Reasonable Adjustments for People with Learning Disabilities – Implications and Actions for Commissioners and Providers of Healthcare

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Sue Turner and Carol Robinson
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Reasonable Adjustments for People with Learning Disabilities – Implications and Actions for Commissioners and Providers of Healthcare

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Executive summary

This paper focuses on the issues facing people with learning disabilities in accessing healthcare, and provides guidance on what reasonable adjustments should be made to ensure equity of access. It draws on the research findings reported in ‘Reasonable adjustments for people with learning disabilities in England: A National Survey of NHS Trusts’ by Hatton, Roberts and Baines (2011).

i. Accessible information

Issue
People with learning disabilities often have difficulties understanding information about health care and may require it to be provided in a range of accessible formats.

Commissioner/provider action
Organisations need a policy or strategy regarding the provision of easy read information across the Trust or service, which includes methods of making accessible information easily available for staff to use, and a way of rectifying any gaps in information. Services should check that people with learning disabilities and family carers receive and use the information they need, and ensure the information is provided in a range of formats.

ii. Working in Partnership with Families

Issue
People with learning disabilities can find accessing services difficult and stressful. Family carers are generally well placed to support their relative, and can be an excellent source of information about the individual. However this expertise is not always acknowledged and family carers don’t always get the support and help they need.

Commissioner/provider action
It is important to plan with the person with learning disabilities and family carer before admission to hospital to maximise the chance of a good outcome. Once in hospital, family carers can be a valuable source of information about the individual and should be involved appropriately in care decisions as long as the individual consents. Having a policy on the support available to family carers and the reasonable adjustments that need to be in place to take their needs into account is important, as is a protocol on the provision of extra personal care.
III. Consent, capacity and advocacy

Issue
Evidence on the implementation of the Mental Capacity Act is patchy, and yet it is crucial that staff understand and comply with the law regarding capacity, consent and best interest decision making.

Commissioner/provider action
Policies on the Mental Capacity Act and Deprivation of Liberty should be readily available to staff, including information detailing when best interest assessments are required. Policies can be reinforced with training and an audit of treatment decisions can identify the need for further action. It is also helpful for the Trust Board to have information on the use of Independent Mental Capacity Advocates and the Independent Complaints Advocacy Service by people with learning disabilities. People with learning disabilities and family carers should be aware of their rights under the Mental Capacity Act, and need accessible information about this.

IV. Service delivery

a. Making and attending an appointment

Issue
People with learning disabilities often need reasonable adjustments made so that they can get the best out of their GP or hospital appointment.

Commissioner/provider action
Record systems should identify people with a learning disability and any reasonable adjustments they require. Reasonable adjustments can include easy read appointment letters and reminder phone calls or texts, appointments at specific times and/or longer appointments and regular health checks. Providers can conduct an audit of appointments to ensure reasonable adjustments are being implemented. Staff can be encouraged to ask if the individual has a health action plan so that this can be updated appropriately.

b. Receiving a service

Issue
It can be more difficult to diagnose people with learning disabilities and there are risks that signs and symptoms are ascribed to the person’s learning disability rather than a physical cause. Treatment can also be less effective if good planning regarding reasonable adjustments does not take place beforehand. It is important to guard against unspoken assumptions about
the current and future quality of life of the individual when making decisions about the risks and benefits of specific treatments.

**Commissioner/provider action**
Staff should use the person’s health passport or hospital book to help plan good care, and if this is not available, should get as much information as possible from people who know the individual well. Information should include how the person indicates pain and distress so staff can respond appropriately and a risk assessment should be completed on admission. There is guidance on good practice regarding people with learning disabilities and dysphagia which should be followed. An audit of incident reports involving people with learning disabilities can be used to improve service provision.

c. **Discharge arrangements**

**Issue**
Without proper regard for the patient’s home environment and support arrangements, the best outcomes from treatment will not be achieved.

**Commissioner/provider action**
Discharge planning needs to begin early and may require careful organisation, particularly if the person has complex needs, or their needs have changed. Health passports may need updating and information about reasonable adjustments should accompany onward referrals.

People with learning disabilities should be identifiable in readmission data to ensure they are not being discharged early.

v. **Monitoring and reporting mechanisms**

**Issue**
People with learning disabilities are not always identifiable in health data, so it can be difficult to know what health care they are receiving and whether it is effective.

**Commissioner/provider action**
In primary care, agree clinical codes with other local services to improve consistency of recording, and in acute care use the appropriate F7 code. Use the information gathered to check uptake of different health programmes and inform the JSNA. Sharing information with people with learning disabilities and family carers can support their meaningful involvement in service planning and evaluation.
A flagging system enables reasonable adjustments required by the individual to be shared appropriately, and use of health passports, health action plans or similar should be encouraged.

vi. Patient and public involvement

Issue
It is difficult for people with learning disabilities and their families to influence policy and practice in healthcare systems as they are not visible within it, and because involvement mechanisms such as surveys and focus groups are not accessible to people with learning disabilities. In addition, complaints procedures are often lengthy and difficult to understand, and people may be afraid of complaining as they are reliant on the care provided.

Commissioner/provider action
Service evaluations and reviews need to be accessible for people with learning disabilities to take part, and the views of people with learning disabilities and family carers need to be identifiable within feedback so service issues can be rectified. Research and Development units could audit service evaluations and research projects to ensure that people with learning disabilities are included.

Complaints procedures and Patient Advice and Liaison Services need to be accessible to people with learning disabilities and emerging Health Watch organisations need to understand the issues people with learning disabilities face. Involving people with learning disabilities and family carers in training is a very effective way of raising awareness.

