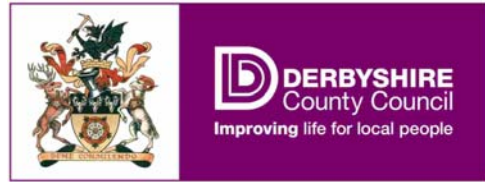


**Adult Health and Care  
Improvement and Scrutiny  
Committee**



**Review of Access to Healthcare  
Services for People with a Learning  
Disability**

**Final Report**

**September 2009**

# Contents

Foreword .....	1
Executive Summary .....	2
Background to the review .....	3
Context .....	6
The national picture .....	6
The local picture .....	7
The review process .....	9
Initial findings.....	10
Engagement and Involvement.....	14
Recommendations .....	15
Joint working .....	16
Recommendations .....	18
Respect and Dignity .....	19
Recommendation .....	20
Corporate Responsibility .....	21
Recommendations .....	22
Training .....	23
Communication .....	26
Summary .....	28
Acknowledgments .....	30
Appendix 1: 'Healthcare for All' Recommendations .....	31
Appendix 2: Care Quality Commission Indicators 2009/10 .....	33
Appendix 3: Questionnaire .....	36
Appendix 4: Accessible Information .....	39
Appendix 5: Traffic Light Assessment Forms.....	41
Appendix 6: Communication Toolkit.....	44

## Foreword



We have found the review of access to healthcare services for people with learning disabilities both informative and interesting.

Accessing general health services is something that we can often take for granted. For some people though it is not always a straightforward process. Throughout the course of this review we have found that people in Derbyshire, whether they have a learning disability or are a family carer or support worker, often come up against barriers when accessing the general health services that they have an equal right to use.

The review has sought evidence and information from a range of health commissioners and providers across the county and from neighbouring areas. Overall, health professionals involved in the review were welcoming and keen to be involved in the review.

An important part of this review was engaging with people with learning disabilities and their carers and support workers within Derbyshire to find out their main issues and concerns. The response we received was overwhelming – there were clear issues that people wanted to raise but they were also quick to praise health professionals that had provided them with a positive experience. Without the evidence that they supplied the review would not have been able to identify the areas for improvement.

We are grateful for the support that we have had in undertaking the review by a wide range of people. I would like to extend this acknowledgement to the members of the former Healthier Communities Improvement and Scrutiny committee that approved this review in January 2009 and the members that led the review working group.

We hope that through the 20 recommendations laid out in this report coupled with the national requirements to improve access to healthcare that people in Derbyshire will have equitable services.

Councillor Gill Farrington  
Chairman  
Adult Health and Care Improvement and Scrutiny Committee

## Executive Summary

The committee set out to review the progress made by health services within the county in implementing a set of national recommendations from Sir Jonathan Michael's 'Healthcare for All' review. It also sought to engage with local people on their experiences of health services. The aim being to identify where improvements were required and explore the most suitable way forward to ensure equity of access.

During the course of the review several themes established themselves in respect of areas for improvement, namely: engagement and involvement, joint working, respect and dignity, corporate responsibility, training, and communication. All of these themes were interlinked with training and communication being key to all aspects for improvement.

The recommendations set out in this report are based on evidence submitted to the review by individuals and organisations across the county. The review has taken a holistic approach when making its recommendations rather than being prescriptive towards individual organisations. A summary of the recommendations is set out below:

- Improve consultation and engagement with people with a learning disability and better promote existing services
- Creation of a shared database on people's health and care needs primarily for use in out of hours and emergency or unplanned admissions
- Ensure there are liaison nurses in acute settings
- Trust boards will actively involve people with a learning disability in their annual performance assessments
- The County Learning Disability Partnership Board will undertake an annual healthcare survey
- Improved training and development for all staff and to involve people with a learning disability in this training
- Improve the accessibility of printed material, from appointment letters through to signage in buildings.

The full recommendations can be found at the end of each themed section in this report.

## Background to the review

- 1.1 In March 2007 Mencap, the UK based charity supporting people with learning disabilities, published 'Death by Indifference' a report which highlighted six cases of people with learning disabilities who died, in their view, unnecessarily as a result of institutional discrimination by the National Health Service (NHS).
- 1.2 The Government responded by establishing a national inquiry, led by Sir Jonathan Michael, to look into the concerns raised by Mencap. The final report of this inquiry, 'Healthcare for All', was published in July 2008.
- 1.3 The 'Healthcare for All' report set out 10 recommendations with clear links to the Disability Discrimination Act 2005 and the requirement that health service providers make 'reasonable adjustments' so services can be accessed by all. A full list of these recommendations can be found at Appendix 1.
- 1.4 The former Healthier Communities Improvement and Scrutiny Committee were approached in December by the Derbyshire Learning Disability Partnership Board to look at the progress being made by health services in the county on implementing the 10 recommendations made by 'Healthcare for All'. The Derbyshire Learning Disability Partnership Board had already initiated the launch of "Be in Control" the charter for people with a learning disability and wanted to press this campaign to further improve the way public and community services respond to people with a learning disability. At a meeting of the committee on 20 January, a review was agreed. The scope of the review focussed on:
  - Experience of people with learning disabilities and family carers in using healthcare services
  - What work local health service providers have already undertaken to meet the 10 recommendations set out in the 'Healthcare for All' report and examples of good practice
  - What work is planned by these service providers and are there any barriers that prevent their implementation
  - What else can be done by service providers and users to make a difference?
- 1.5 A review working group was therefore established comprising:
  - Alan Jones (former Councillor and Chairman of the committee)
  - Councillor Michelle Booth
  - Councillor Sharon Blank
  - Councillor George Wharmby
  - Councillor David Stone

- 1.6 The scoping report included the recommendation that upon completion of the review the monitoring of the recommendations arising from the final report should be undertaken by the Derbyshire Learning Disability Partnership Board. The partnership board will then be asked to provide periodic updates to the committee. This process should ensure that real improvements are made as the people monitoring them are the ones who will be using the services on a daily basis.
- 1.7 Following changes as a result of the local government elections in June 2009, the committee was re-named Adult Health and Care, a new Chairman and Vice-Chairman appointed, and the membership of the committee revised. The new committee agreed to complete the work of its predecessor on this review at its first meeting on 30 June 2009.
- 1.8 'Healthcare for All' was published one month after Lord Darzi's report into the future of NHS services in England – 'High Quality care for all: NHS Next Stage review'. This report set out the improvements required to move the NHS forward in the 21<sup>st</sup> Century so it provides quality services that meet the needs and requirements of individuals resulting in better health for all. This report includes a series of recommendations for Strategic Health Authorities in England to implement within their areas.
- 1.9 This review also coincided with the initiative taken by the NHS East Midlands Strategic Health Authority, as part of the Government's refreshed national strategy for people with a learning disability 'Valuing People Now: The Delivery Plan,' undertaking a self-assessment process to identify services that needed improving for people with a learning disability. The main issues for Derbyshire were discussed at a 'Big Health Day' in May. An action plan is being developed by Derbyshire County Primary Care Trust which will complement the work undertaken by this review.
- 1.10 Therefore, within Derbyshire (and all of England) there are three major reports outlining how health, and to a degree, social care services need to change to ensure they are meeting the needs of the local population. This review was concerned with the progress against 'Healthcare for All' within the county, however, when looking at that review consideration has had to be given to the impact 'High quality care for all' and 'Valuing people Now' have had on the work of the health and social care services.
- 1.11 In June 2009, the Care Quality Commission (the new inspectorate for monitoring health and social care services) published indicators to measure health services including access to healthcare for people with a learning disability. Where appropriate the recommendations of this review have been linked to the Care Quality Commission indicators to

highlight their importance to health services. A full list of these indicators is provided at Appendix 2.

