



Public Health
England



Protecting and improving the nation's health

Working together 2: **Easy steps to improve support for people with learning disabilities in hospital**

Guidance for hospitals, families and paid support staff

About Public Health England

Public Health England exists to protect and improve the nation's health and wellbeing, and reduce health inequalities. It does this through world-class science, knowledge and intelligence, advocacy, partnerships and the delivery of specialist public health services. PHE is an operationally autonomous executive agency of the Department of Health.

About Improving Health and Lives

Improving Health and Lives (IHaL) was set up in April 2010 to provide high quality data and information about the health and healthcare of people with learning disabilities. The information helps commissioners and providers of health and social care to understand the needs of people with learning disabilities, their families and carers, and, ultimately, to deliver better healthcare.

IHaL is a collaboration between PHE, the Centre for Disability Research at Lancaster University and the National Development Team for Inclusion. Since April 2013, IHaL has been operated by PHE.

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Published June 2015

PHE publications gateway number: 2015126



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Acknowledgements

Working group for original 2008 document:

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Kevin Elliott, Gloucestershire Primary Care Trust
Jenny Harkness, social worker, Hft
Crispin Hebron, Hft
Robina Mallett, Family Carer Support Service, Hft
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Kate Robinson, Worcestershire Partnership NHS Trust
Sue Turner, Valuing People Support Team

A number of practitioners and family carers were involved in updating the document for publication in 2015 and we are very grateful for their contributions.

Notes:

- names used in case studies have been changed to protect confidentiality
- all web links checked April 2015

Easy Read summary



Going into hospital can be a little bit scary. It is good to make a plan.



Hospital doctors and nurses need to know how to support people with learning disabilities.



Hospital staff can talk with you, your family and support workers to make a plan.



This book is to help them. The book shows them some easy steps.

1.



Step 1: Making a plan about going into hospital

2.



Step 2: Getting ready to go into hospital

3.



Step 3: Being in hospital

4.



Step 4: Leaving hospital

The pictures in this report are from Photosymbols: www.photosymbols.co.uk

Foreword

The confidential inquiry into premature deaths of people with learning disabilities¹ (CIPOLD, 2013) added yet further evidence to show that there are multiple opportunities both to improve healthcare delivery and to prevent problems in the first place. Without realising these opportunities people with learning disabilities will not have the health outcomes to which they are entitled and they will continue to die avoidably and prematurely.

The NHS, like all other institutions, has a duty to implement reasonable adjustments, and the failure to do so was a contributory factor to many of the premature deaths studied.

People with learning disabilities often have a number of complex health needs, but the inquiry found a lack of coordination between different disease pathways and service providers. Paid supporters and families often struggled to be heard, but we know it does not have to be like this. There are some excellent examples of people working together to improve hospital services for people with learning disabilities. Some are in this guide and there are many more. For a summary of some of the issues people with learning disabilities are concerned about see: www.healthtalk.org/peoples-experiences/improving-health-care/learning-disabilities-health-service

This updated guide is an important resource for hospital staff, families and paid support staff working with people with learning disabilities to help them get the care they need, every step of the way from pre-admission planning to discharge. It includes practical suggestions along with links to further resources.

Please use this guide to stimulate the discussions that need to happen within organisations and between them, in order that care is made as safe and effective as possible for this vulnerable group of citizens. Most particularly use it to confirm or challenge the arrangements that are in place to hear the voices of families and paid supporters and include them in care delivery. When the health of somebody with a learning disability deteriorates or they need hospital care, **their** carers are the experts and need to be consulted and included.

An online version is available at www.improvinghealthandlives.org.uk/publications

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¹ Heslop P, Blair P, Fleming P, Hoghton M, Marriott A and Russ L (2013) Confidential inquiry into premature deaths of people with learning disabilities (CIPOLD). Final report. Bristol: Norah Fry Research Centre, University of Bristol www.bris.ac.uk/cipold

Introduction

Working together 2 is an update of the *Working together* guide published in 2008 to help hospital staff, family members and paid support staff work jointly before, during and towards the end of any hospital admission (unplanned or planned) so an individual with learning disabilities could get good support and treatment. This introductory section is followed by suggested action in four steps, from pre-admission to discharge. Links to further information and useful resources are given in Appendix A and specific checklists are described in Appendix B.

People with learning disabilities in hospital: evidence and policy

Going into hospital, for whatever reason, can be frightening, confusing and stressful. People are often unsure what to expect or how they will cope, and the language used by hospital staff can be hard to understand. It is a time when everyone will feel vulnerable.

For people with learning disabilities² it is likely to be even more complicated. They are likely to find it more difficult than most people to communicate natural anxieties, or explain any pain or discomfort they may be in. They may have difficulty in adjusting to the hospital environment and routines. They may also have had poor experiences of healthcare in the past. Hospital staff may not know or understand the cognitive, health and personal care needs of individuals with learning disabilities. Vulnerability is likely to be further increased by other factors such as epilepsy, mental illness, sensory impairment or risk of choking - all of which are more common amongst people with learning disabilities.

These problems have been known about for some time and were highlighted in a series of critical reports from Mencap, the Disability Rights Commission and the Health Service Ombudsman. The independent inquiry into access to healthcare for people with learning disabilities³ made ten recommendations on reasonable adjustments needed to make healthcare services as accessible to people with learning disabilities as they are to others. The government accepted these recommendations, which are reflected in Monitor's compliance framework for foundation trusts (see Appendix C). The Human Rights Act 1998 and the Equality Act 2010

² Definitions:

Learning disability includes the presence of a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), combined with a reduced ability to cope independently (impaired social functioning), which started before adulthood and has a lasting effect on development. This may also be referred to as intellectual disability.

The term 'carers' often causes confusion and in this document we have therefore used the terms 'family members' or 'family carers' and "paid support staff" (except where a document we cite has just used 'carers').

³ Sir Jonathan Michael. Healthcare for all: independent inquiry into access to healthcare for people with learning disabilities. London: Department of Health; 2008.

http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_099255

place clear duties on trusts to protect all patients' human rights and to promote equal access to treatment and care. The *NHS Constitution*, NHS outcomes framework and the '6 Cs' initiative provide further relevant detail on requirements.