A responsible senior executive can make sure issues for people with learning disabilities are appropriately raised at board level, and ensure the Single Equality Scheme includes reasonable adjustments for people with learning disabilities. Foundation Trusts can encourage people with learning disabilities and family carers to become involved as voters and potential governors.

vii. Employment of people with learning disabilities

Issue
Employment levels for people with learning disabilities are very low, but many want to work and make good employees given the right opportunities and support.

Commissioner/provider action
Recruitment practices should be in line with national good practice regarding the employment of people with learning disabilities, including an accessible application process, working interviews or time limited work trials and job carving. People with learning disabilities...
employed by the service should have the same opportunities for training and development as everyone else.

viii. Equality Impact Assessments

Issue
Equality Impact Assessments do not always address the needs of people with learning disabilities regarding issues like support with communication, emotional distress or help to understand information.

Commissioner/provider action
Ensure that equality impact screening and assessments are planned and carried out by people with a range of needs including people with learning disabilities.
Introduction

Improving Health and Lives (IHaL) includes the Learning Disabilities Public Health Observatory - www.improvinghealthandlives.org.uk – a three year project funded by the Department of Health in response to Sir Jonathan Michael’s 2008 inquiry into access to healthcare for people with learning disabilities. The national observatory aims to provide better, easier to understand information on the health and wellbeing of people with learning disabilities and to help commissioners make use of existing information whilst working towards improving the quality and relevance of data in the future. This paper is the third in a series which aims to translate the key messages from research into advice for commissioners and providers. It focuses on the issues facing people with learning disabilities in accessing healthcare and what reasonable adjustments should be made to ensure equity of access and to comply with legal requirements. It therefore has more of a focus on provider functions than other papers but will be of relevance to a wide range of people who have an interest in the welfare of people with learning disabilities and other significantly disadvantaged groups of people. This paper draws on the research findings reported in ‘Reasonable adjustments for people with learning disabilities in England: A National Survey of NHS Trusts’ by Hatton, Roberts and Baines (2011). There was a 30% response rate to the survey which covered three broad types of health trust: acute, specialist mental health and learning disability and primary care. Therefore this paper considers reasonable adjustments in a number of healthcare settings. However, some sections of the paper will be more relevant to hospital settings than other services. All papers from the IHAL project can be downloaded from: http://www.improvinghealthandlives.org.uk/uploads/

Key actions that all NHS Trusts and health services need to consider are:

1. Ensure that people with learning disabilities are easily identified in records systems.
2. Foster a culture in which everyone understands reasonable adjustments and how they can help everyone when applied in a timely and appropriate manner.
3. Have a policy on accessible information and review coverage and use on a regular basis.
4. Promote the involvement of family carers in the healthcare of people with learning disabilities.
5. Continuously monitor how well the Mental Capacity Act is being implemented.
6. Develop clear and widely used protocols for service delivery and where applicable, discharge arrangements that take account of the additional support needs of people with learning disabilities.
7. Ensure that people with learning disabilities and their family carers can influence what happens within the organisation at all levels.
1. What are reasonable adjustments?

The Disability Discrimination Act 1995 \(^3\) required public bodies to make reasonable adjustments to their premises, policies and services. All staff need to take steps to ensure that people with learning disabilities are treated equitably. Under the Disability Discrimination Act 2005 \(^4\), public bodies were required to produce a disability Equality Scheme and under the Equality Act 2010 \(^5\) to produce a single Equality Scheme. These documents should state what adjustments will be made to policies and practice in order to provide fair access and treatment to people with learning disabilities and other disadvantaged groups.

This Evidence into practice report provides guidance on what types of reasonable adjustments are likely to be needed and how far NHS Trusts have gone to provide them. Readers should also be aware of the Mencap 'Getting it Right' campaign which was developed with health care professionals and the Royal Colleges \(^6\). The charter sets out nine key activities for healthcare professionals to help ensure equal access to health. Health care organisations can sign up to the charter and many have already done so. For further information please go to: [www.mencap.org.uk](http://www.mencap.org.uk)

The document includes fewer good practice examples than previous *Evidence into Practice* papers because there is now a database of reasonable adjustments that Trusts have made on the IHaL website. The database can be accessed at: [www.ihal.org.uk/adjustments/](http://www.ihal.org.uk/adjustments/)
2. Accessible Information

Issue
People with learning disabilities often have difficulty understanding information about healthcare and may require it to be provided in a range of easy to understand formats. While the survey found that a majority of Trusts who responded provide some easy read information especially in relation to their services, this was not commonly available in a range of formats such as audio or DVD. A number of Trusts said that information was available on their website (40%) or intranet (18%); that information was available on request (25%), or personalised (20%). Therefore it was not always clear that easy read information was routinely provided. The role of specialist learning disability nurses/teams was frequently mentioned in relation to the provision of easy read information.

Commissioner/provider action

- Organisations should develop a culture in which the provision of accessible information in a range of formats is part of common practice, as this will be of benefit to a wide range of vulnerable groups including people with learning disabilities. Therefore it is helpful if providers have systematic mechanisms in place to provide accessible information and a communication policy or strategy on the production and availability of accessible communication tools, and the use of plain jargon free language.

- In order to make accessible information easily available to staff, the Trust website could have links to websites such as Easy Health: http://www.easyhealth.org.uk/ and a Picture of Health: http://www.apictureofhealth.southwest.nhs.uk/, and include other accessible information and resources used within the Trust such as Patient Passports.

