable to the energies of individual enthusiasts battling against the odds, rather than to systems designed with people with learning disabilities in mind. Understanding this provides important clues to the most effective way of strengthening health care for people with learning disabilities.

The Inquiry believes the evidence shows that systems for assuring equity and quality of health services for people with learning disabilities need strengthening at all levels. This should start with stronger leadership and better information. Other recommendations concern ways to strengthen the system of inspection and regulation to ensure that data, information and partnership working are effective, and to ensure proper responsibility and accountability for service delivery. In these ways, the public can be assured that health services for people with learning disabilities are effective, safe, fair and personalised.

Recommendations are grouped under the organisational headings to which they refer to help service planners, providers and individual practitioners to identify their responsibilities.

## 5.1 THE DEPARTMENT OF HEALTH

Leadership is essential to deliver policy effectively for vulnerable groups of society. People with learning disabilities are amongst the most vulnerable and many have some of the greatest health needs. Together, the evidence implies that ‘reasonable adjustment’ is needed to policy on devolution of decision-making on health care to local level for people with learning difficulties. Current policy is failing for this vulnerable group. For these reasons, the Inquiry recommends that:

- ◆ 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 difficulties to provide evidence for clinical and professional staff of the extent of the problem and guidance on prevention. [RECOMMENDATION 5](#)

## 5.2 TRAINERS

Diagnostic overshadowing, the term used to describe the impact of ignorance coupled with negative attitudes at the interface between staff and their learning disabled patients, refers to the tendency to attribute symptoms and behaviour associated with illness to the learning disability and for illness to be overlooked. Although diagnostic overshadowing may occur in relation to other groups (such as older people, or people with mental health problems), our witnesses argue that learning disabilities represents a special case. Education and training in these issues for staff is severely limited. Staff without training tend to stereotype people with learning disabilities; they are less likely to listen, or to believe that a life lived with learning disability, could be a life worth living. The Inquiry therefore recommends:

- ◆ 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](#)

### 5.3 COMMISSIONERS

Commissioning lies at the heart of effective service design and there is a strong case for action to strengthen the quality of general health care for people with learning disabilities. The reasons include the evidence of unmet need and the risks of raised morbidity and avoidable mortality. Commissioners rely heavily on their partners to commission effective services, yet in the area of providing general health services for people with learning disabilities partnerships do not appear to be being made effectively. The Inquiry therefore recommends that:

- ◆ 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](#)

### 5.4 PROVIDERS

There is a clear legal framework for the provision of equal treatment for people with disabilities and yet it seems clear that since services are not yet being provided to an adequate standard. It is important to understand the reasons why, and the action to take. The Inquiry therefore recommends:

- ◆ All health care 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. This 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 and support carers to do this effectively. This will include the provision of information, but may also involve practical support and service co-ordination. [RECOMMENDATION 3](#)

## 5.5 INSPECTORS AND REGULATORS

The Inquiry believes it is important to strengthen the systems of inspection and the sanctions for failing to deliver effective, safe services. Systematic checks are needed at all points in general health care services for people with learning disabilities to assure providers and consumers of health care that an equally effective service is delivered for people with learning disabilities as for anyone else. The Inquiry therefore recommends:

- ◆ 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 8](#)



# TERMS OF REFERENCE

# ANNEX 1

- 1** The Inquiry will identify action needed to ensure adults and children with learning disabilities receive appropriate treatment, primarily in general acute health care and with reference to wider health services. The Inquiry will not be conducting a detailed investigation of total provision across the NHS.
- 2** The Inquiry will learn lessons from the six cases highlighted by the Mencap report 'Death by indifference'. The Health Service Ombudsman agreed to conduct an independent investigation of each individual case. The Health Service Ombudsman's investigations will run in parallel with the Inquiry and, subject to the families' agreement, the Ombudsman's reports may be available to the Inquiry panel to inform their conclusions and recommendations. The Inquiry will not be considering in detail any other individual cases.
- 3** The Inquiry will review existing national and international research on the issue, but it will not undertake original research.
- 4** The Inquiry will undertake a stakeholder consultation to listen to people with learning disabilities, their families and carers, and take evidence from key stakeholder groups.
- 5** The Inquiry will take account of evidence and findings from the Disability Rights Commission's Formal Investigation into health inequalities for people with learning disabilities and for mental health problems.
- 6** The Inquiry will not investigate mental health services or learning disability services, or investigate individual cases or new complaints.
- 7** The Inquiry will draw up conclusions from the evidence, make recommendations and report to the Secretary of State.

