Healthcare for All: The Independent Inquiry into Access to Healthcare for People with Learning Disabilities

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Abstract
The Independent Inquiry into Access to Healthcare for People with Learning Disabilities reported in July 2008. Based on a public consultation, a review of research and evidence and the views of witnesses and stakeholders, the Michael Inquiry concluded that there are risks inherent in the care system for people with learning disabilities and that they are largely due to a failure to make ‘reasonable adjustments’ to services, as required under the Disability Discrimination Act. The Inquiry found evidence of a significant level of avoidable suffering due to untreated ill-health, and a high likelihood that avoidable deaths are occurring. Although the report highlights examples of good practice there are some appalling examples of discrimination, abuse and neglect. The article makes ten essential recommendations for urgent change across the whole health system and the Inquiry team report contains practical illustrations of how to implement them.

Keywords
learning disability; health risk; inquiry; reasonable adjustment.

Introduction
The establishment of the Inquiry by the then Secretary of State for Health Patricia Hewitt last summer had its roots in Mencap’s report Death by Indifference (2007) and the Disability Rights Commission Formal Investigation Equal Treatment: Closing the Gap (2006). Both these reports highlighted failings in access to, and delivery of, appropriate treatment in primary care for physical health problems among people with learning disabilities. Death by Indifference described the circumstances surrounding six people with a learning disability who died while in the care of the NHS. Their stories were shocking. For the Inquiry team, and perhaps also for Patricia Hewitt who met the families who had lost loved ones, there was a powerful awakening to awareness that perhaps those
individuals and their families were not alone. Perhaps their experiences were not isolated.

This is why, in addition to an investigation of the individual cases by the Parliamentary and Health Service Ombudsman, the Inquiry was established. Not only were there questions about the circumstances of the individual cases, there were also questions about how widespread the problems might be across the NHS as a whole. And if a significant level of avoidable health risk should be identified for people with learning disabilities, then the Inquiry team’s urgent task was to understand the reasons why, and make practical recommendations to mitigate the risks as soon as possible.

Methodology

The report of the Inquiry, published at the end of July 2008, sets out how the challenge was tackled. It describes how the team approached the work, relying on help and advice from a panel of people with learning disabilities themselves, with their supporters and carers, who had experience of using general health services. In addition, a panel of people with professional expertise was appointed. They consisted of people working in the specialised field of intellectual disability research and service provision, as well as health and social care. Some had no specialised expertise in the intellectual disability field, but were experts in an aspect of medicine or general management. Ensuring that so diverse a range of experts could contribute to the work was central to its progress. This helped to ensure that recommendations could be developed that would be likely to resonate with a diverse audience in the NHS.

With only a year to complete the work, there was a challenge to move quickly. At the same time, the team wanted to ensure that the conclusions were as thoroughly evidence-based as the time restriction allowed. So although there was no time to undertake original research, a public consultation was undertaken. Questions were posed to members of the public, people with learning disabilities and their carers, parents and supporters, academic experts, clinical professionals, managers, inspectors and regulators in the NHS. In addition, the academic and other literature was examined. By the half-way point, well over 600 written submissions had been received, and the Inquiry team had heard evidence from a number of carers and people with learning disabilities, as well as from professionals from the NHS. The team was ready to test some initial hypotheses with health service commissioners, policy makers, providers and regulators.

By the end of the year, face-to-face interviews had been conducted with more than a hundred individual witnesses and groups, and it is important to acknowledge the important contribution they made. Thanks are particularly due to the families of the six people whose deaths Mencap’s report described. Their testimony, inevitably distressing for them to provide, gave the Inquiry team a powerful illustration of the consequences for individuals and families if care is not delivered to the highest standards.

What follows is a summary of the key findings of the Michael Inquiry, and a summary of the recommendations given to the Secretary of State for Health in July 2008.