- Accessible information should be available at all stages of the patient pathway and throughout the Trust or service. Providers can carry out an audit of the information currently available in the service and identify where there are gaps in terms of content (health services, health promotion, specific conditions and treatment, patient rights and how to complain). In addition, providers should ensure that information is available in a range of formats.
In order to rectify any gaps in information, providers can establish a working group with responsibility for ensuring that information exists on all aspects of healthcare in the area. This group should include people with learning disabilities and family carers.

Health services should regularly check whether people with learning disabilities and their families have received the information they need, identify any shortfalls in the way information was imparted and feed back the findings to staff, both in writing and through discussion.

People with learning disabilities have a wide range of communication needs. Therefore staff need the skills or support to take an individualised approach to communicating with patients and make adaptations as necessary. In order to do this, staff will need to understand about alternative communication techniques and tools and know whom they should contact if they cannot communicate effectively. Specialist learning disability nurses had a key role to play in the production and provision of accessible information in those Trusts that responded to the survey. Therefore commissioners of services who do not have these posts should consider commissioning liaison nurses to support mainstream health staff in this task.

For example
In Cornwall, the CHAMPS team (self-advocates who are employed by the Trust and work in health promotion), attend the Royal Cornwall Hospital Trust monthly to consult on practice developments like easy read information and signage. Easy read information is also sent to local People First groups for further consultation.

In summary
- Have a policy or strategy about accessible information.
- Put links on the Trust website to other accessible websites and resources.
- Audit the information currently available.
- Have a working group including people with learning disabilities and family carers to rectify any gaps in information.
- Monitor the availability and use of accessible information.
- Provide staff with the appropriate skills and support to take an individualised approach to communicating with individuals.
- Commission liaison nurses or equivalent support if this is not already in place.
3. Working in partnership with families

**Issue**
Using health services can be frightening and stressful for anyone, and can be particularly so for people with learning disabilities who may not understand what is happening or why they are there. Family carers are generally well placed to both support people with learning disabilities and to provide information about the person in terms of their lifestyle, diet and personal needs. In addition, they often have real expertise about the person’s condition, past and ongoing treatment and factors that should be considered when making decisions about future care. This expertise is not always acknowledged, which can pose serious health risks. Therefore it is important to make sure that family carers are welcomed and treated as allies rather than made to feel marginalised or ignored. They should be given the information and support they need.

Although the survey findings show that a majority of Trusts (69%) had information for family carers either on site or to take away (75%), it was unclear if this was made routinely available. Other reasonable adjustments for carers were mentioned by a small minority of Trusts. These included:

- Having a carers policy (10%)
- Involving carers in planning (13%)
- Involving them in key meetings (6%)
- Altering opening hours (9%)
- Having facilities for carers to stay (11%)
- Changing appointment times (4%)
- Having access to learning disability liaison staff (9%)

**Commissioner/provider action**

- In order to have the best possible chance of a positive outcome for the person with learning disabilities while in hospital, people with learning disabilities and family carers need to be involved from the pre-admission stage onwards, to plan the person’s stay in hospital. There should be a comprehensive pre-admission information pack for carers readily available from the hospital, and a named contact person in the department to which the individual is being admitted.

- Family carers of people with a learning disability often spend a considerable amount of time at the hospital while their relative is being treated, sometimes staying at night.
Therefore Trusts should have a policy which details the support available to carers including facilities for washing, eating, sleeping and parking, as well as the information which should be made available to them.

- Family carers and care staff have sometimes been expected to provide unreasonable amounts of personal care to the person with learning disabilities while they are in hospital. Therefore it is important that clear protocols on the provision of extra personal care, and clear boundaries between the carer supporting role and the responsibilities of nursing, medical and allied professionals are in place.

- Family carers have valuable information about the individual and their care needs. Therefore Trust/service policy should state that where possible, carers are involved in care decisions provided that the person with learning disabilities consents to their involvement, and carers should be involved in best interest decision making if the person lacks capacity. Where possible, family carers should be included in key meetings such as case conferences and ward rounds.

- Family carers often have to make complicated arrangements to support their relative while in hospital and reasonable adjustments should be made to take their needs into account. This could include consideration of appointment times, travel arrangements, information and their health and ability to continue caring (based on their legal right to a Carers Assessment).

For example

HFT, a provider organisation, worked with family carers, health and social care staff to develop a guide for hospitals, families and paid staff called *Working Together: easy steps to improving how people with learning disability are supported when in hospital*.

The guide sets out the actions that family carers, paid support staff and hospital staff can take to achieve the best outcomes for people with learning disabilities at different stages of the admission and discharge process: before admission, at or during admission, during a stay in hospital and on discharge. At the back of the booklet, there is a *Checklist for an admission meeting*, plus links to other sources of useful information, as well as the *Traffic Light Hospital Assessment* and the *Risk, Dependency and Support Assessment* forms.

The guide can be downloaded from: [http://www.hft.org.uk/p/4/121/working_together.html](http://www.hft.org.uk/p/4/121/working_together.html)
In summary

- Involve family carers from pre-admission onwards.
- Have a comprehensive carers’ policy.
- Have clear protocols on the provision of extra care.
- Involve family carers in care decisions as appropriate.
- Ensure appropriate support and facilities are in place for family carers.
4. Consent, capacity and advocacy

Issue
The survey findings show that almost all Trusts who responded (96%) have a policy regarding mental capacity. They provide staff training around communicating with people with learning disabilities (91%) as well as on how to support patients who are non-verbal (99%). However Trusts relied heavily on specialist learning disability staff to give support to clinicians when a patient was non-verbal, and we were unable to tell from the survey how many staff had been trained. Information about use of Independent Mental Capacity Advocates and the Independent Complaints Advocacy Service by people with learning disabilities was also patchy. The poor provision of independent advocacy for people with learning disabilities was raised in the Six Lives progress report.  