Despite this background and the body of advice based on research, in 2013 the confidential inquiry into premature deaths of people with learning disabilities (CIPOLD) found that men and women with learning disabilities died sooner than those without learning disabilities (an average of 13 and 20 years respectively). CIPOLD also found that avoidable deaths from causes related to poor quality healthcare were higher than for those with no learning disabilities. In 29% of these cases there had been significant delay or difficulty in diagnosis and for 30% there had been problems with treatment.

Contributory factors included: a lack of reasonable adjustments (particularly at clinic appointments and investigations); GP referrals not mentioning individuals' learning disabilities, and limited use of hospital 'flagging' systems to identify people with learning disabilities. Information sharing and coherent, appropriate decision-making was hindered by a lack of co-ordination of care provision across different disease pathways and service providers, alongside poor adherence to, and understanding of, the Mental Capacity Act 2005. Families of those with learning disabilities frequently felt that professionals did not listen to them, although the ten year national carers' strategy⁴ stipulated that carers should be treated as partners in diagnosis, care and discharge planning.

Research into the safety of patients with learning disabilities in NHS hospitals⁵ also cited delays and omissions in treatment and basic care. The main barriers to better and safer hospital care for people with learning disabilities were found to be: the invisibility of such patients within hospitals; poor staff understanding of their specific vulnerabilities; a lack of consistent and effective carer involvement and misunderstanding by staff of the carer role, plus a lack of clear lines of responsibility and accountability for the care of each patient with learning disabilities.

Case study: when care co-ordination worked well

Sarah had profound and multiple learning disabilities and lived in a care home near her family, who were closely involved with supporting her. Sarah had a number of health problems and had frequent admissions to two hospitals. There was fragmentation of her care, a lack of co-ordination and information sharing, and her parents submitted formal complaints about her care twice. A new care co-ordinator took over and convened a

⁴ www.gov.uk/government/news/a-national-strategy-for-carers

⁵ Tuffrey-Wijne I, Giatras N, Goulding L, Abraham E, Fenwick L, Edwards C and Hollins S. Identifying factors affecting the implementation of strategies to promote a safer environment for patients with learning disabilities in NHS hospitals. *Health Services and Delivery Research Journal*. 2013; 1(13) www.journalslibrary.nihr.ac.uk/hedr/volume-1/issue-13#abstract

best interests meeting, attended by hospital and community health and social care staff and Sarah's parents. The meeting focused on ways to improve Sarah's care, shorten any hospital admissions, identify the reasonable adjustments that she required to be able to access health services effectively, and to plan for her future care and end-of-life needs. Clear decisions were made at the meeting; Sarah's family and the professionals involved in her care agreed a way forward. The care co-ordinator worked with the newly appointed learning disability liaison nurses at the hospital to arrange the additional funding that Sarah required to meet her needs when she was an inpatient. They also arranged to alert staff to an impending admission so that any delays in Sarah's care could be avoided. Sarah's agreed care plan worked well during a subsequent hospital admission.

What this guide does

We have taken note of positive feedback about *Working together* from relatives, hospital staff and support services. This updated guide is structured in the same way and is based on three key points at the heart of the recommendations about the health inequalities faced by people with learning disabilities:

- like everyone else, people with learning disabilities should get the help they need from health services, applying any reasonable adjustments required
- health professionals should listen more to the families and support staff of people with learning disabilities because they usually know most about the people they support and what help they need
- health staff should not assume that relatives or paid support staff of a person with learning disabilities will provide care while the person is in hospital; any such support must be discussed and agreed, taking account of their needs and supporting them appropriately

The best way to help anyone to manage the natural stresses of going into hospital is for them to have the support of people who know and care about them; we all need this. As many healthcare staff have very limited knowledge about people with learning disabilities, such support becomes even more important. Too often, where a person has additional support needs during their stay in hospital, it has been expected or assumed that family members will provide this or, if the person has some paid support, that this will continue in hospital. Occasionally, additional nursing support is provided by the hospital to meet such needs, (sometimes called 'specialing'), but this is usually provided by a bank or agency nurse who may not know the ward well, let alone the patient, and this can compromise good care.

Roles and responsibilities

Hospitals have a clear duty to promote equality. This does not mean treating everybody the same, but rather that hospitals must make reasonable adjustments to meet the needs of disabled people, who are entitled to expect equality in the outcomes of their hospital stays.

Hospitals are also required to maintain the dignity of all disabled patients. For some people additional support may be required to achieve these things, as well as to maintain safety while they are in hospital. Hospital staff can use a risk, dependency and support assessment (see Appendix B) to identify risks (both physical risks and risks to the effective outcome of the hospital stay) and what additional support may be required to address them. Such an assessment offers a framework to help negotiate for any additional support to reduce risk, by identifying who is best able to provide that support. This gives the hospital clear evidence of where further funding is required. It is recommended that the risk, dependency and support assessment is used by the nurse in charge of the ward alongside the patient and those who know the patient best (such as paid support staff/family members/advocates).

Good practice example: reasonable adjustment care plans

The Cheshire and Wirral Partnership NHS Foundation Trust developed a risk assessment tool for admission of any patient regarded as vulnerable. The tool is filled out with the person and those who know the person best. The results are used to draw up a care plan, including any reasonable adjustments required and any additional support needs, and how those needs could be met.

It is the hospital's responsibility to fund any extra support required in hospital over and above the individually funded support ordinarily available to the person in their own home. For example, if a person has two hours of individual support funded each day to help them at home, this can usually be transferred to provide support in the hospital (by agreement). However, if the person only has paid support that is shared with other people, this cannot usually be transferred and additional support will have to be funded by the hospital if that is required to meet identified needs and promote an equal outcome. Support at home may be funded by the local authority and/or the NHS, either directly or via a personal budget or personal health budget. Support workers may be employed by an organisation or by the individual or family. Hospitals will need to establish who can agree to any changes in funding or working arrangements.

Family members, advocates⁶ and/or paid support staff can make a major contribution to the effectiveness of treatment and support by providing medical histories and other important information. They can also help to identify areas of risk and contribute to risk management plans. Sometimes they can also provide additional support that contributes to maintaining a patient's safety and dignity while in hospital. For example, a family member or paid support worker is probably well placed to provide expert advice on an individual's communication needs. They may be able to help with reducing anxiety over a particular procedure, such as an injection, or simply come in and help with the person's evening meal if that is required.

