

Clinical Practice Discussion Learning disabilities

Keywords Equity of care/Reasonable adjustment/Hospital passport

This article has been
double-blind peer reviewed

In this article...

- What equity of care for people with learning disabilities means
- Examples of reasonable adjustments that can be made in hospital
- Two case studies showing the benefits of making reasonable adjustments

Learning disabilities: making reasonable adjustments in hospital

Key points

In hospital, people with learning disabilities are more likely to experience poor outcomes, including avoidable death, compared with the general population

Reasonable adjustments are additional and/or alternative methods of helping people with learning disabilities to achieve good outcomes

Reasonable adjustments are statutory under the Equality Act 2010

One example of a reasonable adjustment is the hospital passport

Making reasonable adjustments adds value to the service for everyone

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Abstract Being in hospital can be difficult for anybody, but it is particularly challenging for people who have a learning disability. Compared with the general population, this patient group is more likely to need and use health services, and is also more likely to have a poorer experience of care and poorer health outcomes (including avoidable death). Reasonable adjustments (which do not need to be costly) to the hospital care of people with learning disabilities are not only feasible and a statutory duty under the Equality Act 2010, but are also beneficial for all involved – and, first and foremost, for the person who has the learning disability. This article gives tried-and-tested examples of reasonable adjustments that can be made in hospital and features two case studies that clearly demonstrate the benefits of reasonable adjustments.

Citation Phillips L (2019) Learning disabilities: making reasonable adjustments in hospital. *Nursing Times* [online]; 115: 10, 38-42.

People with learning disabilities have the right to the same standard of medical and nursing care as that provided to the general population. However, they commonly experience barriers to healthcare, which can result in poorer outcomes including avoidable death.

Being in hospital can be a difficult time for anybody but for people with learning disabilities, this can be even more difficult. A person who has poor literacy skills may not have understood the appointment letter and therefore not know where to go, on what day and at what time. They may be unable to read signs and find their way around the hospital. If the person has difficulty understanding information, they may not know what is expected of them or why they need treatment, which can result in non-adherence. If they also have communication problems, they may not be able to say that they are in pain. Some people with autism also have sensory

processing disorders, which means lights, sounds, smells and textures may cause them great distress.

Nurses need to be aware of their responsibility in making reasonable adjustments to the care of people with learning disabilities to ensure their health needs are met in the most appropriate way. This article looks at what reasonable adjustments can be made in hospital and features two real-life case studies.

Learning disabilities

The definition of learning disability most commonly used in the UK is taken from *Valuing People*, the 2001 government white paper on the health and social care of people with learning disabilities (Department of Health, 2001). It explains that learning disability is defined as:

- The presence of a significantly reduced ability to understand new or complex information and learn new skills (impaired intelligence);



Clinical Practice Discussion

- Reduced ability to cope independently (impaired social functioning);
- Having started before adulthood with a lasting effect on development.

There are 1.4 million people with learning disabilities in the UK, making up approximately 2% of the general population (Mencap, 2018). The nature of their learning disability varies widely and affects the kind of support they may require. Learning disability can range from mild (the person is able to live independently with minimal support) to significant (the person cannot cope independently and is totally reliant on carers). Many people will fall between these two

categories and require support in some aspects of their life – for example, accessing health services.