The Inquiry was established by Secretary of State, Patricia Hewitt, under Section 2 of the NHS Act 1977 (revised in the NHS Act 2006) to understand how the NHS can ensure adults and children with learning disabilities receive appropriate treatment in general acute health care (see Annex 1 for terms of reference).

## Team appointments May-June 2007

Sir Jonathan Michael MB, BS, FRCP, FRC, formerly the Chief Executive of Guy's and St Thomas' NHS Foundation Trust, was appointed on 31 May 2007 to chair the Inquiry, and a secretariat was provided by the Department of Health (Ms Anne Richardson and Mr Onur Yelekci). Two expert panels with cross-representation (a member on each group represented on the other) were appointed: one of people with experience of working in health and social services or in the field of learning disabilities; another of people with learning disabilities with experience of general medical treatment in the NHS. The panel members were:

Chris Davies CBE	Former Director of Social Services in Somerset and Cardiff and consultant in social care
Sir Leonard Fenwick CBE	Chief Executive, Newcastle upon Tyne Hospitals NHS Foundation Trust
Prof Sheila Hollins	President, Royal College of Psychiatrists, and family carer
Prof Jim Mansell	Professor of Applied Psychology of Learning Disability, Tizard Centre, University of Kent
Prof John Moxham	Medical Director, King's College Hospital NHS Foundation Trust
Ms Ann Norman	Professional Adviser for Learning Disability Nursing Royal College of Nursing
Ms Joan Saddler OBE	Chair, Waltham Forest Primary Care Trust
Mr Paul Adeline	Training advisor at St George's, University of London
Ms Michelle Chinery	Independent consultant and former co-chair of the Learning Disability Task Force
Ms Jackie Downer MBE	Campaigner and advocate for the rights of people with learning disabilities
Ms Karen Flood	Independent consultant and co-chair of the National Forum for People with Learning Disabilities
Mr Fahad Matabdin	Self-advocate and campaigner for the rights of people with learning disabilities
Mr Michael Ratcliffe	Independent consultant and member of the National Forum for People with Learning Disabilities

The Inquiry also wishes to acknowledge Ms Linnett Farquarson, Ms Paula Marie Camborne-Paynter and Ms Chand Matabdin for the support they provided to people with a learning disability in their role as members of the Expert by Experience Panel.

### Definitions

Learning disability is defined in different ways in the literature. This report uses the definition in Valuing People (DH, 2001) that describes learning disability as:

- ◆ a significantly reduced ability to understand new or complex information and 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.

The Inquiry used the term ‘learning disability’ rather than ‘learning difficulty’ to avoid confusion with educational problems such as dyslexia. The report covers people with autism (sometimes known as autistic spectrum disorder) if they also have a learning disability but it excludes conditions such as Asperger’s syndrome amongst people with average or above average intelligence.

### Investigation by the Parliamentary and Health Service Ombudsman

The Health Service Ombudsman’s separate independent investigation of complaints made by the families of those who died was undertaken in parallel with the Inquiry. Powers under the Regulatory Reform (Collaboration etc. between Ombudsmen) Order 2007 also enabled the Health Service Ombudsman and Local Government Ombudsman to work together and report on complaints (three families) that crossed their respective jurisdictions. During the course of their work, the Inquiry team and Health Ombudsman’s team consulted one another regularly. Although the Ombudsman was not able to share details about the individual cases, or her judgements, discussion took place about the emerging common themes. This clarified areas for further investigation by the Inquiry, identified areas of overlap, the important domains for questions for witnesses, the areas where recommendations for the wider NHS were needed, and plans for communication and dissemination of findings.

### Consultation with families featured in the Mencap report

Invitations to meet Sir Jonathan and members of the Inquiry team were made to the families whose relatives’ care and subsequent deaths were featured in Death by indifference. Meetings were held at an early stage and again prior to the development of the Inquiry team’s conclusions and recommendations. The Inquiry is very grateful to the families for being prepared to discuss issues relating to the care their relatives received, and for being prepared to re-experience the distress of loss that this process triggered. The Inquiry is also grateful to them for sharing the draft reports they received from the Health Service Ombudsman, and their comments on the content. Details of the families’ reports are not given here since, at the time of writing, their complaints were still subject to the judgement of the Health Service Ombudsman. However, together with the evidence from the literature, the public consultation and evidence from witnesses, information from the families has helped the Inquiry team to be confident that the conclusions and recommendations of the Inquiry are evidence-based and appropriate.