Key findings

First, the report summarises some of the academic literature on the physical health needs of people with learning disabilities. It describes how adults and children with learning disabilities, especially those with severe disability and the most complex needs, are among the most vulnerable members of our society today. It describes how they have significantly worse health than other people in the general population, how they find it harder to access health care when they have symptoms of physical ill-health, and how they tend to receive less effective treatment than others when they do.

Worse health

Although the literature on the physical health of people with learning disabilities is relatively sparse compared with, say, the literature on cardiovascular disease in older adults or obesity in the general population, it is united on three important points. The first is that people with learning disabilities have a
different pattern of health needs from other people. For example, almost half of those with Down’s syndrome have congenital heart problems, a much higher rate than the general population. They have a higher risk of developing Alzheimer’s disease (Holland et al., 1998), and epilepsy is at least five times as common (Branford et al., 1998). People with learning disabilities have a higher than average risk of developing gastrointestinal problems and cancer (Cooke, 1997), as well as higher rates of mental ill-health (Elliott et al., 2003). Obesity, a risk for cancer, is more common among people with learning disabilities and the opportunities to exercise or eat healthily are more restricted (Messent et al., 1998). These problems challenge those with responsibility for assessment and treatment, who may not always be aware of the risks when someone with a learning disability presents with physical symptoms.

Unmet need

The second point that unites the literature in this area is the suggestion that there is avoidable morbidity and a high probability that preventable deaths are occurring, particularly among those with severe learning disability and complex needs. Evaluations of the impact of health checks in Wales demonstrate, for example, that people with learning disabilities have a higher than average level of unmet need, most of which could be met in primary care. However, measures to identify ill-health at an early stage, such as cervical screening (Davies & Duff, 2001) or mammography (NHS Improvement, Scotland, 2004), are not routinely undertaken. More worryingly, the NICE (2002) audit of deaths among people with epilepsy indicated that almost 60% of child deaths and almost 40% of adult deaths were potentially avoidable. Factors such as poor communication and information sharing as well as poor documentation were cited as the reasons – factors that have little to do with the disease process itself.

As primary care is the place where most health promotion and ill-health prevention are delivered and, as most people with learning disabilities live in the community rather than within or connected to specialised services, the Inquiry team felt that these findings had great significance. Most of the unmet treatment need appears to be of the primary care type, notwithstanding a number of complex cases for whom a good quality of secondary, specialised care can make the difference between life and death.

People with learning disabilities are not alone in showing evidence of unmet need. The Inquiry also heard from many carers whose own needs had been ignored. Not only were they not always welcomed when supporting their relatives with learning disabilities in hospital, also they were not offered a drink or a meal over long periods of staying by a bedside. They were often not allowed to stay overnight, and they were commonly not informed about what was going on. The literature is very clear about the burden that carers typically experience, and the consequences for their own health. For example, informal carers of adults with learning disabilities report 40% more limiting health disorders (McGrother & Hauck, 1996) than the general population with depression – a condition known to have a high co-morbidity with physical ill-health. Overall, it appeared that neither policy, practice nor the legal framework provided sufficient incentive to deliver appropriate care for carers.

Diagnostic overshadowing

Third is the suggestion in the literature and from personal testimony that the health needs of people with learning disabilities are not met because factors extraneous to their health needs are getting in the way. For example, life expectancy was shortest for those with the greatest support needs, according to a review by Bittles (2002). There are also several illustrations in the literature to show that people with learning disabilities are less likely than others to be given pain relief (Tuffrey-Wijne et al., 2007; Ahmed et al., 2004), especially if they are from an ethnic minority. In another controlled study by Halstead and colleagues (2000) behavioural disturbance and disability were better predictors of a low volume and poor quality of primary care than the client’s health or location – findings that were endorsed vehemently by carers.
who provided vivid descriptions of trying to persuade NHS staff to complete even very basic investigations. It was striking how much agreement there was among those consulted on the nature of this problem. For example, respondents were clear that diagnostic overshadowing occurs. This is the term used by the Disability Rights Commission and others to describe the tendency for symptoms of ill-health to be overlooked or misread because they are attributed to the learning disability. A young man with chest pain, for example, was not investigated, despite requests from the member of residential staff supporting him. He died shortly afterwards from a heart attack. The Inquiry team also heard many examples of occasions when treatment was not offered to people with a learning disability because a judgement, albeit inaccurate, was made about its merits. Such judgements implied that a life lived with learning disability is a life less valued.