## Context

- 2.1 A learning disability is a lifelong condition caused by the way in which a person's brain develops. As such there is a broad spectrum of learning disabilities - most of which will develop before a child is born or during early childhood, often as a result of serious illness.
- 2.2 The term learning disability is seen by some as a label to categorise people for convenience and will use the term learning difficulties. However, this term can often be used to refer to people with dyslexia or a mental illness so for the purposes of this review the term learning disability has been adopted.
- 2.3 The Department for Health in their 2001 White Paper "Valuing People"<sup>1</sup> defined learning disability thus:

*Learning disability includes 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*

This is the definition adopted by this review when referring to a person with a learning disability

## The national picture

- 2.4 Learning, understanding, and communicating are harder for people with a learning disability to undertake. People with profound or multiple learning disabilities need full time support to enable them to carry out day to day functions. There are an estimated 1.5million people in the United Kingdom (UK) with a Learning Disability<sup>2</sup>.
- 2.5 It is expected that by 2020 the number of people with a learning disability in the UK will have grown by over 10% as well as a growth in the complexities of learning disabilities<sup>3</sup>. This is in part due to an increased life expectancy of people with a learning disability through better life chances.

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<sup>1</sup> Department of Health. *Valuing People: A New Strategy for Learning Disability for the 21<sup>st</sup> Century*, 2001 March

<sup>2</sup> MENCAP: <http://www.mencap.org.uk/page.asp?id=1684>, 2009

<sup>3</sup> Sir Jonathan Michael *Healthcare for All: An Independent Inquiry into Access to Healthcare for People With Learning Disabilities*. 2008 July



- 2.6 The poor health of people with a learning disability is an area that has been well documented over the years. Research has suggested that people with a learning disability are 58 more times likely to die under the age of 50 than other people in England and Wales<sup>4</sup>.
- 2.7 There is also evidence that people with a learning disability are at a higher risk of some diseases such as cancer than other people. However, being at a higher risk does not help explain some of the attitudes and preventable deaths that were highlighted by Mencap in their 2007 report 'Death by Indifference'.

## The local picture

- 2.8 In 2008 there were 1,506 people aged 18-64 with a learning disability who were helped to live at home with a further 532 in residential and nursing care. It is acknowledged that these figures may not tell the full picture within the county. It is expected that there is under-reporting occurring, due in part to the various information systems used by health and social care organisations and a lack of integration between these systems.
- 2.9 Within Derbyshire there are specialist/dedicated social care and health services for people with a learning disability which are organised by the Derbyshire Learning Disability Services Partnership. This brings together integrated services provided by:
- Derbyshire County Council Adult Care Department
  - Derbyshire Community Health Services
  - Derbyshire County Primary Care Trust
  - Derbyshire Mental Health Services NHS Trust
- Whilst the review was principally about the access people with a learning disability have to mainstream healthcare services provided for people in Derbyshire, the work of the specialist/dedicated services provided through the Derbyshire Learning Disability Services Partnership plays a part in the level and extent of the access people have to the healthcare services they need. Multi-disciplinary Community Learning Disability Teams are particularly important in this respect.
- 2.10 Specialist/dedicated services provided by the Partnership are mostly fully integrated between Derbyshire Adult Care and Derbyshire Community Health Services where the Assistant Director is the same person for both organisations. For those people with a learning disability living in the Glossopdale area of the County specialist/dedicated learning disability healthcare services are

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<sup>4</sup> Hollins S, Attard MT, von Fraunhofer N, McGuigan S, Sedgwick P. *Mortality in people with learning disability: risks, causes, and death certification findings in London*. Developmental medicine and child neurology. 1998 Jan;40(1):50-6

commissioned by Tameside & Glossop PCT and there is no integrated health and social care service provision or multi-disciplinary Community Learning Disability Provision.

- 2.11 Derbyshire County Council is responsible for the Derbyshire Learning Disability Partnership Board. The Board brings together a range of public and community services including the specialist service providers, along with elected representatives of people with a learning disability from district partnership boards and family carers. The Board exists to lead the implementation of national learning disability strategy – Valuing People (2001) and Valuing People Now (2009). A central objective is to promote the rights, independence, choice and inclusion of people with a learning disability as valued and respected citizens in their own community. The Board is supported by a number of groups including the Good Health Group which focuses specifically on actions that promotes the health and wellbeing of people with learning disabilities.
- 2.12 From 1 April 2009, the County Council became responsible for the remaining social care funding and commissioning for people with a learning disability that had been previously carried out by the NHS. This was part of a national transfer from NHS commissioners (in this case Derbyshire County Primary Care Trust) to local authorities. This was outlined in the Government's Valuing People Now<sup>5</sup> consultation paper. The purpose behind this is to ensure that local authorities have direct access to the resources they require to deliver social care services where they are needed.
- 2.13 As a result of these changes the NHS is left responsible for commissioning specialist learning disability healthcare services and access to mainstream health services all of which remain the responsibility of the local healthcare organisations namely:
- Derbyshire County Primary Care Trust
  - All General Practitioners within the county
  - Derbyshire County Community Health Service
  - Derbyshire Mental Health Services NHS Trust
  - Derbyshire Health United (Out of Hours service)
  - Derby Hospitals NHS Foundation Trust
  - Chesterfield Royal NHS Foundation Trust
  - East Midlands Ambulance Service
  - NHS Derby City Primary Care Trust
- The review did not, however, look at privately registered health services such as chiropody, dentistry and ophthalmology.

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<sup>5</sup> Department of Health. *Valuing people now: from progress to transformation - a consultation on the next three years of learning disability policy*. 2007 December.

## The review process

- 2.13 Following the approval of the scoping report the committee invited the Chief Executive's of healthcare organisations in Derbyshire, and surrounding areas, to submit evidence on their progress in implementing the 'Healthcare for All' recommendations. All Derbyshire organisations responded to the request along with:
- Nottingham University Hospitals NHS Trust
  - NHS Tameside & Glossop Primary Care Trust
  - Sheffield Teaching Hospitals NHS Foundation Trust
  - Stockport NHS Foundation Trust
- 2.14 An accessible questionnaire was produced for the committee by the Good Health Group to capture views of people with a learning disability on health services they had used. Copies of the questionnaire were distributed to various health and social care settings across the county and in Derby City and over 270 responses were received. Responses were also received to an advertisement on Peak FM and to articles in the Derbyshire Times and Burton Advertiser.
- 2.15 Review working group members also attended a Choice and Control Taskforce (a group of the Partnership Board) event in Bakewell in March to hear views of people with learning disabilities and their family carers. This was part of an evidence gathering event for the review and to provide feedback to local health services as part of the Healthcare Commission Annual Health Check. Strategic Health Facilitators within the county also organised two consultation events with Derbyshire Advocacy Service to gather views from adults with a learning disability on behalf of the review working group.
- 2.16 The review working group held a meeting on 30 April 2009 and invited representatives from local health services and the Derbyshire Learning Disability Partnership Board to hear what was happening around the county, where changes were needed, and to look at improving services. Further meetings were held throughout May and June with representatives from health services that were unable to attend the April meeting.
- 2.17 The 'Big Health Day' event held in May, as part of the NHS East Midlands Strategic Health Authority's work on Valuing People Now, was seen as a way of capturing any gaps in evidence from members of the Learning Disability Partnership Board and the health services within the county.