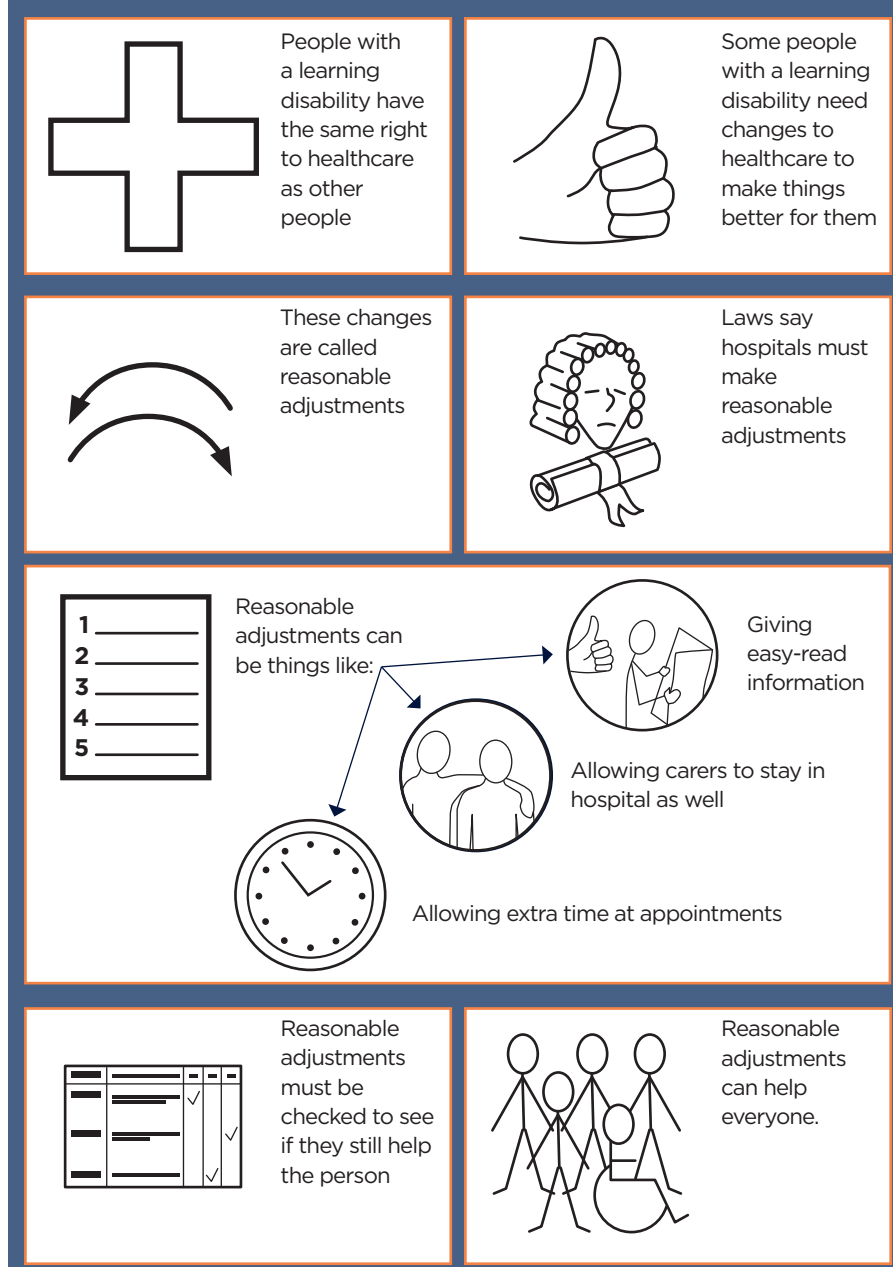
People with learning disabilities are more likely than the general population to experience multiple comorbidities and chronic health problems. Kinnear et al (2018) found that 98.7% of people with learning disabilities have two or more diagnoses in addition to their learning disability; this means they are more likely to attend, and be admitted to, acute general hospitals.

It is expected that the number of people with a learning disability in the UK will continue to grow and that learning

disabilities will become more complex (Michael, 2008). This is because people with learning disabilities live longer than before and more young people with complex disabilities survive into adulthood. The demand of people with learning disabilities and their families and carers for general and specialist health services is expected to increase significantly in the future (Gates, 2011).

QUICK FACT
1.4 million
Number of people with a learning disability in the UK

Fig 1. Accessible summary



Poorer health outcomes

Reports have consistently highlighted the poor experience and poor health outcomes – including premature and avoidable death – of people with a learning disability who come into contact with general hospital services (Learning Disabilities Mortality Review (LeDeR) Programme, 2018; Heslop et al, 2013; Mencap, 2012; Michael, 2008; Mencap, 2007). It has recently been estimated that 1,200 people with learning disabilities die of an avoidable death in the NHS each year (Mencap, 2018) and the LeDeR Programme (2018) found that, on average, men and women with a learning disability die 20 years and 27 years younger, respectively, than men and women in the general population. Many of these deaths are considered avoidable and/or premature.

Heslop et al (2013) identified the central issue as delays in care, specifically relating to investigations, diagnosis and treatment. However, other factors make people with learning disabilities more vulnerable when accessing hospital care, including:

- Lack of coordination across, and between, pathways and care providers;
- Lack of effective advocacy;
- Lack of reasonable adjustments.