### Public consultation August – October 2007

On 3rd August 2007, a Press Release and Call for Written Evidence was issued containing three questions in Easy Read and plain English. These were sent directly to professional, academic, charitable, voluntary, public sector bodies and a number of interest groups. A web site ([www.iahpld.org.uk](http://www.iahpld.org.uk)) was established to provide background information to support the consultation and to provide information to the public (including

in Easy Read format). The questions asked during the public consultation (also available in Easy Read) were as follows:

- ◆ The Independent Inquiry is focusing on the action needed ensure adults and children with learning disabilities receive appropriate treatment in acute medical hospital care and general primary care (not mental health services or specialist learning disability services). What are the issues that concern you most?
- ◆ What, do you think is needed to improve access to appropriate acute medical (hospital) and general primary medical care for people with learning disabilities?
- ◆ Please tell us about any examples of good practice that you know.

### **Evidence gathering phase 1 October 2007 – December 2007**

Initial meetings were arranged with Mencap, the Health Service Ombudsman, and the families featured in the Mencap report 'Death by indifference'. Based on these meetings, an analysis of the themes emerging from the research literature and the public consultation, key stakeholders were invited to meet the panel face to face (the list of witnesses that agreed to be identified is at Annex 4).

Two special consultations were undertaken with carers: first, a group of family carers who support people with moderate learning disabilities; second, a group of family and other carers supporting people with learning disabilities with profound disabilities and complex needs. Annex 5 contains a summary of the discussion and conclusions. A number of visits were also undertaken to services exemplifying good practice.

### **Evidence gathering phase 2 January 2008 – March 2008**

Meetings with and between the two Inquiry panels to identify the most important concerns were held to agree the areas where change is most urgently needed. Invited experts and representatives of organisations with a role in service delivery and/or regulation of the NHS gave their views about the most appropriate action to take, the obstacles and the opportunities. Three meetings were held with representatives of the Equality and Human Rights Commission (incorporating the Disability Rights Commission). A meeting was also held with senior representatives from primary care organisations, including the BMA, NHS Confederation, RCGP, academic primary care, general medical practitioners and the RCPsych.

### **Report writing and communications planning April 2008 – June 2008**

Tenders for communications consultancy services were invited. Three agencies with experience of working in the NHS and/or independent inquiries submitted written proposals and attended for interview. Luther Pendragon was appointed in April. Planning for the launch and dissemination of the report was planned in consultation with the Health Ombudsman.

### **Publication**

The report is also available in Easy Read format at <http://www.iahpld.org.uk>.

# SUMMARY OF THEMES FROM THE PUBLIC CONSULTATION

## ANNEX 3

The Inquiry team received 412 individual written submissions and submissions from 200 people who contributed to group responses. Of the latter, over 100 came from the community of people with learning disabilities and/or their carers and around 90 from professional staff. The Inquiry is very grateful for the summed responses received from:

- a Cheshire and Wirral Partnership NHS trust (75 service users consulted).
- b Eastern Region Forum for People with Learning Disabilities (Cambridge) (approximately 20 service users consulted).
- c Ridleys Drop In Centre for adults with learning disabilities.
- d CHANGE – working for Equal Rights for People with Learning Disabilities.
- e Care Services Improvement Partnership Valuing People Support Team – national team.
- f National Forum for People with Learning Disabilities. Report to the Task Force 2007 (a CD containing information and interviews relating to the Inquiry questions).
- g South Staffordshire and Shropshire Healthcare NHS Foundation trust consultation (approximately 90 staff), to which representatives of the Inquiry team were invited.

Analysis of the individual submissions showed that these came from:

- 148 professional staff
- 100 people with learning disabilities
- 79 family carers
- 32 charitable organisations
- 22 private individuals
- 14 independent sector organisations
- 9 academics
- 8 professional bodies

The submissions contained a wide diversity of information in different formats. At one extreme, the Inquiry received detailed notes, photographs, copies of complaints, and information about the histories of people with a learning disability and their experience of the NHS. At the other extreme, there were some very short submissions – just a couple of lines.