## Initial findings

- 3.1 The scope of the review set out four areas for the review working group to look at:
- Experience of people with learning disabilities and family carers in using healthcare services
  - What work local health service providers have already undertaken to meet the 10 recommendations set out in the 'Healthcare for All' report and examples of good practice
  - What work is planned by these service providers and are there any barriers that prevent their implementation
  - What else can be done by service providers and users to make a difference?
- 3.2 The review group found that all organisations involved in the review process were aware of the 'Healthcare for All' inquiry and the importance of ensuring its implementation. The stage at which organisations are in implementing these recommendations varies. Some organisations have only begun implementation some 12 months after 'Healthcare for All' was published.
- 3.3 In terms of the view of people with a learning disability and their carers the review used various methods to obtain these. The use of a questionnaire to gather people's views proved effective with over 270 responses being received (see Appendix 3). Members of the review group also attended a 'Choice and Control Taskforce' meeting in Bakewell in March, and feedback was provided to the review from two County Advocacy meetings.
- 3.4 A common theme coming from these responses was that people with a learning disability were more likely to feel they had received a good service if they had been spoken to directly and the health professional dealing with them was polite and friendly. In contrast, their carers or support workers often reported that whilst staff may have been friendly the quality of the treatment provided was not always thought to be the most appropriate or adequate or what they themselves would have received.
- 3.5 Some of the key things people with a learning disability said they liked about health services across the county were
- Doctors and nurses
  - Community dentists
  - Chiropody services
  - Information
  - Explanations about what treatment is required
  - Being comfortable in any situation from consultation with a GP to undergoing surgery in a hospital
  - Good manners from health professionals

- Being spoken and listened to and not ignored
- Having carers involved in appointments/ consultations

3.6 Some of the key things they did not like about health services were:

- Waiting times, particularly in GP surgeries
- Bad manners – ignoring person with a learning disability and speaking to their carer or support worker
- Cancellations of pre-booked appointments, often at short notice which can cause disruption to a person's routine
- Fitting into systems
- Unhelpful staff
- Electronic “booking in” systems at GP surgeries
- Not being given information
- Not knowing who to ask
- Jargon
- Complaints systems
- Poor disabled car parking

These are all things that a lot of people will identify as being good and bad about health services, whether they are disabled or not.

3.7 People with a learning disability also commented that they felt health services were not very good in the following areas:

- Providing easy to understand leaflets/ information
- People do not know about Patient Advice and Liaison Services (PALS)
- Telling people how long appointments last, and what happens next
- Assessments and Planning for discharge
- Sending letters to patients
- Consent – contravening the Mental Capacity Act 2005
- Signs in buildings, particularly hospitals and electronic signs in GP surgeries
- Flexibility, doing things differently to help one person (reasonable adjustment)
- Consultations, forums, and patient public involvement
- Looking after family carers.

3.8 It was not all bad news though as some good services were highlighted:

- Special Hearing Clinic at the London Road Community Hospital, Derby
- Free meals had been provided to some carers at Queen's Medical Centre, Nottingham
- Midwife service operating at Royal Derby Hospital
- Good explanations from health professionals in the Accident and Emergency service in Chesterfield Royal Hospital.
- Good working between Derbyshire County Council Adult Care and specialist health services dedicated to learning disabilities.

- 3.9 At the review meeting, on 30 April, Denny Fransman, from Derbyshire Mental Health Service NHS Trust, provided an example where 'reasonable adjustments' had been made by the specialist hearing clinic at the London Road Community Hospital (formerly Derbyshire Royal Infirmary). This joint service between Derby Hospitals and Derbyshire Metal Health Service was highlighted in 'Healthcare for All' as an example of a local service making the necessary changes to provide an equitable service but also having proven beneficial health outcomes for its users.
- 3.10 Some examples of good practice from this service included accessible letters for appointments, and follow up written reports. All letters used images and text to clearly present the information, see also Appendix 4 for examples.
- 3.11 The focus of the service was switched to concentrating on outcomes rather than the process of treatment. By doing this they have changed the way people are seen by the clinic. There are no longer numerous appointments in different rooms with waiting times in between.
- 3.12 There have been positive and negatives in making changes. More time is needed for writing information and there tend to be more follow-up appointments. At the same time there have been improved health outcomes for patients.
- 3.13 East Midlands Ambulance Service was also singled out during the review meeting for the professional manner in which paramedics operate and that this was as a result of very good training provided by the service.
- 3.14 The review also heard of good working approaches from Sheffield Teaching Hospitals NHS Foundation Trust. The Trust has linked the Sheffield Case Register, for people with a learning disability, to their Patient Admission System. Therefore when anyone with a learning disability comes into contact with the Trust an alert is raised enabling local directorates to put a care plan into place.
- 3.15 In reviewing the evidence prior to the scrutiny meeting on 30 April it became apparent that there were six key themes coming out of people's views. These were:
- Engagement and Involvement
  - Respect and Dignity
  - Joined up working
  - Corporate Responsibility
  - Training
  - Communication
- As work on the review drew to a close it became apparent that the areas requiring improvement were all inter-linked and often related to

two key areas – training and communication. A summary of the findings and recommendations for each of these six themes follows.

## Engagement and Involvement

- 4.1 Despite the extensive work of the Derbyshire Learning Disability Partnership Board, people with learning disabilities and family carers (or other people who are part of a person's circle of support) are not being engaged or involved sufficiently in the planning and development of mainstream health services across the county. Important planning documents such as the Joint Strategic Needs Assessment were largely unknown by people – or for those that had heard of them they did not know how it related to learning disability.
- 4.2 During the period of the review Derbyshire County Council's Adult Care department had been working with four other Local Authorities to develop a strategic needs assessment for people with a learning disability "Planning4Care" a strategic needs assessment tool. This work was completed in July. At the request of the Derbyshire Learning Disability Partnership Board. An accessible version of the Derbyshire Joint Strategic Needs Assessment and the work completed using "Planning4Care" will be published.
- 4.3 The Joint Commissioning Group responsible for strategic commissioning specialist/dedicated services for people with a learning disability (led by Derbyshire County Council Adult Care and Derbyshire County PCT) includes carer and voluntary sector representation but it is acknowledged that more work needs to be done to secure the views of people with a learning disability. This is particularly important for the planning, provision and development of mainstream healthcare services, which are commissioned by other commissioning groups led by Derbyshire County PCT, which do not have people with a learning disability or family carers involved. The acknowledgement that more needs to be done in this area was a view also shared by Chesterfield Royal, Derby Hospitals, East Midlands Ambulance Service, and Nottingham University Hospitals.
- 4.4 Sheffield Teaching Hospitals were able to demonstrate some examples of involvement with people with learning disabilities in service planning albeit at a minor level. These included:
- Allocating people with a learning disability the first out-patient appointment slot if appropriate and making the appointment longer
  - Introducing a Changing Place facility (adult changing facility) in the Hallamshire Hospital, the first such facility in the city.
- 4.5 Patient Advice and Liaison Services (PALS) established to help patients, relatives, carers and friends get help and advice from a health service were criticised by some carers as not being visible enough i.e. not actively promoting themselves to people with learning disabilities. There is PALS representation from Derbyshire County Primary Care



Trust on the Derbyshire Learning Disability Partnership Board, but not from other health services in the county. Derbyshire County Primary Care Trust have also acknowledged that it needs to do more work with people with a learning disability.

- 4.6 Complaints were another area of concern. There were a mixture of views and concerns, particularly from carers around complaints. The main issues being the fear of complaining and the perception that if someone was involved in a course of treatment that by complaining they would then either have their treatment stopped or subsequently receive poor care. There is no evidence to suggest this has ever happened but the fact there is a perception highlights that not enough has been done locally to promote complaints services. This has been backed up by comments that people do not know how to complain – something which the PALS teams should seek to rectify particularly in the light of the introduction of the new public sector complaints system within the NHS from 1 April this year.

