

PROGRESS REPORT IN RESPONSE TO
‘HEALTHCARE FOR ALL’ –
Report of the Independent Inquiry Into Access to Healthcare For
People With Learning Disabilities, July 2008

1. INTRODUCTION:

1.1 An independent inquiry into access to healthcare for people with learning disabilities was established under Sir Jonathan Michael's leadership in May 2007 following the Mencap report 'Death by Indifference' that described the experiences of six people who died whilst under the care of the NHS. The Board received a preliminary report in 2008 and this paper summarises the key actions that have been taken so far and those planned.

2. FINDINGS:

2.1 People with learning disabilities find it much harder than others to access assessment and treatment for health problems that have nothing directly to do with their disability.

2.2 Reasonable adjustments under the Disability Discrimination Act to assist with the communication needs or anxieties of individuals concerning their treatment are not sufficiently being made.

2.3 Parents and carers are not listened to, their complaints are not heard and 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.

2.4 There is poor understanding of learning disability and how to adjust healthcare to be effective.

2.5 There is poor communication, partnership working and transition planning between health agencies and services for different age groups. Lack of awareness of the health needs of people with learning disabilities is particularly poor in primary care.

2.6 There were examples of good practice but also examples of discrimination, abuse and neglect across the range of health services were reported. There is a failure to deliver equal treatment or to treat people with dignity and respect.

2.7 The health needs of people with learning disabilities have been a low priority for the NHS and healthcare inspectors, regulators and governance processes do not focus specifically on the experience of this group.

2.8 South Birmingham PCT Learning Disability Directorate is acknowledged in the report for its work on improving primary care services. They are part of the team advising the Department of Health on standardising annual health checks.

3. NATIONAL RECOMMENDATIONS FROM THE INQUIRY REPORT:

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.

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.

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.

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.

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.

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.

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.

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.

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.

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. LOCAL ACTION:

Although only Recommendation 4 is addressed in the report to commissioners we will also have an overview of the recommendations relating to providers (2, 3, 9 & 10) and have also responded to Recommendation 8 regarding the creation of a primary care Enhanced Service.

Recommendation 4 (For Commissioners)

The 3 PCTs in Birmingham together with the Local Authority have had a joint Commissioning Strategy for Learning Disabilities since 2006 and this was underpinned by considerable analysis of needs and trends. I am attaching a copy for your information. This will also be picked up through the JSNA process which will use the existing work as the basis for ongoing review.

Commissioners from the 3 PCTs meet 2 monthly to monitor and plan improvements in access to primary, secondary and specialist LD health care. This forms the basis of LDP investments. As a result of this work, previous LES' for encouraging annual health checks were replaced by investment in a Health Facilitation team to support primary care staff in working with people with LD and to support people with LD who are in-patients in the three acute hospitals in Birmingham. At the moment this group is looking at financial options for

extending the DES into a LES agreement to ensure annual health checks continue on a wider group of people than those in receipt of local authority funded services.

In addition, commissioners are involved in joint work on health issues with specialist health provider staff and the local authority through the Partnership Board and the Joint Commissioning Strategy Implementation Group. This has focussed mainly on building the awareness and confidence of people with LD with the range of health checks available and building a register of people with LD who have received a check and a Health Action Plan. Day services staff are included to enable them to desensitise service users to procedures and facilitate take up.

Recommendation 8

A LES for LD was trialled in HOBtPCT and SBPCT two years ago and abandoned as it had no impact on the numbers of people checked. GPs found their main need was for assistance with the communication needs and the Health Facilitation team was increased in capacity as a result.

However, in light of the national initiative to introduce a new Clinical Directed Enhanced Service we are working with PCT and LA colleagues on the detailed implementation arrangements. The proposed payment though, is restricted to that cohort of patients who have Learning Disabilities and who are also in receipt of a local authority funded service. There are about 2,500 people currently in Birmingham who would qualify for inclusion in this scheme.

There are Data Protection Act issues to resolve as neither the GPs nor the local authority have the agreement of the individuals concerned for this information to be shared. The local authority informs us that it does not hold a comprehensive register of everyone in receipt of its services and would have difficulty in providing this information in a significant number of cases. We are working with the LA to resolve these issues

We are also concerned that there is a potential financial disincentive for GPs to provide health checks for the remaining 5,500 people on their QOF register who have a Learning Disability but are not in receipt of LA funding (mainly because they either do not meet the qualifying thresholds for LA funded services or have chosen to meet their needs through the family resources). The PCTs are meeting to consider the options to redress this issue.

Recommendation 2 *All Health organisations should ensure that they collect the data and information necessary to allow people with learning disability to be identified and their pathways of care tracked.*

The names of 8,000 people with LD are on Birmingham GP QOF registers. This is 5,500 more than the numbers known to the local authority. All have been verified by specialist LD health services as being at high risk of health problems. The Cardiff Assessment Tool has been produced in an electronic version in Birmingham that is adaptable for all the main computer systems used in primary care. This will enable the findings of health checks to be processed and analysed more easily.