The Six Lives progress report also received worrying evidence of failure to comply with the Mental Capacity Act including examples of Do Not Resuscitate orders being placed on patients' records without discussion with the individual or family, and family carers being asked to sign consent forms for adults. Following this report the NHS Operating Framework 2010/11 suggests:

‘particular emphasis should be given to ensuring staff are trained to make reasonable adjustments, communicate effectively and follow the Mental Capacity Act (2005) Code of Practice in all their interactions with patients with learning disabilities to ensure full compliance with the law in respect of capacity, consent and best interest decision making’ (p.41).

Commissioner/provider action
- In order to ensure that the Trust or health service and its staff understand their responsibilities under the Mental Capacity Act, there should be policies on the Mental Capacity Act and Deprivation of Liberty which are readily available to NHS staff.

- To raise awareness of these policies, regular training on both policies as well as training at induction is important. Health services can check on the number of staff who have received this training and ensure there is wide coverage. Agency staff also need to be aware of the Act and understand their responsibilities in relation to it.

- Staff can be better supported to carry out their duties under the Act by making sure there is a Mental Capacity Act protocol in place in all departments which includes details of when best interest assessments are required.
• In order to check that the protocol is being followed, there could be an annual audit of how treatment decisions are reached within the Trust or service for all people with a learning disability. The audit should include details of the way in which family carers have been involved in the decision making.

• In order to determine the use of Independent Mental Capacity Advocates (IMCAs) and the Independent Complaints Advocacy Service (ICAS) by people with learning disabilities, the Trust Board can require a report on an annual basis from these bodies, detailing this information.

• People with learning disabilities, family carers and paid supporters should be aware of their rights under the Mental Capacity Act, and should receive accessible information about this as a matter of course.

**In summary**

- Have a policy on the Mental Capacity Act and Deprivation of Liberty which is widely advertised and discussed with staff.

- Check that staff have been trained on how to implement these policies.

- Ensure there is a protocol in place which details when best interest decisions are required.

- Do an annual audit of best interest treatment decisions for people with learning disabilities.

- Ensure the Board receives reports from the IMCA and ICAS service regarding use by people with learning disabilities.

- Provide information for people with learning disabilities and family carers regarding their rights under the Mental Capacity Act.
5. Service delivery
   a) Making and attending an appointment

Issue
People with learning disabilities may have difficulty understanding the need for a medical appointment, have difficulty understanding the information given about the timing and location, and may be fearful of some tests, equipment or unfamiliar environments. Therefore, there are a number of reasonable adjustments that someone with learning disabilities might need to get the best out of a GP or hospital appointment. Although many reasonable adjustments may need to be individually tailored, there are several reasonable adjustments that should benefit most people with learning disabilities and other vulnerable groups. However, the most popular reasonable adjustment in this area, providing first, last or longer appointment times was only mentioned by 22% of Trusts.

Commissioner/provider action
- In order to identify who needs reasonable adjustments and to alert staff to any specific needs a person may have, record systems should identify people with a learning disability in both primary and acute care. Records should also detail any reasonable adjustments that are known to be helpful to the individual.
- Many people with learning disabilities may find it hard to use the telephone (particularly push-button menus) and find standard letters hard to understand, so Trusts and health services need to ensure that reasonable adjustments such as easy read appointment letters/information and a reminder phone call or text are in place to facilitate the person’s attendance at their appointment.
- People with learning disabilities can find it hard to wait for appointments and can find busy waiting rooms difficult to cope with. Appointments may also need to be longer because people with learning disabilities can find it difficult to tell people what their symptoms are and may be nervous of clinicians. Therefore longer appointment times held at the beginning of surgery or during quiet times should be considered.
- People with learning disabilities are less likely to proactively seek help to address health issues, and research indicates that health checks lead to the detection of potentially treatable conditions and targeted actions to deal with them. Therefore GPs should offer comprehensive health checks on an annual basis. For further information please see Health Checks for People with Learning Disabilities: Implications and actions for commissioners.
For example
In Gloucestershire, the 2gether Trust has developed a Reasonable Adjustment monitoring tool to help facilitate improved access to all types of mainstream service for people with learning disabilities. The tool can be utilised in a range of settings and provides a simple record of the work carried out by learning disability workers to facilitate access to mainstream services along with a record of the outcome. The tool is applicable to approaches based around an individual or to approaches based on influencing wider systems. The tool is part of the database of reasonable adjustments available on the IHaL website: www.ihal.org.uk/adjustments/

In order to check that reasonable adjustments are in place, providers could conduct an audit of appointments involving people with learning disabilities to see what adjustments were offered and made and, in consultation with local self-advocates, create a checklist of reminders that can inform the flagging system.

People with learning disabilities should be supported to understand their health needs and take ownership of their own health. Therefore staff should be encouraged to ask if the person has a health action plan, prior to appointment or admission so that this can be updated appropriately with the individual.

