DH Department of Health

Equal access?

A practical guide for the NHS: Creating a Single Equality Scheme that includes improving access for people with learning disabilities

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Equal access?

A practical guide for the NHS: Creating a Single Equality Scheme that includes improving access for people with learning disabilities

November 2009

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Introduction

"Talk in a way I can understand!"

What is a learning disability?

Valuing People[1] defines learning disability as:

- significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence) with

- reduced ability to cope independently (impaired social functioning)

- that started before adulthood, with a lasting effect on development.

Other terms used include 'intellectual impairment', 'developmental disabilities' and 'mental impairment'. Some people prefer 'learning difficulties', but this usually means difficulties such as dyslexia or dyspraxia.

Learning disability is sometimes confused with autism[2] or mental health problems.[3] These conditions can overlap.

Across the whole range of learning disabilities (mild to profound) there are about 800,000 adults and 200,000 children in England.[4]

A person with learning disabilities may need extra consideration and support from the NHS, as a patient, visitor or employee. Adapting information, communication and other aspects of care for them will help ensure your services are also friendly to anyone who has difficulties with written or spoken English.

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1. Department of Health (2001) *Valuing People: A New Strategy for Learning Disability for the 21st Century* www.archive.official-documents.co.uk/document/cm50/5086/5086.pdf
2. Autism is a lifelong developmental disability that affects the way a person communicates and relates to people around them. People with autism have difficulties with everyday social interaction www.nas.org.uk
3. Common mental health problems include depression and anxiety; less common are psychoses such as schizophrenia www.mentalhealth.org.uk
4. Emerson E and Hatton C (2008) *Estimating Future Need for Adult Social Care Services for People with Learning Disabilities in England* http://eprints.lancs.ac.uk/21049/

"What matters is that people with learning disabilities are included as equal citizens, with equal rights of access to equally effective treatment." Sir Jonathan Michael, *Healthcare for All*.

Legal context

The Disability Discrimination Act 1995 required public bodies to make 'reasonable adjustments' to their premises, policies and services. All staff need to check and adjust their daily practice to make sure that disabled people are treated fairly.

The Human Rights Act 1998, with its emphasis on humanity, dignity, equality, respect and autonomy, applies equally to disabled people.[5]

The Disability Discrimination Act 2005 required public bodies to produce a Disability Equality Scheme. Best practice guidance for the NHS was issued in October 2006.[6] Your organisation may be producing a Single Equality Scheme, anticipating the forthcoming Equality Bill.

The Equality Bill will strengthen equality law, including strengthening protection from discrimination for disabled people, by drawing together current equality legislation such as the Disability Discrimination Act into a single Act that introduces a single equality duty for public bodies. It will also introduce a new public sector duty to consider reducing socio-economic inequalities, which disproportionately affect disabled people.

Policy context

Lord Darzi's review[7] challenged the NHS to place quality of treatment and care at the heart of services: the responsibility for making this happen lies with all staff. The *NHS Constitution*[8] contains principles and values for the NHS, together with rights, pledges and responsibilities for patients and staff. These cover, for example, access to services, quality of care, informed choice and involvement.

Valuing People and *Valuing People Now*[9] set out the Government's policy for people with learning disabilities. In relation to health the overall objective is that: "All people with learning disabilities get the healthcare and the support they need to live healthy lives."

Evidence of the need for action

The Disability Rights Commission Formal Investigation[10] in 2006 confirmed that people with learning disabilities have more health problems than the general population, yet often experience poor access to health services.

Mencap's report[11] the following year described events leading up to the deaths of six people with learning disabilities while they were receiving NHS services. This report led to an independent inquiry and an ombudsman investigation.[12] Recommendations from the inquiry report[13] have been used to structure this guide.

5. Joint Committee on Human Rights (2008) *A Life Like Any Other? Human Rights of Adults with Learning Disabilities* www.publications.parliament.uk/pa/jt200708/jtselect/jtrights/40/40i.pdf
6. Department of Health/NHS Employers (2006) *Creating a Disability Equality Scheme: A Practical Guide for the NHS* www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4139666
7. Department of Health (2008) *High Quality Care for All: NHS Next Stage Review Final Report* www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_085825
8. Department of Health (2009) *The NHS Constitution* www.dh.gov.uk/en/Healthcare/NHSConstitution/index.htm
9. HM Government (2009) *Valuing People Now: a new three-year strategy for people with learning disabilities. Making it happen for everyone* www.dh.gov.uk/en/SocialCare/Deliveringadultsocialcare/Learningdisabilities/index.htm
10. Disability Rights Commission (2006) *Equal Treatment: Closing the Gap* http://83.137.212.42/sitearchive/DRC/library/health_investigation.html#Finalreportsandsummaries
    See also National Patient Safety Agency (2004) *Understanding the patient safety issues for people with learning disabilities* www.library.nhs.uk/learningdisabilities/viewresource.aspx?resid=263506
11. Mencap (2007) *Death by indifference* www.mencap.org.uk/document.asp?id=284
12. Parliamentary and Health Service Ombudsman (2009) *Six lives: the provision of public services to people with learning disabilities* www.ombudsman.org.uk/improving_services/special_reports/hsc/six_lives/index.html
13. Michael J (2008) *Healthcare for All* www.valuingpeople.gov.uk/dynamic/valuingpeople118.jsp (scroll down)

Information for people with learning disabilities and family carers

Information for people with learning disabilities

Why is this important?