Those who know the patient well (relatives, advocates and support staff) also have key parts to play in decision making – helping hospital staff to understand and assess the person's capacity, providing information and support to individuals who have capacity, or contributing to best interests processes if the individual is assessed as unable to make a particular decision. Some people with learning disabilities may have made advance decisions about treatment. Some family members may be court-appointed deputies for decisions about health and welfare. Wherever possible relatives and support staff should be consulted before any decision is made that cardiopulmonary resuscitation should not be attempted. (See 'Do you know about consent?' on page 19 and Appendix A: Where to find further information).

Good practice example: use of NHS contracts

In some areas NHS contracts with hospitals include requirements or incentives to collect data on people with learning disabilities using hospital services. For example, in Salford data was collected on attendances at A&E, admissions, seizures and falls. This data was used to improve liaison with specialist nurses and training. In Wales a 'care bundle' sets out steps that must be taken to ensure the safety of all patients of all ages with learning disabilities who are being cared for in an emergency department, as a day case or as an inpatient in a general hospital.

Using this guide to get support right

Family carers, paid support staff and hospital staff should work together to achieve the best outcomes for people with learning disabilities. Co-ordinating all those people and processes can be complicated, so we have split suggestions into four steps. The next four sections explain what people from each group can be doing:

- Step 1: what you can do before an admission to hospital

⁶ Some people with learning disabilities have advocates such as peer, family or independent advocates whose role is to help the person to understand and make choices and to speak up.

- Step 2: what you can do when a hospital admission is needed
- Step 3: what you can do during a hospital stay
- Step 4: what you can do when a hospital stay is ending

Further detail is given in a series of appendices:

- Appendix A: where to find further information
- Appendix B: preparing for admission:
 - checklist for admission meetings
 - clear ways of recording the most important up-to-date information about an individual with learning disabilities:

one example of this is the traffic light hospital assessment developed in Gloucestershire as a tool for communicating what hospital staff will need to know about a patient with learning disabilities

in addition you will find a description of a risk, dependency and support assessment. As noted above, this can be used to identify risks and what additional support may be required to address them

- Appendix C: governance. Here you will find the learning disability indicators Monitor uses

Step 1: what you can do before an admission to hospital

Steps for family carers and/or paid support staff to prepare for hospital admissions

Be prepared in advance of any hospital admission. Before you are faced with an emergency, consider the suggestions below. This will make things easier for both planned and unplanned hospital admissions.

Information about the individual

Collect together information about the needs of your family member or the person you are supporting. A lot of this may already be written down in an assessment or a care or support plan, a health action plan, health passport or a person centred plan. Make sure it is kept up to date. You can get help to make a health action plan from your local community learning disability team, who may also be able to help get an annual health check organised.

Use the records, plus any other knowledge you have about the person's previous experiences of ill health, reactions to medication or pain, or other important issues to complete a traffic light hospital assessment or hospital passport. We include a link to an example tool in Appendix B. The traffic light assessment helps everyone understand what it is essential to know, what is important to know about the person, their likes and dislikes and anything else important for their stay in hospital. It should include any signals a person has used to demonstrate consent in the past – for example, offering their arm for blood tests.

The traffic light assessment includes information about who the main contacts should be for the person. This might include which family member to contact first, or which paid support staff. The person may be able to say who they would like to have listed, or you may need to decide this.

Case study: preparing for admission to hospital

The community learning disability nurse visited Miriam at the nursing home prior to her planned admission to hospital. The nurse made sure she understood how Miriam liked to be supported and what her needs were. She started a traffic light assessment document for the ward staff, detailing the important information they needed to know about Miriam. She also provided Miriam with easy read information about going into hospital and visited her on the ward to support her with treatments.

Think about reasonable adjustments – how things could be made easier for the person who needs support. Will they need information about any treatment in an accessible format, do they need help to overcome a fear of needles or to express when they are in pain, would you need to avoid long walks from car parks to where treatment will be given? A health action plan can help you make sure a person's health needs are known about and taken care of. List the sorts of adjustments they may need so you can discuss them with hospital staff. You can see some examples of good practice in this document and more in the database of reasonable adjustments:

www.improvinghealthandlives.org.uk/adjustments.

Case study: pre-admission planning

The Mid Yorkshire Hospitals NHS Trust can arrange a 'person-specific pathway', bringing together the person themselves (if possible), their family or others who know them well, the surgeon, anaesthetist, learning disability liaison nurse and other nurses responsible for different steps (for example, theatre, ward). These people work together to make a step-by-step plan. This might include things that are important to the person, such as:

- first on the theatre list
- no other patients around
- no needles involved
- nobody in uniform
- special objects, clothing, etc. that are important to the person

The plan would also include anything the hospital staff need to do differently. For example, the person might be given a sedative at home and the anaesthetist might meet them in the hospital car park to give them another sedative; then they would only go into the theatre when everything was ready. Great flexibility can be achieved when senior staff are committed to this.

It is helpful to consider what you feel should happen if the person's heart or breathing stops during treatment. If a person does not have the capacity to contribute to the decision themselves, doctors may well ask you early into the admission what your views about this would be and whether or not you think the person should be resuscitated. This is a very emotional and difficult question so it will help everyone if it can be thought about before any admission or medical emergency happens. The doctor will make the final decision, but would take your views into account.

Note that if any 'do not attempt cardiopulmonary resuscitation' (DNACPR) decision is made by a doctor it only relates to the situation for which it was agreed. After this it

should be destroyed and the correct process followed again for any other occasion when a DNACPR decision needs to be made for someone. DNACPR only relates to cardiopulmonary resuscitation, not other kinds of active treatment.

Other information to collect

Find out who there is at your local hospital to help when someone with a learning disability needs to be admitted - this would include the patient advice and liaison service (PALS) at every hospital. Many hospitals now have a learning disability or acute liaison nurse. There is an interactive map to help you locate local acute liaison nurses at www.improvinghealthandlives.org.uk/aln

Find out if they use a traffic light hospital assessment or a similar tool that they could send you.

Paid support staff could identify one person from their team to take a lead on preparing for any hospital admission - ensuring assessments are done, contacting hospitals, and so on.

Get copies of the latest policy on carers from your local hospital(s) so it is clear what support relatives can expect during an individual's admission.