Reasonable adjustments

Nurses have a responsibility to ensure reasonable adjustments are made to the care of people with learning disabilities. Equality of care for people with learning disabilities does not necessarily mean they need to receive exactly the same service as anyone else (which is why some prefer the term 'equity of care'). To achieve a positive outcome, the person may need additional and/or alternative methods of support set out with them and/or their families/carers (Department of Health, Social Services and Public Safety, 2010). These additional and

alternative methods of support are what we call 'reasonable adjustments'.

Reasonable adjustments are a statutory duty under the Equality Act 2010, which says that "health and social care providers must make reasonable adjustments to remove any barriers – physical or otherwise – that could make it difficult for disabled people to use their services or prevent them from using them altogether. [...] As far as possible, the effect of the adjustment should be to make services as accessible to disabled people as they are to other members of the public". Under this act, public sector organisations, including the NHS, must make changes in their approach or services provision to ensure equitable care.

Reasonable adjustments can be provided at service level or at individual level. Service-level adjustments include not only physically altering the environment to improve access (for example, installing ramps, wider doors or accessible signage), but also altering policies and procedures, so they take the needs of people with learning disabilities into account.

Individual-level adjustments are the changes needed for a particular individual at a particular time. Nurses have an important role in identifying what these adjustments may be; they need to be anticipatory, responsive and flexible so any intervention takes full account of the needs of the person and the best possible health outcomes for that person can be achieved.

Identifying people's needs

It is essential that hospital nurses identify whether a patient has a learning disability, and whether they need reasonable adjustments, as soon as possible. If a nurse suspects someone has a learning disability, they need to:

- Assess the person's communication and/or support needs;
- Check whether they understand and remember information.

Some people with learning disabilities – for example, those with Down's syndrome – are easy to identify. People with severe learning disabilities may have carers with them or information in the referral or patient notes may alert staff to the fact that a patient has a learning disability. Generally, it is more difficult to identify people with a mild learning disability.

When determining which reasonable adjustments are required, all possible sources of information must be explored. These include:

- The patient – they can be asked what

their needs are and what has helped them in the past;

- The patient's familial carers – these people will have a long history of supporting the patient and be experts in their care. Relatives and carers have an important and unique contribution to make, which should be valued, acknowledged, listened to and acted on. Nurses need to check with the patient whether it is OK to speak with their informal carers;
- The hospital's learning disability liaison nurse – this role exists in many hospitals.

"Making reasonable adjustments is not only achievable but also highly valued"

Hospital passport

Another useful source of information is the hospital passport, which the patient may already have. It will contain key information that will help health professionals inform their communication, diagnosis and treatment. Every health professional in contact with the patient can access the hospital passport (Public Health Wales, 2014). Usually based on a traffic light system, it will feature:

- Red section – information the service must know about the person, including personal details, contact information and health profile;
- Amber section – information the person would like the service to know about them, such as communication needs, personal care, mobility, sight and hearing;
- Green section – information on what the person would like to happen during their hospital stay to ensure it is more enjoyable, including preferences, likes and dislikes.

The information from the green section can also be used to start a conversation, build a rapport and create trust.

A specialist management plan may be attached to the hospital passport. For people with complex needs, this will provide, for example, advice on what can trigger a specific behaviour and what strategies to use to manage that behaviour and keep everyone safe.

Finally, the hospital passport may also include a specialist pain assessment such as the Disability Distress Assessment (DisDAT) tool. The DisDAT tool would have been completed by the carers before

the patient's admission and will explain how the person looks and behaves when they are not in pain, and how they look and behave when they are in pain.

Examples of reasonable adjustments

Reasonable adjustments must be person-centred and respond to the person's particular needs. The aim is to overcome barriers to healthcare by doing things differently (Public Health England, 2016). Adjustments do not have to be costly and can be provided by anyone involved in the care of the person.