One of the barriers to good healthcare for people with learning disabilities is a lack of information that is easy to understand – information about:

• what services are available and how to use them

• health promotion and prevention of ill health

• health problems and treatments

• rights.

Provision of appropriate information helps to promote health and independence.

Best practice

Information is available in a variety of formats, including easy read.[14] This might include information about:

• services

• health promotion and screening programmes

• patients' rights (e.g. how to complain).

Easy-read information is designed with the involvement of people with learning disabilities.

Information for individual patients and communications with them are tailored to their needs (including audio).

"Give me information in easy read."

14. 'Easy read' means very easy English, usually accompanied by pictures that help to explain the idea.
    See section 8 for useful easy-read resources

"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 [otherwise]." [15]

Practical examples	Links to wider NHS policies
The United Lincolnshire Hospitals NHS Trust worked with the learning disability service to develop easy-read leaflets and videos about what to expect if someone goes to A&E with a common injury (such as broken bones, eye injury, head injury) or needs common investigations (such as a blood test, ECG, X-ray).	*NHS Constitution*
	Standards for Better Health, Fourth Domain – Patient Focus
It developed a simple menu for meals to make it easier for in-patients to understand the food choices available; this has also been well received by older people and those whose first language is not English.	Care Quality Commission performance assessment 2009/10: indicator on *Access to healthcare for people with a learning disability*
Contact: audrey.whelan@lpft.nhs.uk	Expert Patient Programme
Pacesetters is a partnership between local communities who experience health inequalities, the NHS and the Department of Health Equality and Human Rights Group. In Walsall the breast-screening unit worked with women with learning disabilities and the local learning disability service to improve information about screening: uptake has increased to 100%.	
Contact (Pacesetters Programme): joanne.mcconnell@dh.gsi.gov.uk	

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15. Recommendation 3 from *Healthcare for All*

Working in partnership with families

People with learning disabilities often rely on their families to support them in relation to their health. Families have a big influence on aspects of healthy living, such as diet, exercise and oral hygiene. They know a lot about how to support a person with these important basics, and with understanding information about health and health care. Family carers can help people with learning disabilities to communicate with health professionals.

Families of people with complex health needs often have great expertise about their relatives' conditions, treatment and important considerations. Failure to respect this expertise can pose serious clinical risks. Provision of appropriate information helps to promote health and independence.

Best practice

Provided the person consents (or based on 'best interests' if they lack capacity), family carers are involved as partners in the health care of their relatives with learning disabilities. This might include:

• sharing information (two way)

• asking their advice about communication and everyday care

• involving them in discussions and decisions about treatment options and risk management.
(Note: involving families is not a substitute for 'best interests' processes – see next section).

Family carers' own needs for support are considered. This might include:

• choice about appointments

• access to basic amenities on hospital wards

• carer's assessment (including attention to their own health).

"Why did the trust take no notice when the family warned of what might happen when M was distressed?"[16]

16. Quote from *Healthcare for All*

"The hospital arranged for my daughter to stay with her sister. They paid for the taxi and sent written information about her medication."[17]

Practical examples

Barnet and Chase Farm Hospitals NHS Trust was an 'early adopter' of efforts to improve the experiences of people with learning disabilities and their families, with a patient-held 'hospital book' of important information about the person and later the introduction of acute liaison posts and a carer protocol. Feedback from family carers showed that these initiatives made a big difference to their confidence in the care their relatives get in hospital.

Contact: sarah.pope@bcf.nhs.uk

The Sheffield Teaching Hospitals Foundation Trust engaged in a consultation with carers, which informed development of the Trust's Carer Strategy.

Contact: rosemary.bollands@sth.nhs.uk

Links to wider NHS policies

NHS Constitution

Standards for Better Health, Fourth Domain – Patient Focus

Care Quality Commission performance assessment 2009/10: indicator on *Access to healthcare for people with a learning disability*

Expert Carer Programme

Carers' Strategy

17. Personal communication

Reasonable adjustments in service delivery

Capacity, consent and advocacy

Why is this important?

Sometimes health professionals assume that a person with learning disabilities lacks capacity, so they do not make adequate efforts to explain information and options or to support someone to make a decision for themselves.

Similarly, health staff may over-estimate the ability of a person with learning disabilities to process and retain information. This can mean that a person seems to understand information about their health or instructions about treatment, but does not.

Under the Mental Capacity Act 2005 a person must be assumed to have capacity to make a decision unless proven otherwise. 'All practicable steps' must be taken to give them information in a way they understand and support them to make such decisions. People may be able to make some decisions and not others, and capacity may fluctuate. No-one can 'give consent' on behalf of an adult. Where a person is unable to make a particular decision about treatment, it may be necessary for clinicians to consult with the person and those who know them best and make a 'best interests' decision. Families have a vital contribution to make to this. Ill-treatment or neglect of a person who lacks capacity is a crime.

This means everyone in contact with patients must think carefully about how they provide information, support decision making (including consent to investigations or treatment), and use 'best interests' decision making for a person who lacks capacity to make a specific decision.

People with learning disabilities may benefit from access to advocacy; there is a legal right to this if an important decision has to be made and a person without capacity to make it has no family or friend to support them.[18]

Best practice

Everyone who has contact with patients understands their responsibilities in relation to capacity and how to adjust their ways of communicating to suit individuals.