Should you have any concerns about your relative's treatment in hospital, it is worth asking PALS for help. They can also help you to lodge a complaint, if that is required. You can also complain to the clinical commissioning group or NHS England (whichever body is responsible for commissioning the service your relative is using). If you need help to make a complaint, complaints advocacy services are commissioned by your local authority.

List the above contacts now and keep them with the other information you have gathered.

Might additional support be needed in hospital?

Up-to-date traffic light hospital assessments provide information on a person's needs; a risk, dependency and support assessment (see Appendix B) maps out how those needs can be met while the person is in hospital. Become familiar with this type of assessment now so you will be able to use it with the hospital whenever an admission is needed.

Consider how much time you could realistically spend supporting the person in hospital. Are there other relatives, advocates, friends or staff who could be called upon?

You could also make a list of the people who are important to the person, who might want to know if they go into hospital.

You can provide staff at the hospital with some of the useful information about people with learning disabilities listed in Appendix A, or keep copies of booklets you think are especially relevant so they can be lent to hospital staff if an admission is necessary.

Do you know about consent?

You should be aware that under the Mental Capacity Act 2005 (MCA) only certain people can give consent to healthcare procedures such as investigations or treatment. If the individual has capacity to decide for themselves, only they can give consent. If they do not have capacity but have a formal representative (under a lasting power of attorney for personal welfare, or a court-appointed deputy for personal welfare), that representative can give consent. Otherwise the decision-maker (see below) must make a decision in the person's best interests.

It is helpful if the decision on whether the individual has the capacity to consent to this procedure has been made and recorded according to the MCA before the initial admission meeting. It is the responsibility of a clinical decision-maker, usually the doctor in charge of the procedure, to make sure the person's capacity to make a decision about the procedure has been assessed. In making the assessment they should listen to the views of people who know the individual well, because those people will have experience of how the person is supported to make decisions and communicate their views in other aspects of their life. Evidence will need to be recorded of what has been done by the hospital, family carers, advocates and paid support staff:

- to help the individual understand what is proposed
- to enable them to give or refuse consent

If it is decided that the person lacks capacity to make a particular decision (and if there is time, not in an emergency), a best interests process must be followed. This will often take the form of a meeting. Family members, advocates and support staff should be invited to give their views, based on their knowledge of the person, but they do not have responsibility for healthcare decisions. These will be made by the person in charge of the procedure; this person is called the decision-maker.

Best interests decisions need to be formally recorded (see British Psychological Society guidance⁷). If there is no family member to contribute to an important decision, an

⁷ Joyce, T. Best interests: guidance on determining the best interests of adults who lack the capacity to make a decision (or decisions) for themselves [England and Wales]. London: Professional Practice Board of the British Psychological Society; 2007. <http://shop.bps.org.uk/best-interests-guidance-on-adults-who-lack-capacity-to-make-decisions-for-themselves-england-and-wales.html>

independent mental capacity advocate (IMCA) would be required and a referral to them would be made by the decision-maker. If there is any disagreement, again an IMCA would be required.

Relatives and paid staff also have responsibilities, along with clinical staff, to help a person understand about any best interests decisions. Even if the person does not have capacity to make the decision themselves, they may be able to contribute their views.

Everyone needs to agree other arrangements for an admission once any best interests decision has been made and recorded. You can use the checklist in Appendix B.

Paid staff should be aware of their duties under the MCA by reading the MCA Code of Practice and/or the guides available from the Office of the Public Guardian. They should also do what they can to provide family members with accurate, user friendly information. They could do this by signposting relatives to resources such as those listed in Appendix A or - better still - having copies of these available. For more information about the MCA, best interests meetings and use of independent mental capacity advocates see Appendix A.

Steps for hospitals to prepare for the admission of patients with learning disabilities

Flag and monitor patients with learning disabilities so you know how many are admitted, and record how well the admission and any additional support went.

Develop and use your own policies for when a person with learning disabilities is admitted, ensuring these include support for family carers. Make sure policies cover accepting and supporting relatives and paid support staff who are offering to help the patient. Good examples of hospital policies are available from the access to acute care (A2A) network listed in Appendix A.

Arrange to pay for additional support, where required, from those who know individual patients (rather than using agency nurses) and be sure key staff know about the agreed process.

Know what your hospital and/or ward's latest carers policy says and where to find copies for relatives of anyone having hospital treatment.

Identify a member of staff on each ward or department to take a lead on support for people with learning disabilities in their area.

Produce easy to understand information about the hospital and make it available to people coming to the hospital either as an outpatient or inpatient. Local groups of people with learning disabilities may be able to help with the drafting of this information.

Have easy to understand information about different procedures, for example from www.easyhealth.org.uk. Links to more useful resources are given in Appendix A.

Gather resources that can help when a person with learning disabilities is admitted (for example, those given in Appendix A) and ensure that your staff know about them. Decide where they should be kept.

Provide training to staff on learning disabilities; local family carers and people with learning disabilities may be able to help with this.

Train staff on how to use any tool adopted by the hospital for assessing and alerting staff to the support needs of a patient with learning disabilities (such as the Gloucestershire traffic light hospital assessment given in Appendix B).

Case study: be prepared

Dartford and Gravesham NHS Trust introduced a system for the local community learning disability team to complete a hospital passport with a person and email it securely to the hospital safeguarding team and learning disability nurse. It can then be added electronically to the patient information centre records. This means that it can be accessed by any of the hospital staff (including A&E). This system was developed after a woman with learning disabilities commented that the passport was too big for her to carry with her in her handbag.

Make available and provide training on a tool such as a risk, dependency and support assessment (see Appendix B) and ensure that all nursing staff are familiar with it.

Ensure staff are up to date with what the MCA says about informed decision making, consent, best interests meetings and other matters related to capacity. (See 'Do you know about consent?' on page 19 under the steps above for family carers and/or paid staff. You will find more information about this in Appendix A).

Step 2: what you can do when a hospital admission is needed

Steps for family carers and/or paid support staff at or around admission time

As soon as you know someone is going into hospital, make sure that their GP and the member of staff at the hospital who takes a lead on learning disabilities is aware of the admission. This may be the learning disability liaison nurse, acute liaison nurse or someone else. Ideally they will be able to attend an admission meeting. The PALS should also be informed.

The person will need to be supported to understand what to expect - what will happen to them, how they may feel and so on.