The call for evidence consisted of three questions:

- ◆ What are the issues that concern you most?
- ◆ What, do you think should be done to improve access to appropriate acute medical (hospital) and general primary medical care for people with learning disabilities?
- ◆ Please tell us about any examples of good practice that you know.

Over two thousand distinct comments were received in answer to the first two questions – although not all of these were independent of each other – and a range of examples of good practice were provided in answer to the last. Amongst the issues provoking most concern were issues relating to communication and information. Almost half of all respondents pointed to communication problems and/or highlighted the need for better information and signposting. Together, these linked categories accounted for nearly 15 per cent of all the comments made.

### People with learning disabilities

People with learning disabilities made fewer than half as many (3 or 4) comments as their non-learning disabled colleagues who averaged around 6 or 7 each. Their comments mostly fell into three areas:

- Satisfaction when staff treated them well and with respect.
- Annoyance when staff spoke to their carers rather than to them, or failed to communicate clearly.
- Waiting times and the importance of having enough time to talk to the doctor.

In addition, their responses were characterised by a degree of fear associated with hospital and medical treatment (e.g. fear of needles, stress and fear associated with waiting).

### Family carers

Family carers (79 people or around 20 per cent of respondents) made 19 per cent of all the comments – between 6 and 7 comments each, on average. The Inquiry is also grateful to the carers' organisations who sent in group responses. The largest categories for comment by carers were as follows:

- The importance of listening to carers (58 per cent mentioned this)
- The need for better education and training for staff (55 per cent mentioned this)
- The problem of communication (52 per cent)
- Twenty two per cent also mentioned the importance of better information and signposting.
- The importance of being flexible about appointments and talking sufficient time was mentioned by 32 per cent.
- Thirty two per cent mentioned a shortage of resources
- Twenty five per cent mentioned the importance of being able to stay close to their relative when in hospital.
- Just under a third (31 per cent) mentioned the value of liaison or link workers.

A number of carers gave vivid accounts of their experience obtaining an appointment and of receiving care in acute hospital settings. Many people caring for people with multiple needs described difficulty with hospital appointments. Several non car-owners described vividly the burden of the cost of taxis and the burden of stress caused a) by waiting and b) the examination failing due to the rising distress of the patient.

### Health and social care professionals

A total of 148 health and social care professionals responded (39 per cent of the total) with an average of 7.2 comments each. Of these, 14 could be identified as primary care staff, a further 24 as acute secondary care staff, 18 as social care staff and 60 as specialised services staff. Information on where the remaining 26 professionals worked was not available. In addition to submissions from individuals, we received submissions from representatives of 14 Hospital trusts (includes two were foundation trusts) and a face to face consultation meeting was held with seven professionals with knowledge and expertise in the delivery and/or management of primary care.

The largest categories for comment by health and social care professionals were as follows:

- Three quarters of health and social care professionals mentioned the need for better education and training for staff.
- Almost the same number (69 per cent) mentioned the problem of communication.
- Most (60 per cent) mentioned the value of liaison or link workers.
- They also mentioned concerns about the values and attitudes of staff (51 per cent).
- Almost half (45 per cent) thought that providing more and better information was important.
- They also pointed to the need for good joint and partnership working (40 per cent).

### Professional bodies

The Inquiry received eight submissions from professional bodies. These varied significantly in their content and length. The Inquiry undertook to guarantee confidentiality, so it is not possible to attribute their views here. However, their comments typically included reference to the importance of education and training; the importance of the legislation, and of appropriate policy and guidance to deliver better care. They also included examples of good practice.

Communication, education and training were also points highlighted by the professional bodies. They described shortfalls in professionals' understanding of the needs of people with learning disabilities and emphasised the importance of using tools to support good communication.

Most professional bodies referred to the phenomenon of diagnostic overshadowing. They highlighted the importance of patient registers, time for consultation, flagging of records, and health checks. Almost all commented on the lack of accessible information about people with learning disabilities.

Several professional bodies referred to the lack of understanding of legislation, inaccessible buildings, poor signage, unhelpful attitudes, and 'unfriendly' systems (e.g. automated telephones). Barriers to partnership working were described. Some highlighted particular examples of unmet clinical needs including dysphagia (swallowing difficulty), challenging behaviour, and management of epilepsy, commenting that these were poorly understood and managed by non-specialist staff.