Patient Advice and Liaison Services (PALS) and Local Involvement Networks (LINks) know about local advocacy for people with learning disabilities and support people to make use of it.

People with learning disabilities get support from the Independent Complaints Advocacy Service (ICAS) or an Independent Mental Capacity Advocate (IMCA) when required.

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18. Much more guidance is available in the *Mental Capacity Act 2005 Code of Practice* www.dca.gov.uk/legal-policy/mental-capacity/mca-cp.pdf

"All Trust Boards should demonstrate in routine public reports that they have effective systems in place to deliver effective, 'reasonably adjusted' health services… This ['adjustment'] should include arrangements to provide advocacy for all who need it." [19]

Practical examples

The Sheffield Teaching Hospitals Foundation Trust and Hull and East Yorkshire Hospitals NHS Trust have comprehensive information available for staff about capacity and consent on their intranets.

Contact:
Sheffield: rosemary.bollands@sth.nhs.uk
Hull: allyson.kent@humber.nhs.uk

A man referred to the Royal Devon & Exeter Foundation Trust for dental treatment, following distressing unsuccessful attempts, was assessed as unable to consent. He had no family, so a referral was made for an IMCA. She worked with the surgeon, GP, care manager and support workers to ensure the proposed treatment was in his best interest.
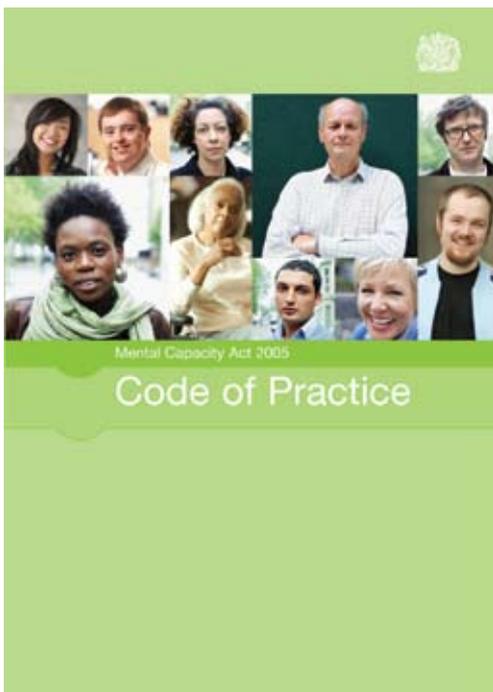
Contact: liz.jennings@rdeft.nhs.uk

Links to wider NHS policies

NHS Constitution

Standards for Better Health, Fourth Domain – Patient Focus

Care Quality Commission performance assessment 2009/10: indicator on *Access to healthcare for people with a learning disability*

Mental Capacity Act 2005
Code of Practice

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19. Recommendation 10 from *Healthcare for All*

Making an appointment

Why is this important?

People with learning disabilities may find it difficult to use the telephone (particularly push-button menus). Standard letters about appointments can be hard to understand, especially when they include requirements about information to bring or things the patient must or must not do before attending.

Some people find waiting very difficult, perhaps because their understanding of time is very limited or because they find waiting rooms and crowds scary.

People with learning disabilities sometimes need a range of investigations to find out what is wrong; this can result in multiple appointments, which can be both distressing for the person and costly.

Some people will need some special arrangements to be made, such as a supporter to come with them, specific equipment to be available, or some support beforehand to understand and accept what is going to happen. Support beforehand might need to include a visit (for example, to a scanner) as well as explanations. Such needs should be checked when an appointment is made, to avoid distress to the person and a possibly wasted appointment.

Best practice

Initial communications with patients use very easy words, offer a range of ways to get in touch, and ask routinely about any special communication needs.

People with learning disabilities may have a health action plan or health passport – ask them to bring it.

Any special arrangements the person may need are discussed, and recorded on the electronic patient record for future reference. These might include:

• first or last appointment; double appointment

• multiple investigations arranged for the same day

• phone or text reminder the day before

• help with travel

• presence of a supporter

• support prior to the appointment

• special equipment (such as weighing scales for a wheelchair user).

"When we make an appointment, ask what help we will need."

Practical examples

The Western Eye Hospital (part of Imperial College Healthcare NHS Trust) produced an easy-read leaflet showing how to get to the Orthoptic Department (with photographs showing each stage of the journey) and what to expect in relation to different tests.

Contact: avril.charnock@imperial.nhs.uk

The Coventry Community Dental Service developed a pre-visit questionnaire that could be completed by people with autistic spectrum disorder (or their carers). This helps the service to prepare; it also offer visits to the surgery before the appointment and has pre-visit packs that can be borrowed (containing mask, gloves, goggles, plastic mirror and dental smells in a bottle or on paper) to help familiarise the patient with some of the experiences before the visit. The pre-visit questionnaire has been so useful that it is now used for all new patients.

Contact: lyn.wales@coventrypct.nhs.uk

The University Hospital of North Staffordshire operates a protocol for triage that prompts consideration of reasonable adjustments.

Contact: judithc.thorley@northstaffs.nhs.uk

Links to wider NHS policies

NHS Constitution

NHS Operating Framework

Standards for Better Health, Fifth Domain – Accessible and Responsive Care

Care Quality Commission performance assessment 2009/10: indicator on *Access to healthcare for people with a learning disability*

You can come to The Western Eye Hospital to have your eyes looked at.

