



Treat me well is Mencap's campaign to transform how the NHS treats people with a learning disability in hospital. We are working with healthcare professionals so that they understand the possible needs and adjustments for people with a learning disability.

Mencap has partnered with Bradford People First, Airedale NHS Foundation Trust and BTM to produce this guide for healthcare professionals who support families and children with a learning disability in hospital.

It is important that the needs of children with a learning disability are recognised in all areas of life, particularly when it comes to healthcare.

The early interactions with medical staff can help to pave the way for better care throughout your child's life. Good, positive treatment, communication and support can make a big difference.

#### Attitudes to learning disability

Mencap conducted a survey into the healthcare experience of parents with children with learning disabilities. The survey found that 45% of parents reported negativity, prejudice and discrimination from healthcare professionals in the weeks following diagnosis. Only half (51%) of parents say that children with a learning disability receive equal hospital care compared to children without a learning disability (Mencap early years survey, 2020)<sup>1</sup>. This clearly shows the need for more support for families in the early years of healthcare.











# Children and learning disability

Many parents feel that hospital staff do not understand learning disability.

14% of parents are unsure whether hospital staff are aware that their child has a learning disability (Mencap early years survey, 2020)

Remember, having a learning disability is just a small part of who a child is; the disability does not define them. Every child with a learning disability is a unique individual, with their own needs; with the right support, children with a learning disability can grow up leading fulfilling lives in the way they choose.

# Getting the right healthcare is the law

Did you know that all disabled people have the right to reasonable adjustments when using public services such as healthcare? This is the law under the Equality Act 2010, which exists to protect people from discrimination.

Only 1 in 5 parents say that hospital staff make enough reasonable adjustments to ensure their child has a positive experience in hospital (Mencap early years survey, 2020)

Reasonable adjustments are simple changes that could help people with a learning disability get better healthcare. They remove barriers and provide extra support that people with a learning disability need. Essentially, this means better communication, more time and accessible information.











# What can you do to help children with a learning disability and their parents?

#### Ask about the best way you can support

As a healthcare professional, you are expert in what you do, but parents are the expert in their own child. That's why it's important to listen to what parents and their children tell you.

Ask parents what would help them or what they would like. Adapt the way you communicate to the child's needs. Encourage parents to be vocal and open up about any concerns they may have.

"Listen to family concerns, adapt to [my] child and don't make assumptions of my child's needs." (Quote from Mencap early years survey, 2020)

**Involve parents in their child's hospital care and treatment.** Take the time to listen and where possible, give children the opportunity to respond in a way that they feel comfortable, for example, via play therapy or through non-verbal communication.

"If we are left in A & E tell us the approximate wait time. Give us the chance to go outside as it is so hard managing behaviour in a waiting area." (Quote from Mencap early years survey, 2020)

All hospital staff are required to help with a reasonable adjustment, whether they are a porter, receptionist, nurse or doctor.

Encourage other members of staff to speak to the family and involve them in decisions. This could include reception staff when making appointments that best fit around the family's needs, or consultants when discussing treatment. It's important that parents know that all members of staff are aware of their child's learning disability and make the necessary reasonable adjustments.











#### Communicate in a positive way

"I received my son's diagnosis over the phone...
There was no follow up appointment, nothing to explain everything to me, just, 'This is where he's at. Deal with it.'" (Quote from Mencap early years survey, 2020)

Good communication with parents and children is really important. Be clear with parents, use positive, supportive language, and be sensitive when talking about their child's disability. Sometimes people may not think before saying something offensive or upsetting, they may not even mean to cause

offense. Words have a lot of power – think before you speak. The way that you talk about learning disability and the things you say could have a lifetime impact on children and their families.

45% of parents have experienced negativity, prejudice or discrimination from healthcare professionals either deliberately or non-deliberately (Mencap early years survey, 2020)

**Check your assumptions -** every child with a learning disability is a unique individual. Make sure you're responding to their needs. It's also important to listen to children as well as their parents. Get to know the children you are treating; build rapport and empathy.