### The independent sector

The Inquiry received submissions from 14 independent sector organisations and 32 charities, including local advocacy groups. For the most part, they highlighted issues similar to those identified by NHS staff. Most focused on the communication problems experienced by staff in acute settings, and their failure to work in partnership with carers or others. Many felt that there was insufficient access to advocacy.

Most commented on the unhelpful attitudes expressed by staff in primary and secondary care, particularly in relation to obtaining and appointment, keeping it and then whilst waiting in reception or A & E. Almost all commented on the difficulty of working in partnership across the health and social care boundaries, describing arguments over funding and a failure to listen to carers.

### Face to face meetings and consultations

In addition, evidence and information relating to the challenges faced by people with learning disabilities accessing general NHS care were discussed in meetings with a

number of individuals and groups. Annex 4 contains a list of all those who supplied information and material who were content to be identified as contributing to the Inquiry's work.



# OTHER CONTRIBUTORS

# ANNEX 4

The Inquiry team is grateful to the following stakeholders and witnesses who agreed to provide personal views and/or information on behalf of their organisations over and above that gathered during the public consultation. The inclusion of their names does not imply endorsement of the information in the report; nor any acceptance of the report's recommendations, nor any responsibility for errors, all of which remain the responsibility of Sir Jonathan Michael and the Inquiry team.

Roger Banks, Vice President, Royal College of Psychiatrists

Mark Bradley, Health Facilitation Co-ordinator, Oxleas NHS Foundation Trust

Karen Breese, Health Access Nurse, South Staffordshire and Shropshire Healthcare NHS Foundation Trust

Richard Brook, Public Guardian, Office of the Public Guardian

Chris Bull, Chief Executive, Hereford Council / Herefordshire PCT

Michael Brown, Consultant Nurse NHS Lothian

Stephan Bruschi, Service Development Manager, Westminster PCT

Jane Campbell, Commissioner, Equality and Human Rights Commission

Allan Cannon, parent

Janet Cobb, Associate Consultant, Foundation for People with Learning Disability

David Congdon, Head of Campaigns and Policy, Mencap

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# REPORTS FROM THE CARERS' CONSULTATIONS

## ANNEX 5

People with learning disabilities, especially those with complex needs and/or challenging behaviour, and their carers, experience a widely different quality and level of care. Carers commented on:

### Attitudes

Examples were given of staff making unwarranted assumptions about the quality of their patient's life related to the fact of their having a profound level of physical or learning disabilities and complex needs rather than to an assessment of the facts.

Ignorance and fear appear to underpin the behaviour of staff, particularly when dealing with people who have complex needs and severe learning disabilities. Examples were given of a reluctance to touch someone with a learning disability with complex needs, and of failures to complete a full and proper medical examination.

The values and attitudes of staff, despite many examples of very good practice, represent a cause for serious concern.

### Communication

Staff attitudes and values underpin their ability to communicate effectively with carers. Some communicate well. Others communicate very badly. Some do not communicate at all and seem to see carers as a nuisance. The difficulties include:

- ◆ Failing to find a good balance between communicating to the person with a learning disability and communicating with the carer.
- ◆ Failing to understand confidentiality issues (failing to share information; sometimes failing to respect a person's rights by saying too much).
- ◆ Failing to use plain language and/or pictures.

In one particularly vivid example, a failure to communicate the seriousness of someone's condition led to a failure to deliver pain management. It may have contributed to her early death and certainly restricted the range of help her family was able to provide.

### Information

For many carers and the adults or children they support, information is the cornerstone of effective healthcare. Information provided in a clear, legible, plain format – or in forms other than words – can make all the difference.

There is a wealth of good practice in the use of, for example, health passports. These contain information about individual needs and fears, preferences, medication, health risks and methods of communication. They are easily transported. They may take the form of a single sheet, a health diary, an electronic tag or a bracelet to alert health staff to the relevant issues.

One of the main challenges is to ensure continuity of knowledge, information and standards of care across service boundaries. There are no nationally agreed methods to

do this, although health passports used in some parts of the country can be helpful. Information is central to:

- ◆ identifying that the person has a learning disability;
- ◆ records (e.g. an electronic flagging system can help to signal special needs);
- ◆ obtaining a clinical and social history;
- ◆ identifying best interests;
- ◆ understanding the patient's preferences;
- ◆ providing good continuity of care across boundaries;
- ◆ ensure effective communication with all relevant stakeholders, including family carers and other carers;
- ◆ Identifying carers' needs so that services can provide appropriate help and support for them;
- ◆ Support commissioners and providers, Trust Boards, and health and social care regulators to assess improve the quality of care.