We will look at your eyes.

We will find out how well you can see.

If you need to have glasses we can help you choose them.

If there is a problem inside your eyes we can ask another eye specialist to see you.

Who can arrange for you to have your eyes looked at?

Your Doctor

Your Community Nurse

You or your carer

Initial attendance

Both patients and clinicians can find their time is not used to best effect if a person's initial attendance is not planned well. This might be because important information about the person is not available; ways of communicating have not been planned; the person has not been well prepared for what is going to happen; needed equipment is not available (such as a hoist to help the person get onto a couch).

This contact is another opportunity to find out about the reasonable adjustments that a person may need for further appointments or admission.

Clinicians need to guard against 'diagnostic overshadowing' and ensure that signs and symptoms are not mistakenly attributed to the person's learning disability. Family carers and others who know the person well will often be able to describe changes in the person in a way that will aid diagnosis.

Reception staff and clinicians establish the best ways to communicate with the person (and their family or other supporters as appropriate).

Important information about the person's history and needs is gathered from the person themselves, family or other supporters, and records such as a health action plan or 'health passport'. This information is shared with others who need to know.

Information for the person and their supporters to take away is provided in a suitable format.

Any support required in order for the person to receive further services is discussed and organised. This might include:

• support from an advocate or the community learning disability team to understand, consent to and prepare for the planned service

• pre-admission liaison with a ward about support needed during admission

• pre-admission visit for the person to the ward or theatre

• addition of key information to the person's health action plan or 'hospital book'

• access to a 'changing places' facility that allows a disabled adult to be changed safely and in dignity.

"Ask us to visit before we have treatment."

Practical examples	Links to wider NHS policies

Southport and Ormskirk Hospital NHS Trust developed a series of care pathways as part of its policy on care of people with learning disabilities in their services. One of the pathways covers initial out-patient attendance. This includes suggestions for reasonable adjustments and links to expertise available from specialist services.

Contact: jackie.brunton@ southportandormskirk.nhs.uk

The University Hospital of North Staffordshire 'Specific Needs Access' team mapped patient journeys, promoted an admission and discharge care pathway to improve assessment and planning of reasonable adjustments, and offered staff training and support. A system for 'flagging' vulnerable patients on the information system was devised.

Contact:
The team drew on a toolkit developed by a steering group through Keele University; the resources can be downloaded from www.keele.ac.uk/depts/ns/toolkitpeopleld judithc.thorley@northstaffs.nhs.uk

The Royal Hallamshire Hospital (Sheffield) and Arrowe Park Hospital (Wirral) have 'changing places' toilets.

Contact:
Sheffield: rosemary.bollands@sth.nhs.uk
Wirral: mandy.whalley@whnt.nhs.uk

NHS Constitution

Standards for Better Health, Fifth Domain – Accessible and Responsive Care

Care Quality Commission performance assessment 2009/10: indicator on *Access to healthcare for people with a learning disability*

"Doctors talked to S rather than her mother and asked how she would like to be 'marked up' for the surgery."

Receiving a service

Technically good treatment can be compromised by failure to plan any reasonable adjustments required. For example, lack of accessible information may mean that pre-operative instructions have not been followed, or lack of consultation with the family about preparation may mean that the person is too distressed to undergo treatment. Appropriate equipment may need to be arranged. Some people may need extra support with personal care; it should not be assumed that family carers or social care staff will do this.

Diagnosis may be difficult in people with learning disabilities if they cannot describe signs and symptoms clearly. 'Watch and wait' will only work if the watching is close and skilful, with a full history taken from those who know the person well and appropriate additional investigations used if the diagnosis remains unclear.

Special attention should be paid to ensuring dignity in caring for a patient with learning disabilities, who may be at particular risk otherwise.

People have different attitudes to risk and to quality of life. It is important to avoid making assumptions about the balance of risks and benefits of a particular investigation or treatment for a person with learning disabilities.

Good communication, tailored to the person, underpins:

• robust planning of the episode of care

• discussion of risks and benefits of treatment options

• consent (or best interests decisions)

• dignified care.

People with learning disabilities are asked for their 'health passport' or 'hospital book' that includes important information about their communication and care needs. Family carers often hold such information too. This can be critical to ensuring patient safety (for example, to avoid allergies, choking, falls or longer term harm such as contractures or distortion of body shape).

Such information is also used to plan for personal care such as eating and drinking, and personal hygiene.

Clear protocols for provision of extra personal care, when this is needed, avoid unfair expectations on family carers and social care staff.

If family carers choose or need to stay with a person during admission (for example, to reduce their distress), attention is paid to their own needs, such as washing, eating and sleeping.

"If I often come into hospital, make it easy." "Look after our carers." "Tell us what is happening."

Practical examples

The Pearl Service is an easy access service offered by the West London Centre for Sexual Health. It offers a direct telephone number to the sexual health adviser team for appointments/information/advice (instead of via the call centre) and double appointments. A story book ("A visit to the Pearl Clinic") and accessible information leaflet were devised with people with learning disabilities and the local community learning disability team. These help the client to understand what might happen when they attend.