Drawing conclusions
How to tackle these problems and reduce the risk of avoidable morbidity and avoidable mortality lay at the heart of the Inquiry team’s work. Perhaps the first conclusion drawn, once the extent of the problem began to be clear, concerned the framework of legislation provided in the Human Rights Act, the Disability Discrimination Act and the Mental Capacity Act. Together, the legislation is clear that universal, fair, equally accessible, effective and safe health care should be available to all those entitled to receive it, including people with learning disabilities.

The legislative framework
The Inquiry therefore concluded that changes were not needed to the legislation. However, it was transparently clear that the legislation is not well understood and, critically, this applies to the concept described in the Disability Discrimination Act as ‘reasonable adjustment’. Although everyone understands the physical adaptations, such as wheelchair ramps, necessary to ensure access by disabled people to buildings, knowledge is largely lacking about the reasonable adjustments needed for people with learning disabilities.

Overall, services, with some notable exceptions, are failing in their obligation to meet the legislative requirements. Compliance with the legislation is not monitored, and service shortcomings are not performance-managed effectively.

The Inquiry report describes this issue in some detail, and it describes some of the good practice – sadly, too thinly spread – to show how services might make the sometimes very small but significant changes to their practice in the interests of reducing risk. The changes might include adjustments to routine appointment lengths and times in general medical practice. They might include alterations to hospital signage for people who cannot read, or new arrangements in A&E departments to ensure that people with learning disabilities with communication problems or difficulty in understanding can obtain an equivalent level of assessment and/or treatment. The Inquiry report makes the point that, in failing to take account of alternative ways to support effective communication with a person with a learning disability, current practice could even be argued to be unlawful.

Recommendations
In recommending change, the Inquiry team was determined to focus on the most important areas, to be practical and evidence-based, and to ensure that recommendations were deliverable. Ten recommendations falling into three broad areas were identified, reflecting the most serious gaps in planning and service delivery: leadership and direction setting, visibility and assurance. These are set out in an abbreviated form below. Readers are advised to look to the full report for the detail. It is available on the web at www.iahpld.org.uk.

At the time of writing, the Government’s policy Valuing People Now is not published, but we remain hopeful that it will support the Inquiry’s recommendations to secure better health care for people with learning disabilities. The team was certainly heartened by the positive and constructive initial response by the Secretary of State and by the NHS Chief Executive, as well as by the constructive comments made by the then Under Secretary of
Leadership and direction setting

Time and again in our discussions with patients, carers and service providers, the critical importance of leadership was emphasised. Leadership is crucial to the change in attitudes and behaviours without which it is so hard to improve performance. While the National Directors for Learning Disability led very significant improvements in policy and service delivery for specialised services for people with learning disabilities, this has not been matched by improvements in the quality of general health services or in management of health risk. This is why the Michael Inquiry recommended amending Core Standards for Better Health, the basis for inspection and regulation in the NHS.

• Core Standards for Better Health should be amended to reflect the requirement to make ‘reasonable adjustments’ to services to ensure that they are accessible to people with learning disabilities.

Direction setting is equally important for commissioners of services who carry responsibility for securing an effective range of services for their populations. Because the evidence shows a paucity of appropriately adapted mainstream services, the Inquiry recommended that the Department of Health should steer PCTs more assertively towards provision of routine health checks, where the evidence is very clear that they are helpful in reducing risks of unmet health need. In addition, it recommended that the support necessary to deliver any necessary treatment should be provided — as exemplified in a number of parts of the country where liaison nurses are employed.