## Recommendations

The health and social care providers within Derbyshire should:

- a) Review existing consultation toolkits and/or strategies to ensure they comply with the Disability Discrimination Act 2005, the NHS Act 2006 duty to consult (section 242) and the findings of 'Death by Indifference' and 'Healthcare for All' to ensure that provision is made for people with a learning disability when planning consultations or other information gathering activities.
- b) Establish an audit process to review the effectiveness of consultation activities through mechanisms such as mystery shopping. Where such processes exist these should be reviewed to ensure they are capable of capturing information relating to learning disability (and other equalities groups).
- c) Review complaints procedures, guidance and processes to ensure they are not preventing people with a learning disability, or their carers, from submitting complaints. The effectiveness of complaints systems should be monitored on a regular basis through clinical governance arrangements within a Trust. (*Care Quality Commission Indicator 2*).
- d) Improve the promotion of Patient Advice and Liaison Services through involvement with local learning disability and advocacy groups. (*Care Quality Commission Indicator 2*).

## Joint working

- 5.1 Derbyshire Health United is the appointed<sup>6</sup> organisation for providing an out of hours General Practitioner service across the county, including Derby City. One of the main problems they reported to the review was the lack of patient information available to them when attending cases involving people with a learning disability. At present there is no access to the person's existing medical history other than that known by the individual concerned or their carer or support worker, which may not always be accurate or complete. A lack of suitable information has the potential to damage the long-term health of an individual, particularly if a response is being made by an emergency service. East Midlands Ambulance Service shared the views of Derbyshire Health United on this issue.
- 5.2 Within Derbyshire there are good practice examples which are being used to try and fill the patient information gap and the work of specialist/dedicated learning disability health and social care services make an important contribution. One example is the 'My Health File' a blue A5 plastic folder containing health details about a person with learning disabilities. These health files are a useful source of information in relation to a person's health but are also useful in enabling people with learning disabilities to understand more about their own health needs. Unfortunately funding only allowed for 3,000 files to be produced, approximately half of which have been distributed.
- 5.3 Another example is the 'message in a bottle' service which operates throughout the county. Although this is often related to elderly or vulnerable people the bottles have been used by people with a learning disability. These plastic containers store key medical information. The bottles are then kept in accessible locations such as a fridge – they can be located by emergency services via a sticker that should be placed in a suitable location within the home e.g. back of the front door, on the fridge door or another visible location.
- 5.4 The lack of information regarding a patient with a learning disability also affects unplanned/emergency admissions to hospitals. At present there is no database within Derbyshire for storing patient information and for sharing it across health services in the county. The use of such a database could provide important information regarding the medical needs of a person with a learning disability and also their care needs.
- 5.5 Sheffield Teaching Hospitals has linked their Patient Admission System to the Sheffield Case Register. This enables the trust to put in place appropriate care plans for unplanned admissions. The register is a list

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<sup>6</sup> Joint appointment between Derbyshire County Primary Care Trust and NHS Derby City.

of people with a learning disability living within Sheffield. It contains information about the person, where they live, the services they use, and problems they have. The register is used primarily for consultation activity and is purely voluntary.

- 5.6 Within the north of the county Derbyshire Community Health Service undertake a monthly statistical audit within their specialist learning disability health services to track the number of people who have been assisted to access generic services for hospital appointments. It was not made clear how effectively this information is used nor whether there is an equivalent system operating within the south of the county.
- 5.7 The review found that across Derbyshire there are different systems being used to capture information about people with a learning disability and track the services they use. The differences in the organisation of the specialist dedicated learning disability health and social care services and the varying degree of integration of these services is an important factor. There was evidence of difficulties with joint working with adult mental health services and access to adult mental health services when specialist Learning Disability Services are involved with someone. What is not clear is how information is being used to tackle issues and whether it highlights services that are under-represented for people with a learning disability.
- 5.8 There are clear data protection issues around the sharing of information between organisations but as the Sheffield Case register example has shown it is possible. Following the review meeting in April, Derbyshire Health United and Derbyshire County Council have been working together to link the individual health action plans of people with a learning disability into the RightCare<sup>®</sup> plans used by the out of hours service. These are plans of care used by the out of hours service established in the absence of access to suitable patient information. Therefore, if a patient has a RightCare<sup>®</sup> plan the service will be better prepared.
- 5.9 As part of delivering the 'Next Stage Review' Derbyshire County PCT working with Derby City PCT published "A Vision for Better Health and Healthcare in Derbyshire". This set out clear objectives for the development of all healthcare provision including six priorities for services for people with a learning disability. NHS East Midlands Strategic Health Authority also established various service related groups with membership from health organisations across the region. A learning disability group has been set up for the region and should have a clinical reference group within each county. This is not the case though for Derbyshire and Derby City. By not having this clinical reference group it will be difficult for any of the regional work to be carried out – work that includes amongst other things the development

of a Joint Commissioning Strategy for learning disability and the creation of acute liaison nurses.

## Recommendations

The health, and where appropriate, social care services within Derbyshire should:

- e) Create a shared database for people with learning disabilities which includes the health needs, care needs, and medical needs of each person. The aim of the database being that anyone entering into a health service setting that can be identified via the system and a suitable care plan, or 'pathway', put in place. (*Care Quality Commission Indicator 1*)
- f) Ensure RightCare<sup>®</sup> plans link in to 'My Health Files' or other health action plans as part of the annual health check that each person with a learning disability is required to have. (*Care Quality Commission Indicator 1*)
- g) Commissioners should ensure that action is taken to address the six priorities for people with a learning disability identified in "A Vision for Better Health and Healthcare in Derbyshire" and a clinical reference group for Derbyshire and Derby City is established to further support the work arising from the 'Next Stage Review' in the East Midlands. The absence of an integrated specialist health and social care service for people living in the Glossopdale area of Derbyshire and the differentials of organisation of specialist services across the County should also be addressed. (*Care Quality Commission Indicator 1*).

## Respect and Dignity

- 6.1 The treatment of people with learning disabilities when receiving care in acute (hospital) settings was a major issue raised by carers at events attended by the review working group and through the questionnaires.
- 6.2 The review group heard instances where family members have had to sleep in chairs on wards or stay in hospital accommodation as there was no suitable support available to provide care for someone with a learning disability, in particularly those with profound or multiple learning disabilities.
- 6.3 Instances where carers have left written instructions to aid in the care of their family member which were ignored by members of staff were brought to the attention of the review group. In one instance this led to a carer having to travel to a hospital at night to deal with her son who was hiding under a bed because the nursing staff had ignored the instructions for his care. Such instances have left some carers with the feeling that they cannot leave their relative in the care of a health service without their supervision.
- 6.4 The suggestion of liaison nurses or someone on a ward who was dedicated to the care of the person in a hospital setting was put forward by carers. In Sheffield, the Hospital Trust has a learning disability champion within each directorate and a link nurse network, which is also tied in to the Patient Advice and Liaison Service – the aim of these being to ensure a co-ordinated and suitable care plan is put in place.
- 6.5 The manner in which people with a learning disability are spoken to by health professionals was an issue raised by some people during the course of the review. The main issues, which will be picked up in the communication and training sections, related to the lack of one-to-one conversations and a lack of knowledge or understanding of learning disability from health professionals and administrative/support staff.
- 6.6 Some recommendations for this section tie in to those of the training and communication sections. The introduction of liaison nurses and Learning Disability champions is a necessary step to ensure both patients and carers get the information and care they need and staff get the support they require to deliver those services. The Derbyshire based hospitals, along with Stockport NHS Foundation Trust are strongly advised to speak to Sheffield Teaching Hospitals NHS Foundation Trust about the work they have undertaken in this area.