In summary
- Have a flagging system which includes details of reasonable adjustments required.
- Ensure that appointment systems are accessible.
- Ensure that reasonable adjustments are put in place regarding appointment times and length.
- Ensure that there is a system in place to offer annual health checks.
- Do an audit of reasonable adjustments that are in place.
- Ensure that staff provide support to people with learning disabilities so they use their Health Action Plan.
b) Receiving a service

Issues
People with learning disabilities die younger than the general population and face avoidable health inequalities that health services have a duty to address. The domain in the proposed Outcomes Framework for the NHS on ‘Preventing people from dying prematurely’ is therefore particularly relevant to people with learning disabilities. However, good treatment can be less effective if proper planning around reasonable adjustments does not take place beforehand. This is important for all people with learning disabilities, but people with profound intellectual and multiple disabilities have complicated and ongoing health needs and may require particular consideration. Arriving at a diagnosis can prove difficult in people with learning disabilities if they cannot describe signs and symptoms easily. Moreover, there is a risk that signs and symptoms that are observed are ascribed to the person’s learning disabilities rather than a physical cause. With regard to treatment, delays may occur if the person is unable to follow pre-operative instructions or is too distressed to co-operate.

It is also important to be aware that decisions about the risks and benefits of proceeding with specific treatments may be affected by spoken or unspoken assumptions about the current or future quality of life of an individual, and to guard against this.

Commissioner/provider action

- In order to ensure that support and treatment is tailored to the individual’s needs, staff should ask about the person’s health passport or hospital book which includes information about communication and care needs, and should cover any potential hazards, such as a risk of choking, known allergies and epilepsy. If this is not available, staff need to ask for as much information as possible from people who know the patient well, to gain a good picture of how current signs and symptoms compare with normal behaviour patterns.

- People with learning disabilities may not express discomfort or pain in a way that health staff understand or recognise, therefore information about the individual should include details of how the person communicates pain and distress, and staff need to be trained to use this information and react appropriately.

- Patient food request cards should be available in an accessible format, and safe swallow guidance should be followed for people with learning disabilities who have dysphagia. The National Patient Safety Agency has produced a guide called ‘Ensuring Safer Practice for adults with learning disabilities who have dysphagia’ 14. The guide can be downloaded at: http://www.nrls.npsa.nhs.uk/resources/?entryid45=59823
In order to ensure that people with learning disabilities are safe while in hospital, a risk assessment of individual need should be carried out on admission, and include information from family carers. The care plan should reflect any issues identified.

To facilitate organisational learning and improve support to people with learning disabilities, incident reporting systems need to allow for the identification of incidents involving people with learning disabilities including safeguarding alerts. Incidents can then be analysed, and learning from them used to improve service provision.

For example

NHS London has produced a toolkit for benchmarking NHS funded services approach to vulnerable people including people with learning disabilities. The toolkit consists of a number of benchmark statements and indicators of good practice which Trusts can rate themselves against and includes sections on safety and reasonable adjustments. The toolkit can be downloaded from: http://www.london.nhs.uk/what-we-do/improving-your-services/better-quality-services/learning-disability-secure-section

In summary

- Support staff to use Hospital Passports or similar where these are in place.
- Ensure staff know how individuals express pain and discomfort and act accordingly.
- Use good practice guidance on dysphagia and ensure there is accessible information about food choices.
- Carry out a risk assessment for all people with learning disabilities admitted to hospital.
- Identify, analyse and learn from incidents involving people with learning disabilities.
c) Discharge arrangements

Issue
Without proper regard for the patient’s home environment and support arrangements, the best outcomes from treatment will not be achieved. If assumptions are made about the level of help available, a person may not have sufficient support to adhere to the recommended treatment plan. However, the survey findings suggest that only a minority of Trusts are making reasonable adjustments around discharge and follow up.

Commissioner/provider action

- In order to ensure a smooth discharge, consideration of what will happen once a person is discharged needs to begin early; either immediately after admission or ideally, beforehand if the admission is planned. Any discharge planning should be based on the patient’s person centred plan and relevant factors in the home environment including any risk factors.

- Because some people have complex needs and support arrangements, discharge planning can require careful organisation, particularly if the person’s needs have changed. Therefore it helps if the acute liaison nurse, community learning disability staff team and family carer are involved in the discharge planning.

- If a person’s needs have changed but they find new environments distressing, consider whether it is more cost effective to provide extra support in the person’s home rather than transfer to an intermediate care setting. Use best interest decision making if the person is unable to give consent. Discharge should not be delayed because of funding disputes or other non-clinical reasons.

- In order to ensure information is up to date, health passports should be updated before the person is discharged, and any onward referrals should be accompanied by information on the nature of reasonable adjustments that need to be made in relation to the patient.

- In order to ensure there is appropriate post-discharge support, follow-up appointments should be clearly communicated to both the patient and relatives/support staff using accessible information, where appropriate.

- If people are discharged prematurely, there is a danger that they will be re-admitted with further health needs. The draft Public Health Outcomes Framework proposes using emergency readmissions to hospitals within 28 days of discharge as an indicator regarding the prevention of ill health. People with learning disabilities
need to be identifiable in readmission data so that appropriate actions can be taken.

**In summary**

- Begin discharge planning on admission or before.
- Include all relevant parties in discharge planning.
- Use best interest decision making if the person is unable to consent and do not delay discharge for funding or other non-clinical reasons.
- Update health passports.
- Ensure follow-up appointments are flagged.
- Ensure people with learning disabilities can be identified in emergency re-admissions to hospitals within 28 days of discharge.
6. Monitoring and reporting mechanisms

Issue

The Ombudsman’s report \(^{16}\) recommended that ‘All health care organisations...should ensure that they collect the data and information necessary to allow people with learning disabilities to be identified by the health service and their pathways of care tracked’. (p.37)

This recommendation has been reinforced by the NHS Operating Framework 2011/12 \(^{8}\) which says:

‘Using information gathered locally in partnership with people with learning disabilities and their families, PCTs should ensure they are taking action to improve healthcare and health outcomes’. (p.41)

However, while two thirds of Trusts say they have some way of flagging up that a person has learning disabilities, only 20% of Trusts who responded could provide specific information about the number of people with learning disabilities who had used Trust services in the past year.