• The Government should direct commissioners of health care to develop more appropriate, proactive, ‘reasonably adjusted’ health services for people with learning disabilities, including health checks and support for access to the NHS.

Leadership and direction setting are important at all levels in the NHS, and partnership working is essential to the understanding of local population health needs. Participation and engagement are also key to reduction of stigma and discrimination. This is why the Inquiry recommended that PCT commissioners should involve people with learning disabilities and their carers more closely in the planning, delivery and assessment of services, and show how they have achieved this in their routine reports to Trust Boards.

• Local experts should be involved in strategic assessments of the health needs of people with learning disabilities.

• Local services should work in partnership with people with learning disabilities and their carers to plan care.

• People with learning disabilities and their carers should be involved as partners in the delivery of care.

Visibility

At all levels within the NHS from the Department of Health, strategic health authorities, primary care trusts and NHS trusts, including foundation trusts, people with learning disabilities are not visible or identifiable to health services. This means that 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 health care system are largely lacking; what exists is inadequately co-ordinated and poorly understood.

An important step forward was taken by the Department of Health, which offered GPs the opportunity to be paid extra for collecting data on their populations with learning disabilities. However, these data are not currently sufficiently accurate or widely used in the service of better health care. For these reasons, the Michael Inquiry recommended establishing a National Confidential Inquiry and a learning disabilities observatory to work in partnership to inform clinicians and managers about the data and the clinical risks, and to capture information to support performance assessment and management. The Inquiry report makes the point strongly that data and information at all levels should be improved.

• The Government should establish a National Confidential Inquiry and a Public Health
Observatory to provide essential information at national and local level.

- Data and information systems must be improved across the board to ensure that all health care organisations can identify people with learning disabilities.

**Assurance**

Responsibility and accountability for the delivery of effective, safe, personalised services lie at different points within the health care system. The Department of Health, regional representatives, strategic health authorities and the Boards of NHS organisations are all involved. Systematic checks are needed at all levels to ensure that people with learning disabilities, like anyone else, can access equivalent health care, and to ensure that risks are managed appropriately. This is why the Inquiry recommended much closer partnership working between the different inspectors and regulators concerned with the assessment and regulation of quality.

- Trust Boards should be able to demonstrate that they have effective, legal, ‘reasonably adjusted’ services in place.
- Systems of inspection and regulation must be strengthened at all levels to include assessment of the provision of health services to people with learning disabilities.

Last but not least, all those working on the Inquiry, and most witnesses and members of the public who spoke to the team, were clear that most health care staff want to do their best for patients. However, it was also very clear that most lack any training in learning disabilities. This means that staff at all levels in the NHS – from the hospital consultant to the surgery receptionist – fail to understand the health needs of people with learning disabilities. We also know that uncertainty and ignorance in the face of challenging behaviour and complex health needs can sometimes provoke fear and reluctance to engage. This means that training is very important. For this reason, the Michael Inquiry recommends that relevant training be included as a mandatory component of pre-registration training for all clinical professionals.

- Education and training on learning disabilities should be compulsory and involve people with learning disabilities and their carers.

**Conclusion**

As the NHS passes its 60th anniversary and continues to develop and grow, it is right to 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. Even more worrying is the evidence that there may be some patients who suffer avoidable ill-health and who die prematurely.

There is no simple or single solution to this problem. The Michael Inquiry did not make recommendations for new legislation or a new national service framework because the team believed that the essential components of an effective framework were already in place. The report argues instead for steps to ensure that the health system across the country works as effectively for this sub-group of the population as it does for any other. It argues for ‘reasonable adjustments’ to make services as accessible to people with learning disabilities as to anyone else. As a minimum, this is interpreted as meaning an annual health check, support when a visit to hospital is needed, help to communicate, better information, more visibility and tighter inspection and regulation.

In the words of the Joint Committee on Human Rights, 2008:

> Public authorities should never be allowed to treat their duties towards adults with learning disabilities under the Human Rights Act and the Disability Discrimination Act as optional.

**References**