## Recommendation

- h)** Acute health services in Derbyshire should introduce liaison nurses and Learning Disability champions within their services. These roles will include the promotion of health and wellbeing needs of people with a learning disability, and their carers to colleagues. They will also lead on the implementation of care plans to secure the provision of care for people with a learning disability when admitted to hospital and provide suitable discharge plans. The work of this recommendation will be dependent upon the implementation of recommendation **g**. (*Care Quality Commission Indicators 1 and 3*)

## Corporate Responsibility

- 7.1 The final 'Healthcare for All' recommendation placed a duty on all NHS Trust Boards to demonstrate they are making 'reasonable adjustments' to services for people with a learning disability in annual reports. The Annual Reports for 2008-09 for all Derbyshire health based organisations are yet to be published so the review is unable to determine whether this recommendation has been carried out.
- 7.2 The review found, as outlined in the engagement and involvement section, that there was a reluctance of people to use complaints systems. Trust Boards need to assure themselves, through their clinical governance functions that they are being made aware of all issues arising to the potential discrimination or poor treatment of people with a learning disability. Certainly it will be hard for a Trust Board to make changes if they do not know where problems exist.
- 7.3 The evidence outlined in the respect and dignity section points to a lack of reasonable adjustments being made as a matter of course by health services. There have been examples, such as the Specialist Hearing Clinic, where a review of the service has been made resulting in changes which have had real benefits for the people using it. However, changes such as this appear to come from the willingness of individuals within a service and not from a top-down systematic strategic approach to reviewing and improving services – at least the evidence provided by health services did not make it clear whether or not service reviews were being undertaken. The recommendations made in the Joint Working section should help health services in making the 'reasonable adjustments' required to improve services and fulfil their legal obligations.
- 7.4 The review heard from Sheffield Teaching Hospitals about an inpatient survey and a carer survey undertaken in 2001 and 2004 and an inpatient, outpatient and carer survey undertaken in 2008. Their 2008 review demonstrated improvements in the service but also proved useful in identifying areas for further work. The learning disability audit has since been integrated into an annual audit of good practice called the Clinical Assessment Tool (CAT). Also, the 10 Key Standards of recommended practice have been integrated into a vulnerable adults framework of assessment, which has been risk assessed.
- 7.5 There was no evidence submitted by health organisations in Derbyshire to suggest similar levels of work were being undertaken. With the implementation of a new performance assessment for health services from 2009/10 by the Care Quality Commission, Trusts need to assure themselves they are providing equitable services to people with a

learning disability. From the evidence submitted it is not possible to say whether this is the case in Derbyshire.

- 7.6 The engagement and involvement section outlined that notwithstanding the work of the Partnership Board (and local Partnership Boards) not enough work is being done by health services to consult and involve people with a learning disability in reviewing services despite their section 242 duty. This was demonstrated further through the Healthcare Commission's self assessments against the core standards for 2008/09. Whereby the Derbyshire Learning Disability Partnership Board had to actively pursue health services to submit the views of people with a learning disability – views which should have been sought by the Trust themselves. The survey used by the partnership board in this process provided a useful exercise and should be considered for future use.

## **Recommendations**

- i) Health Service Trust boards will actively seek the views of people with a learning disability and carers in support of their performance assessment against the new Care Quality Commission performance assessment. (*Care Quality Commission Indicators 3, 5, and 6*)
- j) Derbyshire Learning Disability Partnership Board to conduct an annual healthcare survey to gauge the views of people with a learning disability and carers to provide feedback to healthcare organisations when undertaking the Care Quality Commission performance assessment.



## Training

- 8.1 Evidence submitted to the review pointed largely towards a lack of learning disability specific training for nursing and other medical, clinical and care staff in hospital settings. This extends to dealing with 'difficult or challenging' behaviour which is often seen as dangerous to a health worker, when in many cases it is the only means a person with a learning disability can communicate they are in discomfort, pain, or just do not understand the situation they are in.
- 8.2 There is also an over-reliance on family carers to provide the support in a hospital that should be provided by the staff. This is often due to a carer fulfilling their sense of duty and/or having a lack of trust in the service being provided by the hospital – often as a result of prior negative experiences.
- 8.3 The review group heard from a number of individuals where instructions for the care of their relative had been ignored by nursing staff as outlined in the respect and dignity section. Not all nursing staff were viewed as being unhelpful though, but the underlying problem of a lack of specific training and awareness raising around learning disabilities means that patients will continue to suffer.
- 8.4 Courses provided by Universities and the teaching hospitals in the region aim to provide learning disability training taking into account the findings of the recent reports and inquiries. Nottingham University have built specific training on learning disabilities into their training programmes and try and ensure that all students receive practical training but a shortage of suitable placements means this is not always possible.
- 8.5 Sheffield Teaching Hospitals provided information to the review about an e-learning programme that has been developed in conjunction with people with learning disabilities. The programme is split into modules so that staff can complete the programme in stages rather than in one full session. However, the training is not compulsory, but all staff are encouraged to undertake and complete the programme. The programme also includes sensory impairment of vision and hearing, mobility wheelchair disability and mental health illness, as some of the Trust's patients with a learning disability have multiple and complex needs. The programme also includes the needs of carers. As part of the programme, users of the service who helped to develop it also help to deliver it as part of acting out in video format recommended good practice. There was no evidence submitted by organisations in Derbyshire to state whether such a training package exists and whether senior members of staff had undertaken training on learning disabilities.

- 8.6 Whilst 'Healthcare for All' was clear in making sure that undergraduate and postgraduate clinical training encompassed learning disability training it missed out all those people who currently work in the health service and provide other services, not just clinical ones, e.g. administrative staff. Every member of staff has an individual responsibility to ensure that people receive access to a health service.
- 8.7 General Practitioners (GPs) have been able to access a Locally Enhanced Service which provides them with a one-off payment and access to training to enable them to undertake the annual health checks each person with a learning disability must have. Take up of the service in Derbyshire has seen 85% of practices sign up to the voluntary service and receive training from people with a learning disability and health facilitators. Those practices which, at the time of concluding this review, had not taken part in this important service development are:
- Appletree Medical Practice, Duffield
  - Ashover Medical Centre
  - Blue Dykes Surgery, Clay Cross
  - Evelyn Medical Centre, Hope
  - Gomersall Lane, Dronfield
  - Gosforth Valley Medical Centre, Dronfield
  - Goyt Valley Medical Practice, Whaley Bridge
  - Leabrooks Medical Centre, Alfreton
  - Littlewick Medical Centre, Ilkeston
  - Manor Fields, Swadlincote
  - Old Station Surgery, Ilkeston
  - Ripley Medical Centre
  - Riverdale Surgery, Belper
  - Wellbrook Medical Centre, Hilton

## Recommendations

All health and social care services in Derbyshire and also those involved in the review from outside the county should:

- k)** Review training and development plans of all staff in all service areas to ensure they include practical and/or awareness raising training. That this training will include the findings of 'Death by Indifference', 'Healthcare for All', and the Local Government Ombudsman's report 'Six Lives' and outlines each person's responsibilities in making reasonable adjustments and their responsibilities under the Mental Capacity Act 2005. (*Care Quality Commission Indicator 4*).