Contact: ceri.evans@chelwest.nhs.uk

A number of Trusts (such as Hull and East Yorkshire Hospitals NHS Trust, Sheffield Teaching Hospitals Foundation Trust) have devised 'passports' and 'traffic light' assessments to ensure that vital information is available to all staff involved in the care of a patient with learning disabilities.

Contact:
Hull: allyson.kent@humber.nhs.uk
Sheffield: rosemary.bollands@sth.nhs.uk

The Hillingdon Hospital NHS Trust protocol clarifies the boundaries between the supporting role of social care staff and the responsibilities of nursing and allied health professionals.

Contact: jacqueline.walker@thh.nhs.uk

Links to wider NHS policies

NHS Constitution

Discharge from hospital: pathway, process and practice

Standards for Better Health, Fourth Domain – Patient Focus; Sixth Domain – Care Environment and Amenities

Care Quality Commission performance assessment 2009/10: indicator on *Access to healthcare for people with a learning disability*

Referral

When care has been taken to establish the reasonable adjustments an individual requires, it is important to ensure that this information is included in onward referrals. This will reduce duplication of effort and the possibility of important information being lost. A person with learning disabilities may not be in a position to ensure this continuity themselves.

As before, it is important that the person themselves and their family or other supporters have accessible information about the reasons for referral and what to expect.

Best practice

The information you needed about the person is passed on.

Relevant information is added to the person's 'health passport', 'hospital book' or health action plan. This will help to inform the person themselves and their family or support staff, as well as the service to which they are being referred.

Where the facility exists, information is added to the electronic patient record about any reasonable adjustments the person requires.

Some information systems allow a patient's record to be flagged to show that they have extra needs. This can be used both within a service (to reduce the chance of such information being missed) and on referral.

"If you ask another part of the NHS to help us, tell them what help we need."

Practical examples	Links to wider NHS policies

Calderdale and Huddersfield NHS Foundation Trust is an example of a trust that makes use of the PAS 'flag' system to alert services that a referred patient has learning disabilities and may be carrying a health action plan and 'vulnerable in-patient' (VIP) card. The VIP card is a Z-fold card containing critical information about the person's health. The Complex Needs Care Co-ordinator (matron) also receives an email when a patient is admitted or is put on a pending waiting list for an out-patient appointment.
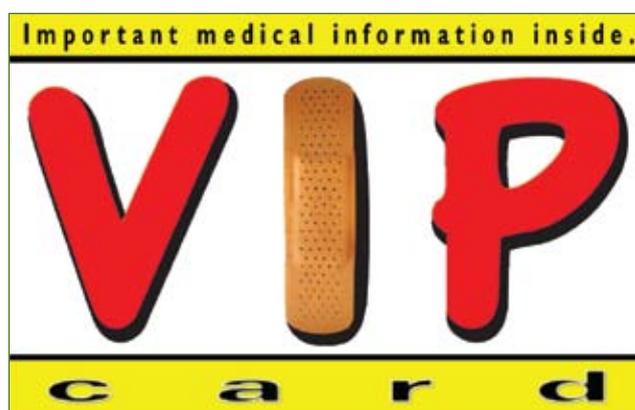
Contact: amanda.mckie@cht.nhs.uk

NHS Constitution

Standards for Better Health, Second Domain – Clinical and Cost Effectiveness

Care Quality Commission performance assessment 2009/10: indicator on *Access to healthcare for people with a learning disability*

Discharge from hospital: pathway, process and practice

Discharge and follow-up

Why is this important?

The value of good treatment from community or hospital services can be reduced if clinicians do not understand and take account of the patient's usual environment and support. It is easy to make wrong assumptions that could affect treatment outcomes. For example, a hospital might assume that the person has 24-hour support, when in fact they only get a few hours' support a week and will need some extra help to comply with the post-discharge treatment plan. Alternatively, staff might assume that the person can do nothing for themselves – because they are seeing the person in an unfamiliar setting – when good discharge planning and extra support at first could result in a safe discharge home. Intermediate care may be a good option for some people, but for others (such as those who find new environments distressing) it may be better to plan discharge home with a substantial package of support that could be reduced over time.

It is particularly important to ensure that the person themselves and their family or other supporters understand any continuing treatment and arrangements for follow-up.

Best practice

Discharge planning starts on (or before) admission, involves the person and their family (and/or paid supporters) and takes the patient's person-centred plan as its starting point. Plans for discharge take account of accurate information about the person's usual environment and support and include risk assessments where appropriate.

The principles of the Mental Capacity Act are followed to ensure that the person is as involved as possible in decision making and that any 'best interests' decisions required are based on good information about their preferences.

The person and their family or other supporters have information about post-discharge treatment and follow-up in a suitable format.

Follow-up appointments are arranged based on any reasonable adjustments noted previously.

Information about the person's diagnosis and treatment is added to their health action plan and/or 'health passport'.

"When we leave, make sure we have enough help."

Practical examples

Southport and Ormskirk Hospital NHS Trust developed a series of care pathways as part of its policy on care of people with learning disabilities in their services. The pathways for both elective and emergency admission cover discharge planning. These pathways include suggestions for reasonable adjustments and links to expertise available from specialist services.

Contact: jackie.brunton@ southportandormskirk.nhs.uk

The University Hospital of North Staffordshire 'Specific Needs Access' team undertook a cost/benefit analysis that showed how the liaison and support role of the team could reduce the costs associated with delayed discharges and repeat attendances.