Without having a clinical code in place it is difficult to:

- Plan for the kind of reasonable adjustments patients are likely to require.
- Identify how many people with learning disabilities are taking up offers of screening.
- Investigate whether there is an over representation of deaths from particular conditions such as cardiac or respiratory diseases.
- Evaluate whether the Trust’s Single Equality Scheme is effective; the experience of people with learning disabilities should be represented in all service evaluations and service reviews.
- Ensure there is transparency in health outcomes, enabling people to choose good quality services and hold the Secretary of State to account for the overall performance of the NHS.

Commissioner/provider action

- Unless people with learning disabilities are identified in health records, it is impossible to compare their uptake of health services with the general population or get good quality data about their health needs. However clinical coding is a complicated area and in primary care in particular, it is often down to local agreements as to which codes are used, so it is important to agree clinical codes with other local services to gain as much consistency as possible. In acute care it is important to use the appropriate F7
code. Once the codes are used routinely, analysis of the data about uptake of different health programmes such as annual health checks, breast and cervical screening can take place to ensure that people with learning disabilities are able to use health services in the same way as other people, and the information gathered can inform the Joint Strategic Needs Assessment.

- Information about use and uptake of health services by people with learning disabilities needs to be shared with them and their families so that they can be involved in service planning and evaluation. The Self-Assessment Framework process enables this to happen.

- As well as using appropriate coding to identify people with learning disabilities in health systems, it is important to have a flagging system in both primary and secondary care which gives information about the person’s needs and any reasonable adjustments that need to be made.

- In order to support people with learning disabilities appropriately within health services, more detailed information is often required. Health passports, health action plans or similar documents contain this information and ought to be accepted by Trusts whether they have been developed locally or not.

**In summary**

- Agree a clinical coding system, analyse clinical data and use it to inform the JSNA.

- Share information with people with learning disabilities and family carers.

- Have a flagging system in place which details any reasonable adjustments that need to be made.

- Support the use of health passports or similar documents.
7. Patient and Public Involvement

Issue

‘No decision about me without me’ is one of the underpinning principles of the government white paper on health care (DoH 2010: p.13)\(^7\), and there is a strong emphasis on gathering patient experience in the NHS Outcomes Framework (DoH 2010)\(^8\). However it has been difficult for people with learning disabilities and their families to influence policy and practice in the healthcare system because they have not been visible within it, and because involvement mechanisms such as surveys and focus groups have not been adapted to enable people with learning disabilities to participate. In addition, people may be unwilling to come forward because they feel they should not complain or speak out when they are reliant on the care provided. The Six Lives progress report\(^7\) has highlighted continuing concern about the existence of difficult to understand and lengthy complaints procedures. For example, although 86% of Trusts said they provided information about complaints in Easy Read, when asked for evidence, only 23% mentioned a specific Easy Read/accessible leaflet.

The response rates to questions about the representation of issues for people with learning disabilities at Board level were also relatively low.

Commissioner/provider action

- Patient experience is a vital element of the NHS Outcomes Framework, and it is crucial that the experiences of people with learning disabilities and their families are included because of the health inequalities they face. Therefore services need to ensure that service evaluation and reviews are designed to enable this information to be gathered. Trust reports should be published on patient experience with specific reference to the views of people with learning disabilities and family carers.

- Unless there is an accessible complaints procedure in place and support to use it, it is very difficult for people with learning disabilities and family carers

For example

NHS South West worked with commissioners to co-ordinate a peer review of acute hospitals’ ability to meet the needs of people with learning disability throughout the region in the autumn of 2010. The process included:

- a baseline of existing performance;
- identification of innovative practice;
- recommendations and action plans for each acute hospital;
- a South West regional report and action plan.

The review has already improved performance and there are details about the process along with innovative practice identified at:

http://www.swacutehospitalreview4ld.org.uk/
to complain. Therefore health services should have an accessible complaints procedure that has been developed in partnership with people with learning disabilities and family carers. Information from complaints ought to be collated, and include evidence of how services have changed as a result of complaints. Patient Advice and Liaison Services also need to be accessible and emerging Health Watch organisations should ensure they understand the issues people with learning disabilities face.

- Involving people with learning disabilities and family carers in training staff is very effective as they can tell staff what needs to happen from their own experience. Health services should ensure that there are mechanisms in place to involve people with learning disabilities and family carers in training, and it is helpful to monitor the effectiveness of this training.

- In order to ensure that services are responsive to the needs of people with learning disabilities and family carers, Trust Boards ought to have a senior executive whose remit is to ensure that issues for people with learning disability are regularly discussed at Board level, and appropriate actions are taken. Actions need to be reported back to groups such as the Learning Disability Partnership Watch and Patient Experience Group and any service changes and improvements recorded.

- To embed reasonable adjustments within Trust thinking, the Single Equality Scheme and associated action plan should detail the reasonable adjustments required for people with learning disabilities, and the action plan should be monitored by the Board.

- In order to see if the Trust is demonstrating awareness of disadvantaged groups including people with learning disabilities and people with complex needs and communication difficulties, the Research and Development (R&D) unit (if one exists) could do an audit of service evaluations and research projects in the Trust. For example, are these groups being included and if so, are appropriate methods used to elicit their views? If not, the R&D unit could require applicants for approval to resubmit their proposals with explicit statements about what they intend to do to include people with learning disabilities in a meaningful way.