Information specifically for carers could contain a list of useful local services and their contact details; how to give feedback on what and how they provide; plus a list of rights and entitlements.

Death certificates could state a person's disability which could help assess whether premature mortality is more prevalent.

### Carers needs

There are many issues relating to the delivery of effective services for people with learning disabilities that relate to carers. For example:

- ◆ Services often take no account of the essential information that carers possess; this is especially important in relation to communication with someone who may have no speech or perhaps no sight; or has special needs or fears and/or challenging behaviour.
- ◆ Services commonly fail to work in partnership with carers to communicate.
- ◆ Services may sometimes be over-dependent on carers and expect them to do too much, including acting as care-coordinators or providing 24-hour personal care
- ◆ At the same time, they fail to provide adequate support for carers to stay near someone with a learning disability and complex needs in hospital – despite the potential cost savings and benefit for patient safety.
- ◆ Carers are commonly forced to be very resilient and assertive, and may make themselves unpopular.
- ◆ The obstacles in the way of their trying to do the best for the people they support can lead to stress and exhaustion.
- ◆ Others besides the primary carer in a family with someone with learning disabilities and complex needs may also be affected. Children's (siblings') lives may also be affected.
- ◆ As carers get older, or get ill and unable to provide care, and people with complex needs live to an older age themselves, the burden and role of caring changes and becomes more complex and potentially more mutual. It is not clear that families or services are well enough prepared for this.

Several carers reported having unmet physical health care needs of their own. At least one had postponed treatment because she was unable to obtain adequate respite care. Another spoke of the challenge of their own ageing and the need to prepare for this. One carer reflected on the fact that some people with a learning disability were now themselves supporting elderly parents.

### Access to assessment and treatment

Access to services is a problem for many carers. One reported having waited many months for a wheelchair for her child; she may have to rely on charitable support instead to obtain the chair her child needs.

Another had to find time for multiple appointments for different services when a one-stop-shop might have reduced costs, time and anxiety for all concerned. There are significant failures in services to support a 'reasonable adjustment' to the needs of people with learning disabilities. This is manifest both at the physical/environmental level as well as the level of communication. In summary:

- ◆ It is often difficult to get an appointment;
- ◆ Waiting rooms, some GP consulting rooms, and ward environments mitigate against a thorough assessment being undertaken;
- ◆ Inadequate transport makes getting there difficult (no one-stop-shop); hospital car parks are expensive;
- ◆ insufficient time is allocated;
- ◆ 'diagnostic overshadowing' and making assumptions about the meaning of an individual's behaviour may obscure ill health;
- ◆ Medical appointments may be overlooked or ignored due to misunderstandings or a failure to communicate.

Out of hours care is a particular problem in some parts of the country with locums refusing to attend and long waits before someone with a learning disability can be seen.

For many people with learning disabilities, waiting times and waiting rooms represent a challenge. Going to the doctor or dentist can be stressful and a noisy environment makes things worse. Pre-booked double slots with the GP can be very helpful. Preparation and information in a language (or pictures) is also very important.

For most people with a learning disability there is a difference between their chronological (actual) age and their developmental stage. This represents a challenge for service providers. In addition, children and adolescents with a learning disability can find themselves placed on adult wards where family carers' roles are less clear, and where their input is typically less welcome.

Adults with a learning disability may also be placed on geriatric wards, even though they are much younger. These practices may be unsafe as well as socially inappropriate.

### Transitions

People do not share information across boundaries. For example, excellent practice in education 'statementing' is lost once someone reaches 18. Either child services do not share information, or it fails to be heard or read by adult services. This is also a problem for young people leaving residential care.

People with learning disabilities and their carers commonly find it difficult to negotiate transitions and/or the boundaries between:

- ◆ children's services and adult services
- ◆ primary and secondary care
- ◆ health and social care services
- ◆ general and specialised services
- ◆ home and independent or supported living
- ◆ school and work
- ◆ Another transition concerns life-stage. The move into adulthood may be more complicated to negotiate for people with developmental delay.