Contact: judithc.thorley@northstaffs.nhs.uk

Links to wider NHS policies

NHS Constitution

Discharge from hospital: pathway, process and practice

Standards for Better Health, Second Domain – Clinical and Cost Effectiveness

Care Quality Commission performance assessment 2009/10: indicator on *Access to healthcare for people with a learning disability*

Information about people with learning disabilities

Gathering information

Why is this important?

It is difficult for health services to make reasonable adjustments if they do not know which of their patients need them; having accurate information about a person makes it easier to offer and arrange such adjustments. Typically, NHS information systems have not recorded a patient's learning disability. Where this is recorded, a very wide range of diagnostic codes have been used. This has made it difficult to track the service usage and experiences of this group of people.

Best practice

Appropriate clinical codes for recording learning disability are agreed with the Primary Care Trust, as local practice varies.

Where the facility exists, information is added to the electronic patient record about any reasonable adjustments the person requires.

Some information systems allow a patient's record to be flagged to show that they have extra needs. This can be used both within a service (to reduce the chance of such information being missed) and on referral. 'Flags' can also be used on paper records.

"Make sure the computer system identifies people with learning disabilities."[20]

Practical examples

The Sheffield Teaching Hospitals Foundation Trust carries out regular audits of its service provision to people with learning disabilities and uses the results to improve the service. The Patient Administration System is used systematically to collect data about people with learning disabilities who use the hospitals' services.

Contact: rosemary.bollands@sth.nhs.uk

Links to wider NHS policies

NHS Constitution

Standards for Better Health, Third Domain – Governance

Care Quality Commission performance assessment 2009/10: indicator on *Access to healthcare for people with a learning disability*

20. Recommendation 2 from *Healthcare for All*

Monitoring and reporting

Why is this important?

Improved clinical coding can enable services to identify:

• under-representation of people with learning disabilities (for example, for breast screening)

• over-representation (for example, deaths from respiratory conditions)

• service gaps and developments required.

Having a way of identifying patients with learning disabilities can also help Trusts to ensure that they include the experiences of these patients in evaluation of services, reviews of access or take-up, and reports on progress with their Single Equality Scheme action plan.

Best practice

Appropriate clinical codes for recording learning disability are agreed with the Primary Care Trust, as local practice varies.

Data collected through improved clinical coding is analysed and used to contribute to the Joint Strategic Needs Assessment as well as the Trust's own service planning and development.

Service evaluations and reviews, whether internal or external, include people with learning disabilities (using suitably adapted methodologies).

Reviews of progress against the Single Equality Scheme action plan include this group of potential and actual users of the service.

"Invite us to your patient groups."

Practical examples

The Royal Cornwall Hospitals NHS Trust worked with people with learning disabilities and family carers to find out about problems people were having with hospitals. The Trust agreed a plan to make improvements. A group of people with learning disabilities called the 'CHAMPS' team now visit hospitals across Cornwall regularly and tell the Trust about their findings.

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sandra.arnold@rcht.cornwall.nhs.uk

Links to wider NHS policies

Standards for Better Health, Third Domain – Governance

Care Quality Commission performance assessment 2009/10: indicator on *Access to healthcare for people with a learning disability*

Section 5

Patient and public involvement

PALS and LINks

Why is this important?

People with learning disabilities have often been excluded from patient and public involvement initiatives because:

• clinical coding systems have not identified the presence (or absence) of this group

• common involvement mechanisms, such as surveys and focus groups, have not been adapted to ensure inclusion of people who may find such methods of communication difficult.

People with learning disabilities and their families often feel particularly vulnerable in healthcare settings and may be less likely to use complaints procedures for this reason (as well as communication problems) if they are unhappy with their care.

Extra effort is therefore required to ensure that the views of people with learning disabilities, and their families, are captured and used to help improve services for everyone.

Best practice

Complaints procedures are available in a variety of formats.

PALS make particular efforts to offer support to patients with learning disabilities and their families, and to include their opinions in reviews of services and policies.

Such feedback results in service changes, which are reported back so that people know it is worth speaking up.

Involvement includes people with complex needs as well as those more able to speak up.

Services encourage people with learning disabilities and their families to connect with Local Involvement Networks (LINks).

"Ask us about local services!"

> **"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… All Trust Boards should ensure that the views and interests of people with learning disabilities and their carers are included."[21]**

Practical examples

PALS at the Royal Bournemouth and Christchurch Hospitals NHS Foundation Trust worked with a group of hospital staff and local people to improve communication with patients with a range of needs. The resulting mini-projects included, for example, a pictorial guide to having an X-ray and an accessible leaflet about PALS.

Contact: linda.witchell@rbch.nhs.uk

Links to wider NHS policies

NHS Constitution

Standards for Better Health, Fourth Domain – Patient Focus

Care Quality Commission performance assessment 2009/10: indicator on *Access to healthcare for people with a learning disability*

21. Recommendation 9 from *Healthcare for All*

Trust governance

All NHS trust boards have a duty to promote equality and human rights, which is central to the proper discharge of governance responsibilities for the NHS.

The governance arrangements for NHS foundation trusts include a membership body that elects Governors, who in turn appoint the Chair and non-executive directors. This provides an important route through which the voices and interests of people with learning disabilities can be heard alongside all the other potential users of the Trust's services.