A visit to the ward before the admission can be very helpful. You can introduce yourself and the person concerned to staff. You can also find out the titles of senior staff and how to recognise them/their uniforms. You can find out where bathrooms, communal areas, rest areas, car parking, carers' notice boards, 'carers champions', telephones, gardens and other services are in the hospital. You could begin to discuss any reasonable adjustments that will enable the individual to get treatment in an effective way.

For unplanned admissions these suggestions of good practice should happen at the earliest opportunity.

Case study: preparing for investigations

Edana complained of stomach aches and was referred to a hospital specialist. They tried to do a scan, but she was afraid of the machine and would not lie still, so it was abandoned. Edana lost a lot of weight; she was anaemic and very unwell. She was referred to another specialist and this time the learning disability liaison nurse was asked to help support Edana to have the scan she required. The nurse showed Edana and her family some easy read materials about having a scan and took her into the scanner to have a look round, test out the bed and meet the staff. Edana was much more relaxed when she came for the actual scan; the scan was successful and her illness was diagnosed. She required surgery, so a similar process took place to prepare her: she visited the anaesthetic room and the recovery ward, understood why people wore particular clothing and masks and became familiar with what would happen. Edana's surgery and hospital stay were subsequently a positive experience for her and her family.

Giving and receiving information

For planned admissions it is best to contact the learning disability or acute liaison nurse (or the learning disability lead nurse for the ward or department, if there is no learning disability or acute liaison nurse) and ask for a pre-admission meeting.

Case study: adjustments to Choose and Book

The Royal Cornwall Hospitals NHS Trust have a system⁸ for involving the acute liaison nurse when someone with learning disabilities needs to book an appointment or admission. This means the nurse can help with planning any reasonable adjustments that will be needed to make the visit a success. Examples have included:

- first or last appointment, double appointment
- providing quiet waiting areas, minimising waiting time
- arranging pre-admission visits
- considering a side room
- ensuring appropriate equipment is available
- allowing extra time, arranging staff support

This kind of preparation has been shown to be of benefit to the hospital as well as to the person.

For unplanned admissions, arrange for a meeting to take place at the earliest opportunity after admission; where possible the person with learning disabilities should be part of this meeting.

Provide the department at the hospital with the information that you have about the individual, summarised if possible in a way that will be useful to hospital staff. You could use a tool such as the traffic light hospital assessment.

There is a checklist of things to discuss at the meeting in Appendix B. The list includes issues of consent and best interests, covered by the MCA. (You will find more information available about the MCA in 'Do you know about consent?' on page 19 and in Appendix A.) The appendix also includes a resource about how information can be shared, confidentiality and who should be informed of what.

Think about what information **you** would like to get from this meeting. Does the hospital have the equipment and the space needed for hoists, wheelchairs or other equipment that the person needs? What happens about any medication they take? Do you need to find out about any equipment that might be needed on discharge, some of which may

⁸ www.improvinghealthandlives.org.uk/adjustments/index.php?adjustment=249

take a while to arrange - who will organise this and when? If there are unexpected difficulties with medication, appliances or other continuing treatment once the person is back where they live, who should you (as their family carers or support staff) contact for advice if the GP is unable to help? How will any nicotine addiction be managed - will patches be used?

Make a list of your own questions, including your likely needs for accommodation, sustenance, toilets/showers and so on if you are going to spend time at the hospital. Find out about any special parking arrangements; some hospitals run schemes such as free parking for carers. You could use space on the *Checklist for admission meeting* in Appendix B, where you will also find some questions suggested by families to help you. The PALS, which offers confidential advice, support and information to patients and families can help with many of these questions. Call 111 for details of the PALS office you need.

Work with the ward to complete a risk, dependency and support assessment (see Appendix B) in order to agree any additional support that may be required and who is best to provide it.

The decisions following completion of the risk, dependency and support assessment should be shared with anyone else involved with the individual (including the local authority through their care manager where appropriate).

Help others to understand what is likely to happen or how you think the person might respond, especially if you have been with them when they have been in hospital before.

Find out how the ward runs: when are ward rounds (the individual is likely to need support with giving and receiving information, and you may have questions to ask then), as well as meal times, staff handover times and visiting hours?

Steps for hospitals when an admission for a patient with learning disabilities is needed

Host a pre-admission meeting (for planned admissions) with those who know the patient best, using the checklist in Appendix B. Unplanned admissions will require this admission meeting to take place at the earliest opportunity.

Use any assessment information provided by family carers and paid staff to make nursing care as appropriate as possible (for example, how to interpret body language).

Ensure that the ward team are informed and as prepared as possible for the admission.

Case study: real-time automated patient alert (RAPA)

At Derriford Hospital in Plymouth the RAPA sends an automated text or email alert to the community learning disability team and the relevant hospital team when one of their patients with learning disabilities attends A&E, is admitted to hospital, transferred to another ward or discharged. Alerts can also go to GPs and other community health services if they have the same system. The software produces a list of all current inpatients with learning disabilities; through this ward staff and the learning disabilities team can review patients, set 'attributes' (such as reasonable adjustments required) and communicate with each other. Data can be audited (for example, numbers of people who have used a hospital passport, or repeat admissions). The system requires the NHS numbers or hospital numbers of people with learning disabilities to be loaded into it. Benefits to hospitals of this type of system include: the implementation of efficient and effective pathways; improved staff skills, knowledge and attitudes; evidence to inform planning of learning disability liaison nurse capacity, and cost savings⁹.

The ward team should introduce themselves to the patient and their family carers and support staff and explain fully what will happen.

Work with those who know the patient best to fill out a risk, dependency and support assessment (see Appendix B) or similar tool so you can identify and agree what additional support may be required, and who is best to provide it.

Carry out further hospital risk assessments on any areas of likely risk identified in the risk, dependency and support assessment.

The senior member of hospital staff with responsibility for patients with learning disabilities should be informed of the admission and the outcome of the risk, dependency and support assessment in order to authorise and secure any additional funding required. Explain to family members and support staff when to expect a response to a request for funding.

Familiar paid support staff, with the help of families, are usually the best people to provide any additional support required during a hospital stay. The individual is used to them and they know the individual's needs and how the person likes to be supported. Ensure all hospital staff concerned understand this and accept the presence of supporters.