- Foundation Trusts should develop a membership that is representative of the local population. Therefore people with learning disabilities and their families should be encouraged to become involved as both voters and potential governors and the Trust should provide accessible information for them on what Trust membership entails.
In summary

- Ensure service evaluation and reviews include the experience of people with learning disabilities.
- Ensure there is an accessible complaints procedure in place and monitor use.
- Involve people with learning disabilities and family carers in staff training.
- Include reasonable adjustments for people with learning disabilities in the Single Equality Scheme.
- Ensure there is a senior executive at Board level responsible for services for people with learning disabilities and family carers.
- Ensure that recruitment to Foundation Trust membership is accessible to people with learning disabilities and the profile of membership is monitored.
8. Employment of people with learning disabilities

Issue
Employment levels for people with learning disabilities are very low (6.4% in 2010) but many want to work and make good, reliable employees if given the right opportunities and support. The Government has set a target of 47% of people with moderate to severe learning disabilities in employment by 2025 and Trusts must make reasonable adjustments under the Disability Equality Duty to enable them to work. The survey did not yield a high response rate in relation to the questions about employment and only 12% said that they had people with learning disabilities doing paid work, with 13% mentioning examples of people doing voluntary work. Although 75% said that their procedures under the appraisal scheme or personal development programme were appropriate for employees with learning disabilities, it was not always clear from the responses what action had been taken to make them appropriate.

Commissioner/provider action
People with learning disabilities can be excellent employees but unless Trust recruitment procedures are accessible, people will be unable to apply. Online adverts and applications will disadvantage people with learning disabilities (and some other groups) and alternative approaches need to be considered including:

- Commissioning the local Supported Employment provider to be a recruitment agency for the trust. They can then match people with the right skills to job vacancies and can provide ongoing support if needed.
- Easy read adverts that are circulated to local advocacy groups and through the Learning Disability Partnership Board.
- Becoming a Project SEARCH site to offer internships within the organisation. For further information, go to: http://odi.dwp.gov.uk/odi-projects/jobs-for-people-with-learning-disabilities/project-search.php
- Alternative approaches to the traditional interview such as working interviews or time limited work trials.
- Job carving where specific tasks or aspects of jobs are matched to the abilities of individuals.
- People with learning disabilities who are employed are less likely than other employees to put themselves forward for development opportunities and promotion. Therefore
Trusts need to ensure that once people are employed, they are able to feedback about their experiences and are given opportunities for training and personal development.

There is a wealth of good practice information about employing people with learning disabilities including case studies available at: http://www.valuingpeoplenow.dh.gov.uk/content/employment-resources-hub, including information about Valued in Public events which are specifically aimed at the public sector.

In summary

- Take positive steps to improve the diversity of the Trust’s workforce.
- Ensure recruitment practices are in line with national good practice regarding the employment of people with learning disabilities.
- Ensure that employees with learning disabilities are given the same opportunities for training and development as anyone else.
9. Equality Impact Assessments

Issue
There is a requirement for all NHS Trusts to screen their policies, processes and functions to see if they might have an impact on race, gender or disability equality. If they do, an Equality Impact Assessment is needed. This would also apply if the service is provided by a contractor on behalf of the NHS. Sometimes these assessments are too focussed on physical access arrangements and do not properly address the needs of people with learning disabilities for support with communication, emotional distress or help in understanding information. In addition, people who face more than one type of discrimination based on race and disability or mental health issues may not be considered. Response rates to this section of the survey were relatively low.

Commissioner/provider action
- In order to make sure the needs of people with learning disabilities and family carers are properly included in Equality Impact Assessments, make sure that any equality impact screening and assessments are planned and carried out by people with a range of needs including people with learning disabilities. There are some helpful materials published by the Department of Health on Equality Impact Assessments: www.dh.gov.uk/en/Publicationsandstatistics/PublicationsPolicyandguidance/DH_093377

In summary
- Include people with learning disabilities in Equality Impact Assessment planning and implementation.
Conclusions

The work of Hatton et al (2011) on which this paper is based, shows that there is progress in the provision of reasonable adjustments within NHS Trusts in England, particularly in relation to information giving, use of health passports and health action plans. However there is still a long way to go, especially in relation to embedding these adjustments into routine practice, and there is some suggestion that Trusts rely on learning disability liaison nurses or other specialist workers to carry out reasonable adjustments, rather than using them to help embed reasonable adjustments within the service. The researchers propose that a truly personalised approach to healthcare may be a better way forward, and a number of good practice examples are on the IHaL website: http://www.improvinghealthandlives.org.uk/adjustments/ This database also provides the facility for NHS Trust staff to upload and share further examples of reasonable adjustments.

Implementation of reasonable adjustments is likely to lead to real progress in meeting the needs of not only people with learning disabilities but also other significantly disadvantaged groups of people in a wide range of health service settings.
## Appendix I