- l)** Ensure training and development plans are reviewed on a regular basis and identify outstanding areas of training. (Ensuring staff have consistent and equitable opportunities to update and develop their skills was a recommendation in Lord Darzi's 'Next Stage Review'). (*Care Quality Commission Indicator 4*)
  
- m)** Derbyshire County Primary Care Trust ensure that the principles of the Department of Health Direct Enhanced Service are followed in Derbyshire by ensuring that all adults with a learning disability are offered an annual health check with clear pathways into secondary (acute and mental health) services. (Care Quality Commission Indicators 2 and 4)
  
- n)** Ensure that in areas where GP practices have not signed up to the Local Enhanced Service there is access for people with a learning disability to receive their annual health check, as outlined in Valuing People Now.
  
- o)** Training and development should, where appropriate, be delivered through local providers such as the Derbyshire Learning Disability Partnership Board, Reps on Board, Good Health Group, Derbyshire Advocacy Service etc. Where this is not possible there should be a suitable level of involvement of people with learning disabilities and carers in the planning and provision of training. (Care Quality Commission Indicator 4)

## Communication

- 9.1 The quality of written information provided to people with learning disabilities is often no different to the information provided to someone without a learning disability. This information can be confusing for many people, regardless of their ability to read and comprehend written material. Providing accessible information is a key part of meeting the Disability Discrimination Act 2005 in that it can be seen to be making a 'reasonable adjustment'.
- 9.2 At the review meeting in April, one hospital trust stated that they were not able to make changes to any printed material. Such corporate views are not conducive to the duty to make reasonable adjustments. By altering the information provided, particularly around appointment letters, health services will be helping more people than just those with a learning disability. Vulnerable adults, the elderly and people with learning difficulties such as dyslexia will also benefit.
- 9.3 A good example of a reasonable adjustment to patient information was provided by Denny Fransman at the review meeting as outlined in the initial findings section. The use of images and symbols and clear and concise text was both simple and effective on the literature provided to patients both before and after appointments. An example of an appointment letter and follow-up letter from the special hearing clinic can be found at Appendix 4.
- 9.4 Sheffield Teaching Hospitals NHS Foundation Trust include traffic light hospital assessment forms as part of the nursing care assessment on admission. These highlight what staff need to know about patients in terms of risk, dependency and support. This is cross referenced with their nursing care guidelines and health action plans. The traffic light assessment forms were taken from the 'Working Together' guidance document published by the Home Farm Trust. However, despite the promotion of this service a carer from Derbyshire found that the forms were not accepted by a member of staff at Sheffield Hallamshire. Copies of the traffic light assessment forms are provided at Appendix 5.
- 9.5 The manner in which patients are spoken to has been highlighted as an area of concern. Feedback from the questionnaires showed a mixture of positive and negative views about staff in health services. The fact that words like 'rude', 'unhelpful', and 'ignorant' were used by people with learning disabilities shows just how frustrating it must be for them to access a service in an equitable fashion. The way in which these people are spoken to needs to be addressed and is in part down to training, as well as common-sense, and good manners.

- 9.6 The accessibility of buildings was also highlighted as an area for improvement. Hospitals are often large and confusing buildings that are not easy to navigate around and signage in hospitals is not always easy to use. The use of automated admission systems in GP surgeries and electronic signs was also highlighted as something that causes confusion to people with a learning disability (and to elderly and vulnerable people). Using symbols on signs as well as on printed information would make them easy to follow for people. For example a black eye symbol on yellow background for services relating to the treatment and care of eyes.

## Recommendations

All healthcare providers need to:

- p)** Review what information is made available to the public and assess how accessible it is. Advice is available through the health Communication Toolkit<sup>7</sup> and the Easy Health<sup>8</sup> website. The standards set out in the toolkit should be adopted across all health services within the county. A copy of the communication toolkit is provided at Appendix 6.
- q)** Existing patient involvement groups within health services should be reviewed to see if membership includes people with a learning disability or family carers. If they do not then the organisation should actively seek to recruit to these positions or link into local support/development groups for people with a learning disability.
- r)** Health services should review the signage and notices in public buildings to ensure they comply with the Disability Discrimination Act 2005. It is recommended that suitable symbols are used instead of or in conjunction with names of departments or wards for the most frequented services by people with learning disabilities.
- s)** Undertake an audit of publicly available information to see what the most popular publications are for people with a learning disability. Copies of these should then be made available in formats accessible to people with a learning disability.
- t)** Hospital pre-appointment letters should include as a matter of course a traffic light assessment form outlining the needs of a patient and these forms used in the development of care pathways. Training should also be provided to staff on the importance of these forms and how they should be used. These forms should compliment the work to be undertaken in recommendation **d**.

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<sup>7</sup> Developed by Derbyshire speech and language therapists.

<sup>8</sup> [www.easyhealth.org.uk](http://www.easyhealth.org.uk)

## Summary

- 10.1 At the 30 April meeting one family carer commented that they had not seen any real improvements in the health services around Derbyshire in the past 20 years. In undertaking this review and putting forward the recommendations of the review group people with a learning disability and their carers will see real changes and outcomes from the health services they have received.
- 10.2 These changes will take time to implement as attitudes and working cultures will need to change. However, there are plenty of improvements that can be undertaken now that will begin to bring about these changes and make a real difference.
- 10.3 There is plenty of good work being undertaken in Derbyshire, and in neighbouring areas, to secure good health outcomes for people with learning disabilities. Unfortunately it is not yet part of a joined-up strategic approach by the NHS to securing improvement but is on the back of hard work and campaigning by advocates, carers, support groups and some health professionals. The work already done by the Derbyshire Learning Disability Partnership Board through the “Be in Control” charter campaign and the work of the Good Health Group and now developing Local Partnership Boards, provides an important foundation for the further work that is needed to achieve improvement.
- 10.4 The recommendations contained within this report, along with the other national work to be undertaken in improving health services at a local level means there is no excuse for services not to make improvements. The introduction of the Care Quality Commission’s performance assessment indicators for learning disability services also provides a national benchmark for health services and service users to measure the quality of the services being provided.
- 10.5 The monitoring of the recommendations within this review will be undertaken by the Derbyshire Learning Disability Partnership Board. The Adult Health and Care Improvement and Scrutiny Committee will receive periodic reports on progress against these recommendations. Where the partnership board identifies that recommendations are not being implemented the Adult Health and Care Improvement and Scrutiny Committee will consider whether to undertake a further review.
- 10.6 NHS East Midlands will be requiring local health services to provide a self assessment on their progress against a local health framework for people with learning disabilities as part of the Valuing People Now initiative. The recommendations contained within this report should be linked into that process by health services to demonstrate their commitment to improving services for people with a learning disability.

10.7 The Derbyshire Learning Disability Partnership Board should also liaise with the Derbyshire Local Involvement Network (LINK) over any issues the LINK may uncover in relation to the scope of this review. If these issues cannot be resolved by local health services then the Adult Health and Care Improvement and Scrutiny Committee may have to undertake further review work.