Reasonable adjustments can include:

- Using simpler language and avoiding abbreviations and jargon;
- Using communication aids, such as Makaton symbols (makaton.org), Widgit symbols (Bit.ly/WidgitSymbols) or Talking Mats (talkingmats.com). Talking Mats is an interactive resource that uses symbols to help people with communication difficulties understand and consider issues discussed with them, express their opinions effectively and clarify what is to be included in decision making. It is particularly useful when obtaining consent for treatment;
- Allowing extra time for appointments;
- Providing written information in an accessible, easy-read format, and using symbols to reinforce the written word (as in the accessible summary of this article in Fig 1);
- Providing a quiet waiting area;
- Using a pager so patients can wait in a place of their choice until they are ready to be seen;
- Inviting patients to pre-admission visits so they can familiarise themselves with the environment and know what to expect;
- Giving people appointments at the start or end of clinics, when the environment is less busy;
- Ensuring patients are first on the theatre list to reduce their waiting time;
- Providing meals or overnight stays to family carers;
- Arranging for multiple procedures to be carried out under one general anaesthetic.

These are examples of reasonable adjustments that have been used in practice. The list is not exhaustive.

Case studies

Box 1 describes the case of a patient with a learning disability admitted for planned

Clinical Practice Discussion

Box 1. Case study 1

Margaret Davies* is 40 years old. She has Down's syndrome and a mild-to-moderate learning disability. She lives in Carmarthenshire with three other women in a supported-living scheme, where 24-hour support from carers is available. She works five days a week in a café that is run by people with learning disabilities.

Miss Davies has had problems with her ears for many years and her hearing has been greatly affected by a build-up of earwax. Several visits to the GP proved unsuccessful at clearing it, as Miss Davies could not tolerate the procedure. To reduce her hearing impairment, she received advice from a speech and language therapist, and developed alternative methods of communication. It was recommended that the earwax be removed in hospital under a general anaesthetic.

The learning disability health liaison nurse at the hospital first became aware of Miss Davies during a telephone call from the care manager, who explained that Miss Davies had no previous experience of hospital and was very anxious. The nurse organised a visit to the surgical ward at a convenient time so the staff could show Miss Davies around.

Key people involved in Miss Davies' care were present, as well as her speech and language therapist, who took photographs of the ward, staff, patient bed and procedures, such as having blood pressure and temperature taken. These pictures were put together in a communication book, which was used by her carers to reassure Miss Davies in the days leading up to her admission.

During the visit, a hospital passport was completed for Miss Davies and she met staff who would be present on the day of surgery, experienced some of the procedures, and even tried on a gown. Margaret and her carer were able to ask questions, including on practical issues that could therefore be dealt with beforehand.

On the day of her procedure, the learning disability liaison nurse met Miss Davies and her carer on the ward. Staff came to introduce themselves again and the communication book was used to explain what was going to happen. She appeared happy and excited about being in hospital, which was a surprise to those who knew her. She was first on the list so she would not have to wait. She did become a bit tearful and apprehensive when going to theatre, but was accompanied by her carer and the learning disability liaison nurse, who reassured her right up until she was anaesthetised. Her carer waited in the recovery room to support her as soon as she came out. Once back on the ward, she was happy and relaxed, listening to her favourite music on her CD player. She was discharged home later that day.

The operation successfully cleared the earwax and subsequent hearing tests have found Miss Davies' hearing to be back to normal. The learning disability community nurse helps her to see the practice nurse on a regular basis to prevent further admissions.

All in all, Miss Davies' admission was successful and potential difficulties were avoided thanks to the reasonable adjustments made to her care. Everyone benefited: Miss Davies had her hearing restored, her carers were prepared for the practicalities of the admission, and the ward staff understood her needs and could adapt procedures to meet them.

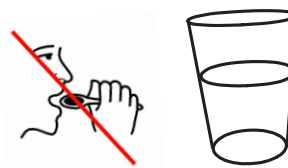
*Margaret Davies has given consent for her story to be shared to help everyone learn how reasonable adjustments can make a difference to hospital care. Her name has been used with her consent



Margaret's
hospital book



The doctor said I need an operation
to help me to hear.

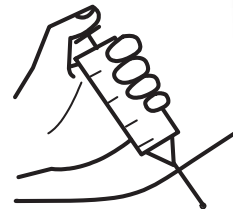


I must not eat any food for breakfast.

I can have sips of water.



I will go on the trolley to have my operation when I
am asleep.



They will put special cream on my hand to make it go
numb and then I will have an injection in the back of
my hand.

It will put me to sleep.



The nurses might want to take my temperature.



The nurses might want to take my blood pressure.

surgery. The reasonable adjustments made to that person's care were:

- Pre-admission visit;
- Hospital passport;
- Communication book;
- Being first on the theatre list;
- Having a carer present in the anaesthetic and recovery room.