People with a learning disability may express pain or discomfort in different ways. **Diagnostic overshadowing** is when it's assumed that a child is behaving in a certain way because of their learning disability, not because they are responding to symptoms. This could result in a failure to investigate which could have life-threatening consequences. Getting to know how children communicate and express themselves helps to reassure them and ensures that they feel included in their care. **Listen and observe for any verbal and non-verbal cues that may indicate symptoms.** 

"Speak to my child in a way they understand instead of ignoring them." (Quote from Mencap early years survey, 2020)

**Avoid jargon or complicated medical terms.** Speak to parents and children in a way that they can understand.











#### Makaton

"Speak to my child in a way they understand instead of ignoring them." (Quote from Mencap early years survey, 2020)

Many children with a learning disability communicate using Makaton - a unique language programme that uses symbols, signs and speech to enable people to communicate. Even learning basic Makaton can make a big difference to the way you communicate and can significantly improve the healthcare experience of children with a learning disability.

The charity Makaton provide communication resources - <a href="https://www.makaton.org/">www.makaton.org/</a>

## **Information**

"I would have liked to have been pointed in the direction of where I could get relevant info, instead of relying on Google." (Quote from Mencap early years survey, 2020)

Throughout the journey from <u>diagnosis</u>, through <u>early years</u> and on to transition into adult services, it is vital that families are given accurate, up to date and balanced information, to help them make informed decisions. Mencap provides a range of information, advice and support for families.

"She's 4 and I only found out about the learning disabilities team last week." (Quote from Mencap early years survey, 2020)

Most hospitals will have a specialist paediatric learning disability team, or play therapy team, on site. It is important all hospital staff – from receptionists to consultants – know they are there and call on them to support with communication and making reasonable adjustments. The learning disability team will also provide information about learning disabilities to families.

58% of parents have not received the right type and amount of information from the hospital care team in the weeks and months following the diagnosis (Mencap early years survey, 2020)











## **Hospital passports**

Parents will know their children better than anyone and will be able to tell you important things about them. There will be essential information held within the hospital passport, but parents will be able to update you on any information and may feel empowered by you asking them. This could be how a child expresses pain, what makes them happy or what reasonable adjustments they need.

As well as giving vital information about a child's health, ability and needs, the passport will help you make simple adjustments to the way you communicate, such as talking about a favourite football team or cartoon character, this can help reduce anxiety.

Each trust will have their own version of a hospital passports. The hospital learning disability team will be able to point families toward the version that they use and can support them filling it in.

Mencap has information on hospital passport, including a template passport - <a href="https://www.mencap.org.uk/advice-and-support/health/health-guides">https://www.mencap.org.uk/advice-and-support/health/health-guides</a>











### Be creative

Children with a learning disability may express their anxiety through challenging behaviour. This may include responding to stressful environments such as a busy, noisy waiting room, or becoming anxious at a procedure, such as a blood test.

Although parents will want to support their child in hospital, they may have additional caring responsibilities.

Creating a calm, creative, flexible environment helps children with a learning disability feel comfortable and reassured and helps reduce anxiety and behaviour that others may find challenging.

"Make appointments fun rather than a chore. They're children, hospitals are scary enough without staff ignoring child or thinking they can't vocalise." (Quote from Mencap early years survey, 2020)

Making simple reasonable adjustments, such as carrying out a blood test on a favourite toy to demonstrate the procedure first, can also help reduce anxiety.

## Be aware of the needs of the whole family

Although parents will want to support their child in hospital, they may have additional caring responsibilities.

Only 28% of parents feel the wider needs of their family are considered by the hospital staff (Mencap early years survey, 2020)

**Support the wider family in any way you can.** By being flexible and reassuring the family that you understand the needs of the whole family, you can build trust and provide a healthcare experience tailored around them. An example could be something as simple as making appointments that fit around the family's needs.

"It's as if healthcare professionals don't understand that our other children need us too." (Quote from Mencap early years survey, 2020)











## Supporting children with complex health needs

Children with profound and multiple learning disabilities are likely to be at high risk of complications because of their complex health needs.

Each child with profound and multiple learning disabilities (PMLD) will have a unique way of communicating which may be difficult for others to understand. In most cases, children with PMLD will need others such as family or support staff who know them well to interpret their unique ways of communicating and introduce hospital staff to the communication information, detailed in their child's hospital passport. It is important that healthcare professionals listen to and involve families to understand the needs of children with PMLD.

Mencap has produced <u>resources</u> to support healthcare professionals and families to work in partnership - <u>https://www.mencap.org.uk/get-involved/campaign-mencap/treat-me-well/healthcare-people-profound-and-multiple-learning</u>



Mencap ran a survey with 116 parents or carers of a child with a learning disability aged between 0-5 years responding. We asked families in Northern Ireland, England and Wales about hospital care for their young children. The survey ran from 28/09/2020 to 21/10/2020