## Acknowledgments

The Adult Health and Care Improvement and Scrutiny Committee would like to thank everyone who contributed to the work of the review. The committee would also like to acknowledge the following people for their help and support in the review:

Andrew Milroy	Assistant Director Disability & Learning Disability	Derbyshire County Council
Pauline Dawson	Partnership Board Co-ordinator	Derbyshire County Council
Carol Marsh	Elected Representative	Derbyshire Learning Disability Partnership Board
Wayne Collins	Elected Representative	Derbyshire Learning Disability Partnership Board
Sandra Mills Melanie Rose	Support Worker Elected Representative	Derbyshire County Council Derbyshire Learning Disability Partnership Board
Bernie Aston Kay Milton	Support Worker Elected Representative	Derbyshire County Council Derbyshire Learning Disability Partnership Board
Helen Worsley Denny Fransman	Family Carer Specialist Speech and Language Therapist/Audiologist	Derbyshire Mental Health Service NHS Trust
Jackie Fleeman	Health Facilitator	Derbyshire Mental Health Service NHS Trust
Louise Rowe	Team Administrator	Derbyshire Mental Health Service NHS Trust
Rose Bolland	Nurse Director	Sheffield Teaching Hospitals NHS Foundation Trust

The committee would also like to thank the former members of the Healthier Communities Improvement and Scrutiny Committee:

- Alan Jones, former Chairman
- Councillor George Wharmby
- Councillor Sharon Blank

Finally the committee extends its gratitude to all the members of the Good Health Group for their hard work and support in this review.



## Appendix 1: 'Healthcare for All' Recommendations

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.
2. All healthcare organisations, including 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.
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 them to do this effectively. This will include the provision of information, but may also involve practical support and service co-ordination.
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 disability organisations and use the information to inform the development of Local Area Agreements.
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 in with learning disabilities to provide evidence for clinical and professional staff of the extent of the problem and guidance on prevention.
6. The Department of Health should immediately amend Core Standards for Better Health to include an explicit reference to the requirements 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.
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 Patients Safety Agency and Office for Disability Issues.

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.
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.
10. 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 difficulties.

## **Appendix 2: Care Quality Commission Indicators 2009/10**

### **Performance assessment 2009/10**

#### **Access to healthcare for people with a learning disability**

##### **Rationale**

Equality in access to healthcare is central to the delivery of healthcare. The Independent Inquiry into Access to Healthcare for People with learning Disabilities, led by Sir Jonathan Michael, published its findings 'Healthcare for All' on 29th July 2008.

The inquiry was ordered following Mencap's 'Death by indifference' report, which told the stories of six people with a learning disability who died while in NHS care. The Inquiry sought to identify the action needed to ensure adults and children with learning disabilities receive appropriate treatment in acute and primary healthcare in England.

Central to the development of these performance indicators is adherence to the Human Rights Act 1998 and the Disability Discrimination Act 1995, to ensure equality of access and equity for all people with learning disabilities and that a human rights approach is adopted by the NHS and that 'reasonable adjustments' are made in the delivery of services to reduce health inequalities.

This indicator will seek to respond to the recommendations made in the Inquiry report for providers, specifically around the collection of data and information necessary to allow people with a learning disability to be identified and the arrangements trusts have in place to ensure the views and interests of people with learning disabilities and their carers are included in the planning and development of services.

##### **Indicator**

##### **NOTE**

This indicator will not be included in the scored assessment for 2009/10. However, trusts will be expected to collect the requisite information and report on it separately and we will publish this along side the results of the review to ensure visibility.

Trusts will be assessed on their responses to the following six questions, based on the recommendations set out in 'Healthcare for All' (2008) – the Independent Inquiry into Access to Healthcare for People with learning Disabilities. For each question, a response of 1 to 4 is required depending upon the extent to which plans and protocols are in place and are fully implemented for all aspects of each question.

The scoring guide for all questions (except question 2) is as follows:

(1) = Protocols/mechanisms are not in place.

(2) = Protocols/mechanisms are in place but have not yet been implemented.

(3) = Protocols/mechanisms are in place but are only partially implemented.

(4) = Protocols/mechanisms are in place and are fully implemented.

1. Does the trust have a mechanism in place to identify and flag patients with learning disabilities\* and protocols that ensure that pathways of care are reasonably adjusted to meet the health needs of these patients? (1-4)

2. In accordance with the Disability Equality Duty of the Disability Discrimination Act (2005), does the trust provide readily available and comprehensible information\*\* (jointly designed and agreed with people with learning disabilities, representative local bodies and/or local advocacy organisations) to patients with learning disabilities about the following criteria:

- treatment options (including health promotion)
- complaints procedures, and
- appointments

Scoring:

1. Accessible information not provided

2. Accessible information provided for one of the criteria

3. Accessible information provided for two of the criteria

4. Accessible information provided for all three of the criteria.

3. Does the trust have protocols in place to provide suitable support for family carers who support patients with learning disabilities, including the provision of information regarding learning disabilities, relevant legislation\*\*\* and carers' rights? (1-4)

4. Does the trust have protocols in place to routinely include training on learning disability awareness, relevant legislation\*\*\*, human rights, communication techniques for working with people with learning disabilities and person centred approaches in their staff development and/or induction programmes for all staff? (1-4)

5. Does the trust have protocols in place to encourage representation of people with learning disabilities and their family carers within Trust Boards, local groups and other relevant forums, which seek to incorporate their views and interests in the planning and development of health services? (1-4)

6. Does the trust have protocols in place to regularly audit its practices for patients with learning disabilities and to demonstrate the findings in routine public reports? (1-4)

\* Learning disabilities (Valuing People, 2001) include the presence of:

1. A significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with;

2. A reduced ability to cope independently (impaired social functioning);

3. which started before adulthood, with a lasting effect on development.

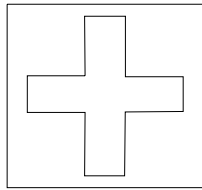
\*\*As described in the Mental Capacity Act (2007), organisations should take 'all practicable steps' to present information in a way that is appropriate to the person's circumstances.

\*\*\*To include the Mental Capacity Act (2007), the Disability Discrimination Act (1995) and the Carers Act (1995)

### **Data source and period**

Care Quality Commission special data collection (as at 31st March 2010)

## Appendix 3: Questionnaire



### Your ideas about Health Services.

Thank you for filling in this form. It will help us to understand what it is like to use the NHS. We will use what you tell us to make things better. We want to know about all the parts of the NHS, such as chiropody, dentists, hospitals and doctors.

Please fill in a new form for each place that you want to tell us about. We would like to hear your good and bad stories.

If you would prefer to talk to someone instead of filling in the form you can. Please phone Graham Spencer on



01629 585263.

Some people might be asked to tell us more. If you would be willing to talk to us please fill in your details. You can send us your form without telling us who you are.



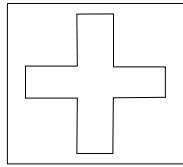
Name



Address

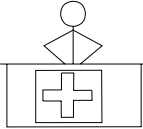
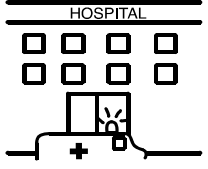
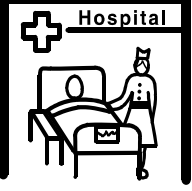
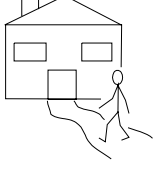


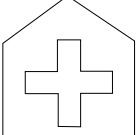
Phone number.




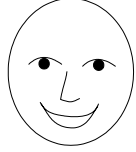
## Your ideas about Health Services.

Please choose the service you used.

 <p>I had an appointment.</p>	 <p>I went to accident and emergency.</p>	 <p>I stayed in hospital.</p>	 <p>A health worker visited me.</p>
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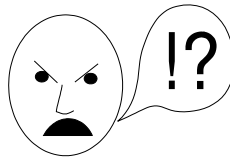
 <p>Which department or service did you use?</p>	<p>e.g. dentist, eye clinic, diabetes nurse.</p>
--	--

 <p>Where was it? What town?</p>	<p>e.g. Royal, Hospital, DRI, clinic.</p>
---	---

 <p>What did you like about the service?</p>
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What didn't you like about the service?



Did you complain about the service?