### Table of summary actions

<table>
<thead>
<tr>
<th>Actions</th>
<th>Who is responsible?</th>
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</thead>
<tbody>
<tr>
<td><strong>Accessible information</strong></td>
<td></td>
</tr>
<tr>
<td>- Have a policy or strategy about accessible information.</td>
<td>• Health care providers</td>
</tr>
<tr>
<td>- Put links on the Trust website to other accessible websites and resources.</td>
<td>• Health care providers</td>
</tr>
<tr>
<td>- Audit the information currently available.</td>
<td>• Health care providers</td>
</tr>
<tr>
<td>- Have a working group including people with learning disabilities and family carers to rectify any gaps in information.</td>
<td>• Health care providers</td>
</tr>
<tr>
<td>- Monitor the use and availability of accessible information.</td>
<td>• Health care providers</td>
</tr>
<tr>
<td>- Provide staff with the appropriate skills and support to take an individualised approach to communicating with individuals.</td>
<td>• Health care providers</td>
</tr>
<tr>
<td>- Commission liaison nurses or equivalent support if this is not already in place.</td>
<td>• PCT commissioners/GP consortia</td>
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<tr>
<td>Actions</td>
<td>Who is responsible?</td>
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<tr>
<td><strong>Working in partnership with families</strong></td>
<td></td>
</tr>
<tr>
<td>• Involve family carers from pre-admission onwards.</td>
<td>• Health care providers</td>
</tr>
<tr>
<td>• Have a comprehensive carers’ policy.</td>
<td>• Health care providers</td>
</tr>
<tr>
<td>• Have clear protocols on the provision of extra care.</td>
<td>• PCT commissioners/GP consortia and health care providers</td>
</tr>
<tr>
<td>• Involve family carers in care decisions as appropriate.</td>
<td>• Health care providers</td>
</tr>
<tr>
<td>• Ensure appropriate support and facilities are in place for family carers.</td>
<td>• Health care providers</td>
</tr>
<tr>
<td><strong>Consent, capacity and advocacy</strong></td>
<td></td>
</tr>
<tr>
<td>• Have a policy on the Mental Capacity Act and Deprivation of Liberty which staff know about.</td>
<td>• Health care providers</td>
</tr>
<tr>
<td>• Check that staff have been trained on how to implement these policies.</td>
<td>• Health care providers</td>
</tr>
<tr>
<td>• Ensure there is a protocol in place which details when best interest decisions are required.</td>
<td>• Health care providers</td>
</tr>
<tr>
<td>• Do an annual audit of best interest treatment decisions for people with learning disabilities.</td>
<td>• Health care providers</td>
</tr>
<tr>
<td>• Ensure the Board receives reports from the IMCA and ICAS service regarding use by people with learning disabilities.</td>
<td>• Health care providers</td>
</tr>
<tr>
<td>• Provide information for people with learning disabilities and family carers regarding their rights under the Mental Capacity Act.</td>
<td>• Health care providers</td>
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<tr>
<td>Actions</td>
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<tr>
<td><strong>Service delivery</strong></td>
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</tr>
<tr>
<td>Making and attending an appointment</td>
<td></td>
</tr>
<tr>
<td>• Have a flagging system which includes details of reasonable adjustments required.</td>
<td>• Health care providers</td>
</tr>
<tr>
<td>• Ensure that appointment systems are accessible.</td>
<td>• Health care providers</td>
</tr>
<tr>
<td>• Ensure that reasonable adjustments are put in place regarding appointment times and length.</td>
<td>• Health care providers</td>
</tr>
<tr>
<td>• Ensure that there is a system in place to offer annual health checks.</td>
<td>• PCT commissioners/GP consortia</td>
</tr>
<tr>
<td>• Do an audit of reasonable adjustments that are in place.</td>
<td>• Health care providers</td>
</tr>
<tr>
<td>• Ensure that staff provide support to people with learning disabilities so they use their Health Action Plan.</td>
<td>• Health care providers</td>
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<tr>
<td>Actions</td>
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</tbody>
</table>
| **Service delivery**  
**Receiving a service**  
- Support staff to use Hospital Passports or similar where these are in place.  
- Ensure staff know how individuals express pain and discomfort and act accordingly  
- Use good practice guidance on dysphagia and ensure there is accessible information about food choices.  
- Carry out a risk assessment for all people with learning disabilities admitted to hospital.  
- Identify, analyse and learn from incidents involving people with learning disabilities. | - Health care providers  
- Health care providers  
- Health care providers  
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- Health care providers |
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<td><strong>Service delivery</strong></td>
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<tr>
<td><strong>Discharge arrangements</strong></td>
<td></td>
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<tr>
<td>• Begin discharge planning on admission or before.</td>
<td>Health care providers</td>
</tr>
<tr>
<td>• Include all relevant parties in discharge planning.</td>
<td>Health care providers</td>
</tr>
<tr>
<td>• Use best interest decision making if the person is unable to consent and do not delay discharge for funding or other non-clinical reasons.</td>
<td>Health care providers</td>
</tr>
<tr>
<td>• Update health passports.</td>
<td>Health care providers</td>
</tr>
<tr>
<td>• Ensure follow-up appointments are flagged.</td>
<td>Health care providers</td>
</tr>
<tr>
<td>• Ensure people with learning disabilities can be identified in emergency re-admissions to hospitals within 28 days of discharge.</td>
<td>Health care providers</td>
</tr>
<tr>
<td><strong>Monitoring and reporting mechanisms</strong></td>
<td></td>
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<tr>
<td>• Agree a clinical coding system, analyse clinical data and use it to inform the JSNA.</td>
<td>Health care providers, PCT commissioners/GP consortia</td>
</tr>
<tr>
<td>• Share information with people with learning disabilities and family carers.</td>
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</tr>
<tr>
<td>• Have a flagging system in place which details any reasonable adjustments that need to be made.</td>
<td>PCT commissioners/GP consortia, health care providers and Health and Wellbeing Boards</td>
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<td><strong>Patient and public involvement</strong></td>
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<td>• Ensure service evaluation and reviews include the experience of people with learning disabilities</td>
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<td>• Ensure there is an accessible complaints procedure in place and monitor use.</td>
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</tr>
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<td>• Include people with learning disabilities in Equality Impact Assessment planning and implementation.</td>
<td>Health care providers</td>
</tr>
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</table>
References


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