Birmingham has commissioned LD services on a collaborative basis since PCTs were established in 2002. We have also developed a joint commissioning process with the LA. Performance management arrangements are well established with our major providers and a

range of data is routinely collected and submitted to commissioners,. However we will be reviewing all of our data collection processes to ensure that we have effective systems to identify individual patient needs and that those needs are appropriately tracked

Joint work between commissioners and provider staff in specialist health services and the local authority has begun to build a register of people with LD who have received an annual health check and a Health Action Plan. This will enable Health Facilitators to track people through services.

A Health Event was held on October 17th 2008 at Aston Villa Football ground to increase the numbers of people known to have accessed health checks. It showcased health services for people with learning disabilities in fun ways to build confidence and reduce fears in accessing health screening. 400 people attended the event, of whom 179 were adults with a learning disability who used day centres or care homes. Non invasive health checks and healthy lifestyle advice were provided for all the people with a learning disability and the findings recorded. Consent was obtained from all those checked to have their details recorded on a database and to be followed up by the Health Facilitation team. Those who had findings of concern will be signposted to appropriate clinical services and all will be offered a Health Action Plan.

There was strong support for a repeat event in June 2009 with a slightly different target group and plans are far advanced.

Recommendation 3 Involvement of Carers

Carers have been involved extensively in health developments through the same mechanisms as people with LD. In addition, specialist health staff and commissioners meet with them through a carers forum where health issues can be raised.

Carers were specifically asked to submit evidence of their experiences to the Jonathan Michael Enquiry.

Recommendation 9 Section 242, Consultation with patients and the public

Anna do you want to add to this??

Birmingham has a well established LD Partnership Board with dedicated health subgroups that is attended by commissioners, providers and service users and is routinely consulted on matters relating to LD.

There was extensive consultation with people with LD on the Joint Commissioning Strategy for Adults with LD and they were asked to prioritise the areas for action. Health was selected as a top priority as a result of this process.

We are increasingly improving our consultation with people with an LD on broader health issues and for example the Joint Commissioning Strategy for Sexual Health currently out for consultation has been produced in easy words and pictures. People with LD are formal members of the PCT Diversity Action Group.

In 2007, the Health Facilitation team surveyed all the people with LD known to have been admitted to Birmingham hospitals and their carers and summarised the findings. The findings bore a striking resemblance to those of the Jonathan Michael Enquiry and were submitted in evidence.

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 including access to Advocacy*

All 3 PCTs in Birmingham are/will be asking their providers to report on the arrangements they have made to respond to the needs of this client group as part of regular performance and quality monitoring meetings

In addition Birmingham PCTs together with the LA have reviewed and invested additional resources in a citywide provision of advocacy services which can be accessed through 3 provider agencies. This is especially focussed on people facing Mental Health Review Tribunals.

Furthermore the Health Facilitation services commissioned by PCTs, and provided by SBPCT since 2004, support primary care and secondary care staff with the communication needs of patients and understanding their health needs. They provide training, professional advice and guidance on LD issues for health care staff. Some years ago the major acute trusts were unable to pick up funding of their own LD Health Facilitators piloted through the LDDF. As a result the Health Facilitator team was expanded to provide two staff to visit hospital wards daily to seek out individuals with LD who are in need of additional support.

Each acute hospital has been allocated a named Health Facilitator to provide training and telephone or face to face advice on a range of health care management issues arising in learning disability. They meet monthly with the Modern Matrons, ward staff and physicians to identify areas for development. An intranet link is being developed between SBPCT and City hospital as a pilot.

Health Facilitators dedicate significant time each week to wards that frequently admit people with learning disabilities.

The Birmingham Partnership Board has produced a Hospital Book for individuals that documents key information about their health care, personal care and communication needs that is intended to assist health care professionals in working with them as well as a guide for carers on medication. 'My Hospital Book' was developed in 2007 to record for each person with a learning disability their known health needs and medication, the best way to communicate or engage with them, tips on how to do their personal care and their likes and dislikes to give acute hospital staff information about the person admitted. 2,000 copies have been distributed and master CD ROMs given to all GPs and acute hospitals to print off additional copies.

Nurses on the local 3 year nurse training course now do a placement working with adults with learning disabilities as part of their training, most of which are with the SBPCT Learning Disability Directorate.

Commissioners through the Partnership Board have got agreement for Birmingham libraries to stock health information in easy words and pictures and have been producing a series of easy words and pictures leaflets on a range of health care topics for people with LD who are ageing.

Board Recommendation

The Board is asked to Receive this Report and to Note the Action Taken

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