All NHS boards should aim to provide a comprehensive service, available to all, and pay particular attention to vulnerable groups and listening to the views of 'hard to reach' minorities such as people with learning disabilities.

The results of listening to patients and their families can be used to ensure that NHS trusts develop plans for driving service improvements and delivering high quality care for all.

Foundation Trusts should grow a representative membership that takes account of the diversity of the local population.

People with learning disabilities and their families are encouraged to become members of foundation trusts and to take part in elections – both as voters and as potential governors.

Practical examples

Hillingdon Hospital NHS Trust set up a Learning Disability Action Group, supported by a non-executive champion on the Trust Board, and worked with them to draw up a local improvement plan. A learning disability awareness day was held to launch the new local protocol to Trust staff. People with learning disabilities talked about their experiences of accessing and receiving health care. A staff survey has recently been completed to assess current knowledge and awareness to determine required training and information needs, and a specific patient survey is planned for the near future.

Contact: jacqueline.walker@thh.nhs.uk

Links to wider NHS policies

NHS Constitution

Standards for Better Health, Third Domain – Governance

Care Quality Commission performance assessment 2009/10: indicator on *Access to healthcare for people with a learning disability*

The NHS Foundation Trust Code of Governance

Other important links to Single Equality Schemes

Employment

Why is this important?	Best practice
Many people with learning disabilities wish to work and are capable of making a useful contribution. The Government has set public sector bodies a new target[22] to increase their employment of people with learning disabilities. A range of reasonable adjustments may be needed to meet this commitment.

People with learning disabilities may also be interested in volunteering. | A range of recruitment methods are used to reach people with learning disabilities. This might include:

• easy-read advertisements circulated through the Learning Disability Partnership Board and local advocacy and self-advocacy groups

• work experience and tasters

• alternatives to conventional application and interview processes, such as video applications, 'working interviews' (trials)

• apprenticeships and internships

• job carving to match elements of jobs to a person's specific skills

• links with supported employment organisations that can help to match potential candidates with specific tasks and can organise support such as job coaches and benefits advice.

People with learning disabilities may be less likely than other employees to put themselves forward for training, development opportunities or promotion. Particular care is therefore taken with their appraisals and personal development plans to ensure that they are not treated unfairly with respect to retention and career development.

Similar considerations apply to recruiting and supporting volunteers. |

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22. *Valuing Employment Now* (2009) www.dh.gov.uk/en/Publicationsandstatistics/Publications/ PublicationsPolicyAndGuidance/DH_101401

Practical examples

The City Hospitals Sunderland NHS Foundation Trust offers a work experience programme for teenagers with severe physical and learning disabilities. This involves six-week placements across the Trust in a variety of departments and roles. Students are matched carefully with these opportunities; each student has a mentor and the mentors in turn are offered training and support. The scheme has been so successful that it is being extended to other local public sector employers.

Contact: stephanie.smith@chs.northy.nhs.uk

NHS Bristol's Single Equality Scheme action plan includes active encouragement of job applications and internships from under-represented groups. Three health trainers with learning disabilities were recruited to work with local NHS staff to raise awareness about the needs of people with learning disabilities and to offer health education to people with learning disabilities.

Contact: lesley.russ@bristolpct.nhs.uk

Links to wider NHS policies

NHS Constitution

Standards for Better Health, Third Domain – Governance

Mapping impact

NHS bodies are required to screen their policies, processes and functions to check whether they might have an impact on race or disability equality. If so, equality impact assessments are required. This applies to existing policies and procedures as well as to new ones. NHS bodies also have to make sure that any services provided on their behalf by contractors are assessed.

NHS bodies should have these arrangements for equality impact assessments well established; however, further consideration of the particular needs of people with learning disabilities may be required (including those from Black, Asian and minority ethnic communities). Equality impact assessments should consider people who may experience multiple forms of discrimination, such as disability plus race, or a learning disability plus a mental health problem. It is common for disability equality impact assessments to focus on physical disabilities and the reasonable adjustment that may be needed (such as wheelchair access, 'changing places' toilets), whereas the adjustments that people with learning disabilities need are often more to do with communication, memory, emotional support and information.

The results of equality impact assessments can be used to identify and prioritise staff training and development needs.

Equality impact screening and assessments take account of the needs of different groups of disabled people.

The best way of ensuring this is to involve disabled people – including people with learning disabilities – in planning and reviewing such work. People with learning disabilities and family carers can also be involved as trainers for staff.

The examples given earlier in this guide will help NHS bodies to think about the types of impact and adjustments that should be considered.

It is also important to take account of the Equality Impact Assessment published alongside *Valuing People Now – A New Three-Year Strategy for People with Learning Disabilities* (*Making it Happen for Everyone*, DH, 2009). This sets out the Government's commitment to ensuring that the Valuing People policy (DH, 2001) is implemented more fully, and impacts on those groups of people with learning disabilities which, to date, have benefited least from its policy objectives, including people with more complex needs, people from black and minority ethnic groups and newly arrived communities (*The Story so Far*, DH, 2005). It also recognises that family carers, including carers with learning disabilities, have not benefited fully from its policy objectives.