⁹

Case study: additional support in hospital

Hanif lived on his own with two hours' support per day. This support stopped when he was admitted to hospital. He was discharged, then re-admitted after three days. He had not been able to explain his needs or what was 'normal' for him and the support workers who knew him best had not been involved.

Bart's Health NHS Trust have introduced an approach to provision of additional paid support to avoid situations like this. This was developed using the ideas from the original *Working together* document.

Agree practical arrangements such as parking, breaks and refreshments with anyone providing additional support.

Agree that someone who knows the individual and their communication well must be present when ward rounds happen.

Remind staff to prevent groups of students from being present during ward round discussions if this is likely to be unsatisfactory for the patient.

Step 3: what you can do during a hospital stay

Steps for family carers and/or paid support staff during a hospital stay

Provide any support that you have agreed as part of a risk, dependency and support assessment (see Appendix B).

Contribute to any re-assessment of needs as required, using the risk, dependency and support assessment, for example following surgery.

Continue to help the person to understand procedures and progress.

Provide information about how the person is responding to medication/treatment for the nurses' handover meetings, when they pass on information to nurses coming on shift.

Try to make a point of talking to the senior member of staff on duty.

Involve the PALS in any disagreements or concerns that you may have regarding the hospital stay.

Help to identify what additional needs the person may have after their hospital stay.

Inform the person's local authority (where appropriate) of any needs that are likely to be higher after the hospital stay and, if there are changed needs, ask for a re-assessment so that the allocation of any additional funding required upon discharge is available in time. Some people may need to be assessed for eligibility for NHS continuing healthcare funding. You can find more information about this in Appendix A.

Steps for hospitals during a hospital stay for a patient with learning disabilities

Continue to explain procedures, medication, changes in condition or treatment and check that both the patient and any family carers and support staff understand the information and have the opportunity to ask questions.

Include family carers and/or paid support staff in the nursing handover, or at least seek information from them to share at the nursing handover.

Undertake a reassessment of risk, dependency and support needs whenever it is indicated that the patient may require more or less additional support.

If there are any concerns to do with paid support staff who are providing additional support, raise these directly with the paid supporter's employing organisation. Remember that this may be the patient or their family if the person has a personal budget.

Help to identify any increased support needs the patient may have following their hospital stay and explain to relatives and support staff what you are doing to arrange any equipment they are likely to need on discharge.

Ensure any actions suggested by the pre-admission meeting are being undertaken. For example, has a physiotherapy assessment been booked so an exercise programme will be available on discharge?

Step 4: what you can do when a hospital stay is ending

Steps for family carers and/or paid support staff when it's time for the person to leave hospital

Ask for a discharge planning meeting with ward staff and the local authority care manager or hospital social worker.

Continue to request an assessment of changed needs from the person's local authority if required, so that the allocation of any additional funding required upon discharge is available.

Think about what will be needed at home, discuss this with the care manager or social worker, and confirm who will be doing what and when, including how paid staff or family carers are to be involved.

Check again what is happening about any equipment, medication or follow up appointments required.

Find out about hospital transport for the person to get home if needed.

Ask for reports to inform anyone who needs to know (for example, other paid support staff) about any changed needs and what support may be required.

Make sure everyone who needs to know (such as the person's GP) is aware of when the person will be leaving hospital and knows who to contact if there are any concerns after discharge.

Tell the hospital how you think the stay went, what worked well and any improvements that could be made. If possible, this is best done in writing. If it has gone well, write a note of thanks.

Update the person's traffic light assessment with any information you have learnt from their hospital stay.

Steps for hospitals when it's time for the patient with learning disabilities to leave hospital

Organise a formal discharge planning meeting, wherever possible including family carers and any paid support staff.

Remember to check what kind of support the person gets at home: is it 24 hour or short visits? What sort of training do support staff have? Do they or family carers need any specific training related to the person's needs on discharge?

Inform the patient, family carers and paid support staff of any requirements following the patient's hospital stay, such as bed rest or no lifting. This should include any possible side-effects of new medication and should confirm what to do if any complications arise. Remember to do this in time for the information to be passed on to everyone who may need it. Some patients may need support to understand the importance of information like this being shared. Some people may lack capacity to consent to information being shared; it is then the responsibility of the clinical decision maker to make a best interests decision about information sharing to ensure supporters have the information they need to help keep the person healthy and safe.

Remember to check arrangements have been booked for any outstanding specialist assessments that may still be needed, such as occupational therapy, and any follow up appointments.

Inform the community learning disability team that the person will be leaving hospital.

Organise transport if needed.

Invite the patient, their family and paid support staff to give feedback on the hospital experience - what has gone well, what could be improved?

Case study: using data for quality improvement

Salford Royal NHS Foundation Trust are able to 'flag' patients with learning disabilities in the trust's information system. This makes it possible to identify people who are admitted and place a symbol (a butterfly) on the 'patient at a glance' board. It also enables data on usage of hospital services to be audited. For example, it is possible to see how many patients with learning disabilities have attended A&E three times or more, or how many 'did not attend' appointments. Data is used to identify areas for improvement. The trust involves people with learning disabilities and family carers in service improvement through different engagement groups.

Conclusion

As noted at the start, admission to hospital can be confusing and stressful for anyone. This is often worse for people whose cognitive or communication skills make it hard for them to understand new environments. There are many straightforward steps that family members, paid support staff and hospital staff can take to smooth the path and ensure that admission, the hospital stay and discharge are well planned and executed. This guide offers a wealth of practical advice, together with examples of useful tools and a substantial range of links to further information.