Box 2 describes the reasonable adjustments made to the care of my daughter Nia, who has a profound learning disability and complex health problems (Down's syndrome, attention deficit hyperactivity disorder, autism, cardiac and respiratory problems). It shows how small changes can make a huge difference.

The reasonable adjustments made to her care were:

- Hospital passport;
- Side room;
- Allowing both parents to stay;
- Providing a low bed;
- Multiple interventions under one anaesthetic.

Clinical Practice Discussion

Box 2. Case study 2

My daughter Nia^{*} underwent her first cardiac surgery in 2005 aged 19 months. Being in hospital with a very poorly baby was extremely difficult and emotional. My husband and I took it in turns to stay with her, as only one of us was allowed to be by her bedside at night. Whoever's turn it was to sleep in the hospital accommodation took a pager so they could be contacted should the worst occur, which led to more anxiety. There was a distinct lack of learning disability awareness on the ward. One nurse, no doubt well intentioned, told us not to worry as "these don't feel pain like other children".

In 2013, Nia had further cardiac surgery at the same hospital but, this time, the experience was completely different. Before admission, we received a hospital traffic-light assessment to complete online. It detailed information relevant for hospital staff to know, including a brief medical history, how Nia communicated, her eating and drinking needs, her sleep routine, how she took medication, her likes and dislikes, her favourite toys and so on.

Then we received a phone call from the learning disability liaison nurse. We spoke at length about Nia's needs and how best to support her while in hospital. Nia was a lot older now and her behaviour, due to ADHD and autism, was much more difficult to manage. She had difficulty sleeping and no awareness of danger. At home, she had a single bed with full-size cot sides to prevent her from getting out. This could not be provided by the hospital; however, Nia would have a side room so she would not disturb other children on the ward. Both my husband and I would be allowed to stay with her overnight, and a bed that could be adjusted to floor height would be brought in from another hospital. During the discussion, I also

explained that Nia needed further anaesthetics for a dental examination and a hearing test. The learning disability liaison nurse arranged for Nia to be seen by the dentist and audiologist during the same anaesthesia as for the heart surgery.

These reasonable adjustments made a big difference. Staff were aware of Nia's needs and able to anticipate how best to help her. I did not have to repeat Nia's medical history to every health professional we met (and re-live the traumatic memories this would usually provoke). Having a side room took some of the stress away, as we did not have to explain to other children and parents why Nia made strange noises or behaved the way she did, and she would not keep them awake in the early hours.

Allowing both of us to be with Nia meant we could share the caring responsibilities and provide emotional support to each other. It also relieved nurses from helping with Nia's personal care – something that could prove difficult, not only for Nia (who finds it hard to have people in her personal space, especially people she does not know well), but also for the nurses (on the receiving end of her behaviour).

The low bed was not exactly what Nia needed, but it was a good compromise.

Another reasonable adjustment was to have the dental examination and hearing test carried out at the same time as the cardiac surgery. The cardiac surgeon successfully repaired the pulmonary stenosis via balloon dilation and stent insertion. The dentist then examined Nia's teeth and applied a varnish coating, and the audiologist conducted the hearing test. This avoided two further hospital admissions and the risks that go with Nia having further general anaesthetics.

^{*}Name has been used with the consent of the patient's parent

Ongoing monitoring

As with all care plans, reasonable adjustments must be monitored and evaluated. People's needs change over time, so the type of adjustments needed will also change. It is important to re-assess people's needs at each admission and tailor reasonable adjustments accordingly. The LeDeR Programme's (2018) report states that "providers should clearly identify people requiring the provision of reasonable adjustments, record the adjustments that are required, and regularly audit their provision".

At Hywel Dda University Health Board, learning disability health liaison nurses keep a record of what reasonable adjustments have been made and monitor their use. This data is forwarded to the Welsh government every six months to inform a national audit of reasonable adjustments.

Recommendations

Evidence has shown that making reasonable adjustments is not only achievable but also highly valued and can support safe and effective person-centred care (MacArthur et al, 2015). To prevent further avoidable

deaths of people with learning disabilities, the LeDeR Programme (2018) recommends:

- The use, record and audit of reasonable adjustments;
- Mandatory learning disability training for all staff.

Conclusion

Making reasonable adjustments can benefit other people and have a positive impact on the wider community. It is good practice and adds value to the service for everyone. **NT**

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