It was suggested that at transition points a full handover with a review and notes should be undertaken.

Standards of care are not uniformly bad, or good. For example, one carer experienced an excellent quality of effective primary care. Yet her daughter received a very poor standard of care when she went into hospital. Another carer had the opposite experience.

Although the electronic health record may, in time, help to overcome some of these problems, there is little to stop professionals (other than unwillingness or ignorance about confidentiality) from sharing information.

Carers acknowledged it was difficult to find the right solution to effective care across boundaries and transitions. Not everyone is the same, so dedicated specialised provision would not always be the right answer even with unlimited resources. Above all, an individualised assessment of needs is the most important thing.

### Personal health care

Many carers identified problems in relation to the provision of general health care for the people they support. Podiatry (feet) and dental care (teeth) are basic services but the importance of ensuring access to effective provision is often underestimated. Neglect can lead to complications and the need for more expensive treatment later. Obesity and a lack of exercise are also, increasingly, problems for people with learning disabilities. It is not always a case of needing more services. Often, services just need to be different.

### Resources

Staff cutbacks in some services mean that liaison posts, commonly seen as 'extra' services rather than essential services' are not securely funded.

Carers are often told that providing services (e.g. in primary care) for people with learning disabilities and complex needs are more expensive and therefore cannot be afforded.

Neither individualised budgets (NB ILF funding stops on admission) nor residential fees is normally sufficient to pay for the support that is needed in hospital for someone with complex needs.

### Workforce and education and training

Specialist staff and acute liaison staff to work with people with learning disabilities are employed in different ways within the NHS. Sometimes by PCTs, but also by specialised and/or acute trusts.

They provide a valuable service. They offer support, information, negotiation, and practical help when someone with a learning disability needs medical treatment (in primary and/or secondary care) but this may vary from area to area.

However, no central data are available on staff numbers or their impact. There are also reports that many are insecurely funded.

Education and training in work with people with learning disabilities is not a compulsory part of any pre-registration training (except clinical psychology), although it now forms part of the specialised training to become a GP.

There are many examples of good practice in training, especially using people with learning disabilities and their carers as trainers.

Training should be compulsory and should be values-based as well as evidence and competence-based.

# ACKNOWLEDGEMENTS

I would like to acknowledge all the assistance I have received in undertaking this independent Inquiry and preparing this report. The two Panels have supported and guided me throughout the last twelve months whilst undertaking this Inquiry and I owe them all a tremendous vote of thanks.

The Report would have been impossible without the exceptional co-operation I have received from all those who contributed to the independent Inquiry. This includes all who submitted written information from a professional perspective as well as from the perspective of parents, carers and supporters of people with learning disabilities who described their personal experience and shared their views. The evidence about their experiences of the NHS, received from people with learning disabilities, whether directly or indirectly was most powerful and moving. My particular thanks go to the families of those who lost much loved relatives, under circumstances that were described in the Mencap report 'Death by indifference', for providing invaluable insights to the Inquiry. Thanks are also due to Beverley Dawkins from Mencap for the role she took as their advocate and supporter.

It is unusual for an Independent Inquiry to be established at the same time as a separate, independent investigation of related matters by the Health Service Ombudsman. Thanks are therefore also due to Ann Abraham, the Health Service Ombudsman and her team for their help, advice and support over the course of the past year. Whilst respecting the bounds of their statutory obligations, the Health Service Ombudsman provided invaluable support to me in the course of the Independent Inquiry. This collaboration will I hope, deliver two reports that, whilst separated in time, are united in a determination to ensure that the NHS delivers equality of access and quality of healthcare, to this most vulnerable group of citizens.

Thanks are also due to the Department of Health for its cooperation and to the many policy officials who provided input to the work of the Inquiry. I would particularly like to thank David Behan, Director General for Social Care, Local Government and Care Partnerships and my sponsor within the Department, for his support and encouragement.

Finally I would like to say a particular thank you to Anne Richardson, who led the Inquiry Secretariat, and Onur Yelekci, Assistant Secretary, both of whom were seconded to the Inquiry from the Department of Health, for their organisation and professionalism throughout the last 12 months. As a result of their commitment and support I have been able to complete the Inquiry within the timeframe originally agreed with the Secretary of State in spite of my other commitments.

Sir Jonathan Michael