Appendix A: where to find further information

Health inequalities and access to healthcare

The IHaL learning disabilities observatory is part of Public Health England. The website offers a wealth of information about: the health of people with learning disabilities, health inequalities and common health problems experienced by people with learning disabilities, and access to healthcare. There is a database of reasonable adjustments (including in hospital) and a range of guides on reasonable adjustments in specific circumstances (such as end of life care). In collaboration with the Royal College of General Practitioners and the Royal College of Psychiatrists, IHaL published an evidence-based commissioning guide on improving the health and wellbeing of people with learning disabilities. All publications available from www.improvinghealthandlives.org.uk

There is a series of reports on problems experienced by people with learning disabilities in hospital. They are listed here in chronological order:

- Mencap (2004) Treat me right! Better healthcare for people with a learning disability www.mencap.org.uk/node/5880
- Disability Rights Commission (2006) Equal treatment: closing the gap: a formal investigation into physical health inequalities experienced by people with learning disabilities and/or mental health problems. Part 1 of the DRC's Formal Investigation disability-studies.leeds.ac.uk/files/library/DRC-Health-FI-main.pdf
- Mencap (2007) Death by indifference. Following up the Treat me right! report www.mencap.org.uk/death-by-indifference
- Sir Jonathan Michael (2008) Healthcare for all: independent inquiry into access to healthcare for people with learning disabilities http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_099255
- Parliamentary and Health Service Ombudsman (2009) Six lives: the provision of public services to people with learning disabilities www.gov.uk/government/publications/six-lives-the-provision-of-public-services-to-people-with-learning-difficulties-2008-to-2009
- Mencap (2012) Death by indifference: 74 deaths and counting. A progress report five years on www.mencap.org.uk/74deaths

The General Medical Council offers a range of practical advice for doctors on providing better care for people with learning disabilities www.gmc-uk.org/learningdisabilities/

Giraud-Saunders A. (2009) Equal access? A practical guide for the NHS: creating a single equality scheme that includes improving access for people with learning disabilities. London: Department of Health
http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_109753

Heslop P, Blair P, Fleming P, Hoghton M, Marriott A and Russ L. Confidential inquiry into premature deaths of people with learning disabilities (CIPOLD). Final report. Bristol: Norah Fry Research Centre, University of Bristol; 2013.

The findings and recommendations from research into the deaths of 247 people with learning disabilities within five primary care trusts in the South West of England between 2010 and 2012. Copies of the report and easy read version, an executive summary and an easy read short summary are downloadable from: www.bris.ac.uk/cipold

Mental capacity, consent and confidentiality

Information about the Mental Capacity Act 2005, including the code of practice and information for different audiences, can be downloaded from:

www.gov.uk/government/collections/mental-capacity-act-making-decisions

Copies of some documents may be available free of charge to family carers from TSO, PO Box 29, Norwich NR3 1GN or requested by calling 0870 600 5522

Hft. Using the Mental Capacity Act: a resource for family and friends of people with learning disabilities. Bristol: Hft; 2010

Guide and series of videos, which can be downloaded from: www.hft.org.uk/Supporting-people/Family-carers/Resources/Using-the-Mental-Capacity-Act

Family carers can request a free copy: send a self-addressed A4 envelope with postage for a large letter weighing 350gms to Hft Family Carer Support Service, 5/6 Brook Office Park, Folly Brook Road, Emersons Green, Bristol BS16 7FL, or call 0117 906 1700

The best interests decisions study was the first large scale national research to find out about professional practices in best interests decisions made under the Mental Capacity Act 2005. The study was led by the Norah Fry Research Centre at Bristol University, in collaboration with the University of Bradford and the Mental Health Foundation. Report downloadable from www.mentalhealth.org.uk/publications/bids-report

'Deciding right' is a north-east initiative to integrate the principles of making advance care decisions for all ages. It brings together advance care planning, the Mental Capacity Act, cardiopulmonary resuscitation decisions and emergency healthcare plans. Key documents are downloadable from the Northern England Strategic Clinical Networks website www.nescn.nhs.uk/deciding-right

NHS (2012) Your guide to decisions about cardiopulmonary resuscitation (CPR): when's the right time to think about it, talk about it and write it down?

This is a patient information leaflet from the NHS about 'do not attempt CPR' decisions, to help people have conversations about this with health and social care staff:

http://dyingmatters.org/sites/default/files/DNACPR%20Patient%20leaflet_A4.pdf

British Medical Association, Resuscitation Council (UK) and Royal College of Nursing (2014) Decisions relating to cardiopulmonary resuscitation

Comprehensive updated guidance for health professionals. Downloadable from:

www.resus.org.uk/pages/dnacpr.htm

Northumberland, Tyne and Wear NHS Foundation Trust. Commonsense confidentiality: a guide for carers, family and friends. Newcastle-upon-Tyne: Patient Information Centre, Northumberland, Tyne and Wear NHS Foundation Trust; 2012.

The leaflet provides advice and guidance on the sharing of information between staff and carers, family and friends of patients. Downloadable from:

www.ntw.nhs.uk/pic/leaflet.php (type 'commonsense' into the search box).

Accessible information

The website 'A picture of health' helps clinicians to offer easy read information to people with learning disabilities: www.apictureofhealth.southwest.nhs.uk

Beyond Words produces books, eBooks and other resources for people who find it easier to understand pictures than words. 'Books beyond words' use pictures to tell stories that engage and empower people, on themes such as love and relationships, health, death and dying, and crime. They are also a tool for professionals to use with people in many different teaching and counselling situations. For further information:

www.booksbeyondwords.co.uk

Easyhealth (part of the voluntary organisation Generate) produce a range of accessible information to help people with learning disabilities understand health issues and prepare for health appointments and medical procedures. The website also lists resources produced by other organisations, such as NHS trusts:

www.easyhealth.org.uk

Involving family carers

Carers Trust. The triangle of care - carers included: a guide to best practice in mental health care in England. London: Carers Trust; 2013.

The triangle of care guide was a joint piece of work between Carers Trust and the National Mental Health Development Unit, emphasising the need for better local strategic involvement of carers and families in the care planning and treatment of people with mental ill-health. Downloadable from:

<https://professionals.carers.org/working-mental-health-carers/triangle-care-mental-health>

Inclusion North and NHS North East. Model family/carer involvement and advocacy policy. Leeds: Inclusion North; 2013.

Model policy for adoption by local organisations. Downloadable from:

<http://inclusionnorth.org/projects/what-we-are-doing-now/advocacy-project>

Other relevant resources and networks

A2A (access to acute care) network offers a library of resources in addition to networking: <http://a2anetwork.co.uk>

For example, Imperial College Healthcare NHS Trust produced good practice guidelines on supporting patients with learning disabilities, using the 'essence of care' benchmarks.