Yes

No

Please tell us about it.



What could make the service better?



# Appendix 4: Accessible Information



Derbyshire  
Mental Health Services and  
Southern Derbyshire Acute Hospitals  
NHS Trusts

Special Hearing Clinic  
(Learning Disabilities),  
Department of Audiology,  
Derbyshire Royal Infirmary,  
Derby DE1 2QY.  
PHONE: (01332) 254711

Dear, \_\_\_\_\_

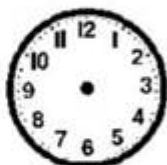
We would like to see you at the Special Hearing Clinic.

date

1	2	3	4	5	6	7
8	9	10	11	12	13	14
15	16	17	18	19	20	21
22	23	24	25	26	27	28
29	30	31				

on \_\_\_\_\_

time



at \_\_\_\_\_

place



place \_\_\_\_\_



If the time is not good please phone  
Carl Davies on



01332 254711

Carl Davies :  
Denny Fransman:

Chief Audiologist.  
Hearing Services for People with Learning Disabilities:  
Amber Valley CTLD.

Joe Bloggs  
Hearing clinic – 1 April 2009



ears

- ✓ Good
- ✓ No wax
- ✓ No infections



hearing aid

- ✓ Gave you a hearing aid
- ✓ Showed you how to use it
- ✓ Try to use it every day. It will help you to get used to it
- ✓ You said you like it



next time



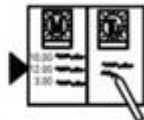
- ✓ look in ears



- ✓ check aid



- ✓ hearing test – November 2007



date for next visit

Tuesday  
27 May 2009  
1.30 pm  
Alfreton Primary Care Centre

**Notes for support staff:**

Please help Joe to use his hearing aid. We have provided you with written guidelines to help you. He needs support to put it in each morning. The more he uses the aid the quicker he will get used to it. It is however, important that Joe determines when and where he uses it.



Denny Fransman  
Speech Therapist



Carl Davies  
Audiologist

@@ DoB: Appointment Date: Report Date:  
Copies: AVCTLD.

## Appendix 5: Traffic Light Assessment Forms

The following are examples taken from *'Working Together: Easy steps to improving how people with a learning disability are supported when in hospital'*, Home Farm Trust.

RED-ALERT

Things you must know about me

Name -	NHS number -	
Likes to be known as -		
Address -	Tel no-	
Date of Birth -		
GP -	Address:	
Next of Kin -	relationship -	Tel no -
Key worker/main carer -	relationship -	Tel no -
Professionals involved -		Tel no -
Religion -	Religious requests -	

Current medication -

Current medical conditions - e.g. epilepsy, allergies, heart problems, breathing problems, eating & drinking issues.

Brief medical history -

Medical Interventions - how to take my blood, give injections, take temperature, medication, BP etc.

Behaviours that may be challenging or cause risk -

Level of comprehension/ capacity to consent -

Completed by: ..... Date:.....

**AMBER**

## Things that are really important to me

<u>Communication</u> - How to communicate with me.
<u>Information sharing</u> - How to help me understand things.
<u>Seeing/hearing</u> - Problems with sight or hearing
<u>Eating (swallowing)</u> - Food cut up, choking, help with feeding.
<u>Drinking (swallowing)</u> - Small amounts, choking
<u>Going to toilet</u> - Continence aids, help to get to toilet.
<u>Moving around</u> - Posture in bed, walking aids.
<u>Taking medication</u> - Crushed tablets, injections, syrup
<u>Pain</u> - How you know I am in pain
<u>Sleeping</u> - Sleep pattern, sleep routine
<u>Keeping safe</u> - Bed rails, controlling behaviour, absconding
<u>Personal care</u> - Dressing, washing etc.
<u>Level of support</u> - Who needs to stay and how often.

Completed by: ..... Date:.....

GREEN

Things I would like to happen

Likes/dislikes

THINGS I LIKE		THINGS I DON'T LIKE	
Please do this:		Don't do this:	
Think about - what upsets you, what makes you happy, things you like to do i.e. watching TV, reading, music. How you want people to talk to you (don't shout). Food likes, dislikes, physical touch/restraint, special needs, routines, things that keep you safe.			

Completed by: ..... Date:.....

Review of Traffic Light Hospital Assessment form : March 2010  
Produced by the Learning Disability Health Facilitation Team

## Appendix 6: Communication Toolkit



### Communication Toolkit. (what you say)

This is a toolkit to help you make communication easier for people with a learning disability.

**You will still need to support people. Accessible information is not meant to stand alone.**

You can use it as a checklist. Please feel free to photocopy it on blue paper as you need to.

This page is about the **content** or **what** you are trying to say.

Vocabulary (the words you use).

- Use **familiar** words e.g. "drink" rather than "refreshment".
- Use words with **one meaning** e.g. "happy or sad" rather than "moody".
- Use **concrete**, not abstract words e.g. "after lunch" not "later".
- **Avoid jargon** words, explain or substitute them e.g. use "car" not "transport or vehicle".
- **Avoid abbreviations** such as "Rd" for "road" and "no." for "number".
- **Use names** not pronouns e.g. "the Doctor", not "she".
- **Check** people can understand the words you use.

Sentences.

- Use **short sentences** with one main idea.
- Use **active** not passive sentences e.g. "Paul drove the bus" not "the bus was driven by Paul".
- Keep sentences **uncluttered**, miss out words you don't need e.g. " we need to write a shopping list" rather than "I think we could do with writing a list before we go out shopping".
- **Avoid unnecessary punctuation marks** such as !!! for emphasis.
- Use **positive sentences** whenever you can e.g. " Simon should eat breakfast" rather than "Simon should not miss breakfast".
- Use **straightforward, unambiguous** sentences, e.g. avoid things like "thinking outside the box" and "taking your ball home".

# Communication Toolkit.

## (how you communicate)

This page is about **how** you say or write your message.

You can use it as a checklist. Please feel free to photocopy it as you need to.

Speaking.

- **Avoid distractions** like noise, clutter, interruptions and being uncomfortable.
- Make sure people can **hear and see** any screens, flipcharts and speakers.
- Ensure **seats** are in the right place and the sun doesn't dazzle people.
- Make sure people are **listening** before you start. Check people keep listening and **understand** after each main item.
- Give people **breaks**, at least every 45 minutes.
- Lots of people (at least 40%) have a hearing loss. Speak **clearly and loudly** enough for people to hear. Use the **loop system** if it is available. Carpeted rooms and soft furnishings help.
- Make sure your tone of voice and **facial expression** matches what you say.
- Use **signing, symbols or pictures** to help people understand (see standardised list).

Writing.

- **Big clear typeface** helps. Use Arial font size 18 to 24 if possible, 14 minimum.
- **Avoid underlining, italics and block capitals.**
- Some groups use **coloured paper** to identify them, e.g. Quality Forums are purple.
- The layout of documents should be **clear and uncluttered**. Use lists, bullet points, boxes, keywords, headings and symbols to help people. Colour coding of topics can also be used.
- Keep documents as **short** as possible.
- **Symbols or pictures** should be used for extra information wherever possible. Usually we put the symbol on the left or directly above the message or idea.
- Do not use symbols or pictures to just decorate a document. They must have a **specific meaning** and help the reader.
- Use symbols or pictures from the **standard list**.
- **Avoid coloured** symbols or pictures if possible, as they don't photocopy as clearly. Also too much colour can be confusing.
- Make sure symbols and pictures are **big enough** for people to see.
- Visually impaired people need non-glossy paper (e.g. not laminated) and high contrast ink to paper, such as black ink on white or yellow paper.

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