The Equality Impact Assessment provides a detailed analysis in terms of ethnicity, gender, disability, age, sexual orientation, religion or belief, as well as taking account of family carers issues (particularly those linked to ethnicity, gender and age) and the wider issue of promoting human rights. It is available at www.dh.gov.uk/en/Publicationsandstatistics/ Publications/PublicationsPolicyAndGuidance/ DH_093377

Practical examples

The Sheffield Teaching Hospitals Foundation Trust provides reports to the Learning Disability Partnership Board about progress against its equalities improvement plans and uses the results of its regular audits to support a continuous process of improvement. This includes the 'Imagine you are me' e-learning resource for staff.

Contact: rosemary.bollands@sth.nhs.uk

NHS Bristol's Single Equality Scheme and action plan includes some actions aimed at a number of groups (such as employment opportunities) and some aimed specifically at people with learning disabilities (such as patient profiling, help with creating easy-read documents). People with learning disabilities were involved in developing the scheme.

Contact: lesley.russ@bristolpct.nhs.uk

Links to wider NHS policies

NHS Constitution

Standards for Better Health, Third Domain – Governance

Care Quality Commission performance assessment 2009/10: indicator on *Access to healthcare for people with a learning disability*

Creating a Disability Equality Scheme: A Practical Guide for the NHS

Valuing People Now – A New Three-Year Strategy for People with Learning Disabilities (*Making it Happen for Everyone*, DH, 2009) Equality Impact Assessment.

Top tips

Communicate, communicate – check how the person communicates, use easy English, provide easy-read information, show and tell.

Speak to the person – ask questions in different ways to check whether they have understood.

Check whether family carers or other supporters have something to add – they may have important information.

Use simple words to explain – what will happen, what the health problem is, what equipment is for. Let the person see and touch equipment.

See the person, not the disability – don't allow assumptions about capacity or what is 'normal' for that person to colour your judgement about investigations or treatment.

Be flexible – be prepared to change the way you usually do things; be creative in offering reasonable adjustments that go beyond physical access.

Involve local people with learning disabilities – in carrying out equality impact assessments and service audits, and then planning reasonable adjustments.

Offer your staff training so they are confident in supporting people with learning disabilities – involve people with learning disabilities and family carers as trainers.

Be aware that getting it right for people with learning disabilities will also help people with dementia and people who find written and spoken English difficult.

Capture and use data about people with learning disabilities to improve your services – use clinical coding and 'flags' to track their usage and experiences.

Get to know your local learning disability service and find out what support they can offer you to improve your services.

Resources

Networks

Access to Acute Hospitals Network (A2A) **http://a2anetwork.co.uk**
UK Learning Disability and Health Network **www.learningdisabilities.org.uk/ldhn**

Websites

Foundation for People with Learning Disabilities **www.learningdisabilities.org.uk/our-work/improving-service/health**
Getting It Right **www.mencap.org.uk/page.asp?id=4363**
Human Rights in Healthcare **www.dh.gov.uk/en/Managingyourorganisation/Equalityandhumanrights/Humanrights/DH_088783**
Learning about intellectual disabilities and health **www.intellectualdisability.info/home.htm**
NHS Evidence – Learning Disabilities Specialist Collection **www.library.nhs.uk/learningdisabilities/ViewResource.aspx?resID=262616**
Pacesetters Programme **www.dh.gov.uk/en/Managingyourorganisation/Equalityandhumanrights/Pacesettersprogramme/DH_078778**
Picker Institute (specialists in patient feedback) **www.pickereurope.org**
Valuing People Now **www.valuingpeople.gov.uk/dynamic/valuingpeople118.jsp**

Publications

Basic guidelines for people who commission Easy Read information **www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_097667**
Care Quality Commission performance assessment 2009/10: indicator on access to healthcare for people with a learning disability **www.cqc.org.uk/guidanceforprofessionals/healthcare/nhsstaff/periodicreview2009/10/qualityofservices/existing/accesstohealthcareforpeoplewithalearningdisabilityacsp.cfm**
Discharge from hospital: pathway, process and practice **www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4003252**
Hardy S (2009) *Dignity in healthcare for people with learning disabilities*. London: Royal College of Nursing
Meeting the health needs of people with learning disabilities: Guidance for nursing staff **www.rcn.org.uk/__data/assets/pdf_file/0004/78691/003024.pdf**
Seeking consent: working with people with learning disabilities **www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4007861**
Standards for Better Health **www.cqc.org.uk/guidanceforprofessionals/healthcare/nhsstaff/annualhealthcheck2008/09/qualityofservices/corestandards.cfm**
The NHS Constitution handbook **www.dh.gov.uk/en/Healthcare/NHSConstitution/index.htm**
Top Ten Tips for Effective Consultation **www.intellectualdisability.info/values/top_ten_tips.htm**
Working Together: Easy steps to improving how people with a learning disability are supported when in hospital **www.valuingpeople.gov.uk/dynamic/valuingpeople118.jsp**

Easy-read information about health

Books Beyond Words **www.rcpsych.ac.uk/publications/booksbeyondwords/aboutbbw.aspx**
CHANGE (current project on information about cancer) **www.changepeople.co.uk/showPage.php?id=5**
easyhealth website **www.easyhealth.org.uk**

Acknowledgements

We are most grateful to everyone who contributed examples of good practice. It was so encouraging to hear about the great work that is happening across the country. We hope that their achievements will inspire more people to try these ideas.

We have included contact email addresses; these were correct as at September 2009, but please be aware that they may change. You can post enquiries through the networks listed inside the back cover.

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(DH) Department of Health