The A2A East of England network produced a film to highlight five core reasonable adjustments that can be made to help support people with learning disabilities and autism when accessing acute hospital services:

www.youtube.com/watch?v=umNftsB3_nU&feature=share

Dying Matters is a coalition (set up by the National Council for Palliative Care) that aims to change public knowledge, attitudes and behaviours towards dying, death and bereavement. Their website has an excellent film and resources for and about people with learning disabilities: www.dyingmatters.org/page/people-learning-disabilities as well as good information for carers: www.dyingmatters.org/page/carers-information-public and resources on planning ahead: www.dyingmatters.org/page/planning-ahead

Foundation for People with Learning Disabilities hosts the UK Health and Learning Disability Network (electronic forum with weekly bulletin):

<http://learningdisabilities.org.uk/help-information/uk-health-learning-disability-network>

NHS continuing healthcare is a strand of funding for people with complex, unpredictable health needs. All the government guidance (including an easy read guide) is available from: www.gov.uk/government/publications/national-framework-for-nhs-continuing-healthcare-and-nhs-funded-nursing-care

A guide for family carers of people with learning disabilities is available from: www.learningdisabilities.org.uk/publications/continuing-healthcare

The universities of London and Hertfordshire offer a range of learning resources for health students and professionals through this website: www.intellectualdisability.info

Appendix B: preparing for admission

This appendix contains:

- a checklist for an admission meeting
- information about assessment tools that can be used to summarise the most important information for hospital staff to know about a person with learning disabilities
- information about tools that can be used to assess risks and any additional support that may be required to mitigate them

Checklist for admission meeting

The purpose of an admission or pre-admission meeting is to agree all of the arrangements for admission. To achieve this the agenda for the meeting will probably need to include:

Introductions and clarifying **roles**.

Consent: before this meeting it is helpful if the decision has been made and recorded on whether the individual has the capacity to consent to this procedure, according to the MCA. If not, see Appendix A and 'Do you know about consent?' (page 19) and establish who will undertake the necessary work.

Confidentiality: record how information will be shared and with whom. Record key people who will need to be consulted throughout the process, along with their contact details. See resource on *Commonsense confidentiality* in Appendix A.

Key contacts within the hospital: identify and record.

Recorded information provided by the person themselves, their family and/or paid support staff - and including any assessments, care plans and traffic light assessment - should be shared. Specific points to consider might include:

- communication aids or communication patterns should be explained to hospital staff so they become aware of the ways the patient expresses themselves
- the person's likely reactions to the hospital environment and procedures - might restraint be necessary? If so, how is this best delivered?
- any reasonable adjustments required to make the service as accessible and effective as they would be for a person without their disabilities

The current medical need: share and discuss:

- the presenting medical need, including investigations or treatment required and how will this be carried out
- expected outcome and possible areas of risk
- whether or not the patient should be resuscitated if a cardiac arrest occurs and breathing stops

Information and support needs of relatives and paid support staff involved with the individual's hospital stay (see list of possible questions below).

What additional support may be required to ensure the best outcome is reached. A risk, dependency and support assessment (see information in this appendix) should be completed and signed with all present.

Further tasks, such as ward based and risk assessments, along with practical arrangements of who will take what actions: to be listed.

Likely timing of other multi-agency meetings, such as discharge meeting.

Note for family carers and/or paid support staff

Below we give a list of possible questions suggested by family members. Mark those you would like to ask at the hospital meeting and add your own.

Are drinks offered to relatives/non hospital staff when they are beside patients, or should they take their own refreshments?

Should you take special cups, spoons and so on with you or does the ward always have them?

Will relatives and members of support staff need to be provided with passes to leave and enter the ward during the night?

If the person needs incontinence pads (perhaps temporarily because of the treatment), will the correct type be available?

Does the hospital provide accommodation for family carers/support workers providing additional support? If not, will a mattress be available or a comfortable chair for night support?

What and where are bathroom facilities for family carers/support workers?

Specialist equipment needs, such as hoists, accessible baths and so on - does the hospital have them and where?

Will drinks be provided during the night?

How will I as family carer or paid support staff get necessary breaks in **my** support role?

Travel practicalities - bus, car, taxi, parking, costs and so on

Now add your own questions:

The traffic light hospital assessment

This assessment tool was developed by Gloucestershire Primary Care Trust in partnership with the 2gether Foundation NHS Trust and the Gloucestershire Hospitals NHS Foundation Trust. It is designed to give hospital staff important information about the person, under the following headings:

- red (alert): things you must know about me (includes vital information such as medical conditions, current medication, how to approach basic interventions such as taking blood pressure)
- amber: things that are really important to me (includes issues such as communication, personal care, swallowing)
- green: likes and dislikes (for example, food preferences, touch, important routines)

It is suggested that the information should be completed before a hospital visit and should accompany the person. During an inpatient stay it could hang on the end of the bed.

You can find a copy of the assessment form on the IHaL website:

www.improvinghealthandlives.org.uk/adjustments/?adjustment=332

Other tools are available on the same website from other areas (for example, from trusts in Salford and Humber):

- Salford: www.improvinghealthandlives.org.uk/adjustments/?adjustment=336
- Humber: www.improvinghealthandlives.org.uk/adjustments/?adjustment=334

Risk, dependency and support assessment for patients with learning disabilities

A risk, dependency and support assessment was designed by the original working group to follow on from a record such as the traffic light hospital assessment. This concept has been developed and is now in use in a number of areas (see below for links).

A risk, dependency and support assessment identifies risks (both physical risks and risks to the effective outcome of the hospital stay) and what additional support may be required to address them, offering a framework to help negotiate for any additional support to reduce risk and identifying who is best able to provide that support. This gives the hospital clear evidence of where further funding is required. It is recommended that the risk, dependency and support assessment is used by the nurse in charge of the ward alongside the patient and those who know the patient best (such as paid support staff/family members/advocates).

The assessment is designed to be completed at the earliest opportunity for any patient with learning disabilities being admitted to hospital so that likely areas of vulnerability and risk can be effectively identified and appropriate responses made.

You can find an example of an assessment tools on the IHAL website:

- London A2A network:
www.improvinghealthandlives.org.uk/adjustments/?adjustment=333

Appendix C: governance

Monitor's compliance framework sets out the following governance indicators for NHS foundation trusts:

- there is 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 their needs. There is readily available and comprehensible information for patients with learning disabilities about treatment options, complaints procedures and appointments
- protocols are in place to provide suitable support to family carers
- protocols are in place to routinely include training on providing healthcare to patients with learning disabilities for all staff
- protocols are in place to encourage representation of people with learning disabilities and their family carers
- protocols are in place to regularly audit practices for patients with learning disabilities and to demonstrate the findings in routine public reports