



THUMBS UP TO GOOD HEALTH SERVICES FOR PEOPLE WITH LEARNING DISABILITIES

TRAINING FOR HEALTH SERVICES STAFF



GUIDANCE ON GOOD SUPPORT

FOR PEOPLE WITH LEARNING DISABILITIES
IN HEALTH SERVICES

CREATED BY
BRIGHTON AND HOVE SPEAK OUT ADVOCACY

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THUMBS UP TO GOOD HEALTH SERVICES FOR PEOPLE WITH LEARNING DISABILITIES PROJECT



This project has involved consulting with 40 people with learning disabilities on how accessible local health services are. From this feedback, an animated film *The Waiting Room* and accompanying workbook and guidance have been created to highlight the issues raised by this group of patients. These tools will support health professionals to reflect on ways of addressing these issues.



There is a wealth of expertise and good practice within Health Services and some people with learning disabilities reported on this. However there were many examples where small adjustments could have significantly improved patient experience.

This training pack draws on this direct feedback as well as Guidance by the Brighton and Hove Learning Disability Liaison Team and Health Facilitator, and national guidance.



We hope that it will support Doctors, Nurses and other health professionals, Managers and Administrators to think about how they can improve practice, make reasonable adjustments and meet the needs of individuals with learning disabilities better. This will help them to comply with Equality Act 2010, and the Accessible Information Standard 2015.

The Project has been funded by the Brighton and Hove Clinical Commissioning Group.

THE HEALTH OF PEOPLE WITH LEARNING DISABILITIES

There are approximately 1.5 million people with learning disabilities in the UK and it is estimated that in Brighton and Hove there are about 5000 residents with learning disabilities. People with learning disabilities are a diverse group of individuals with varying levels of learning disability and need for support in daily living.

People with learning disabilities are more likely than the general population to develop health problems. For some these go undetected due to difficulties in communication.

According to the Foundation for People with Learning Disabilities between 25-40% of this group have mental health problems. Approximately 40% of people with learning disabilities have a hearing impairment and about 33% have a visual impairment. People with learning disabilities are less likely to access health screening.

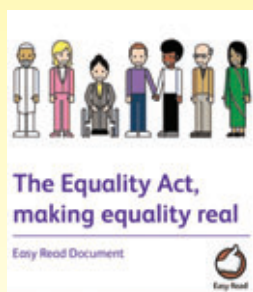
Following on from a Mencap report '*Death By Indifference*' (2007), CIPOLD (2013, Bristol University), a confidential inquiry into the premature deaths of people with learning disabilities was undertaken. The inquiry found that people with learning disabilities die much younger than those without, 13 years for men and 20 years younger for women. The research suggested there are 1200 preventable deaths of people with learning disabilities each year.

The report identified 18 recommendations that if implemented would reduce the risks of premature death for people with a learning disability. Some key themes from the report include:

1. Identifying people with learning disabilities, anticipating their likely needs and making reasonable adjustments
2. Diagnosing and treating illness quickly
3. Co-ordinating care and sharing information
4. Understanding and adhering to the Mental Capacity Act 2005.
5. Listening to people with learning disabilities, their family and carers.

In this guidance we will particularly focus on numbers 1 and 5.

EQUALITY ACT AND ACCESSIBLE INFORMATION STANDARD



Equality Act 2010

The Equality Act requires health services to make reasonable adjustments so people with learning disabilities can have equal access to health care.



Accessible Information Standard 2015

All health services have to comply with the NHS England, Accessible Information Standard by July 2016 which requires identifying access needs of particular group, recording and sharing this information across health services and making sure reasonable adjustments are made.

IDENTIFYING PEOPLE WITH LEARNING DISABILITIES



Valuing People, a Government White Paper, (2001, Dept of Health), defined Learning Disability as including the presence of:

'A significantly reduced ability to understand new or complex information, to learn new skills.' (impaired intelligence)

'A reduced ability to cope independently' (impaired social functioning) 'which started before adulthood with a lasting effect on development.'

Social functioning means the individual's ability to cope on a day to day basis with their life. The individual will need help with some or all of the following, communication, self care, home living, social relationships, accessing community resources, keeping healthy, work, leisure and safety.

This is a diverse group of individuals and includes people with a mild, moderate learning disability and people with profound and multiple learning disabilities. Ways of communicating and levels of understanding are diverse.

Identifying that someone has a learning disability and any additional information such as recording if they also have a mental health issue, hearing impairment, have autism, mobility issues is key to provision of reasonable adjustments and a better patient experience.

Some people with mild learning disabilities do not identify with this as a label but still need extra support. It may not be obvious that someone has a learning disability.

Where health professionals share information about an individual and their support needs, it can make all the difference to that person's experience of health care.

Recording access needs is now required under the Accessible information Standard.



***"Went back to the hospital.
Treated me like a mature adult this time.
The consultant had spoken to them
told them I had autism.
I didn't get so cross and angry."***

SPEAKING UP AND SUPPORT

Some people with learning disabilities will be able to say what adjustments would give them better access to their service. Other people may not be able to. Support workers/ carers may be able to support the individual to speak up about what will help. However the person may not have any support.

Many people with learning disabilities find it hard to speak up if they are not happy with something or they do not understand.

Individuals with learning disabilities receive varying levels of social care and support, ranging from 24 hour care, to no support at all. Housing situations include: living independently, sheltered accommodation, supported living services, residential care homes, with family, with partner, with child, or shared lives carer.

The amount of support someone receives to meet their health needs and to access health services will vary.

Some people may have been supported to use the following tools which give health professionals crucial health, communication and support needs information. They may bring these tools with them to hospital.

COMMUNICATION AND HEALTH TOOLS



A Hospital Passport tells you information about communication, pain, medication, anxiety, behaviours, safety, medical interventions, important people, personal care, and likes and dislikes. It is key for you to use the Hospital Passport.



A Communication Book can contain pictures you can use to help ask questions and understand preferences.



A Disability Distress Assessment Tool will help you to understand distress for someone with severe learning disabilities who does not use verbal communication.

GUIDANCE ON REASONABLE ADJUSTMENTS FOR ALL HEALTH SETTINGS



Anticipating Access Needs and Making Reasonable Adjustments

Equal access should look at all areas of health care including:

- Values of staff and the way they treat patients.
- Accessing buildings and equipment.
- Booking and administrative systems.
- Involving patients in care planning and treatment.
- Communication needs.
- Support needs around care and treatment.
- Getting feedback from patients.

The ideas and suggestions in the guidance that follows come from people with learning disabilities consulted, as well as local and national guidance.

GUIDANCE FOR ALL HEALTH SERVICES AND STAFF



Values

- Ensure privacy of information and sharing information only with consent.
- Ensure dignity and privacy for the patient within the health setting.
- Do not make assumptions about a patient. Check out health and support information with the person.
- Do not make judgements about the communication, abilities or support needs of the patient with learning disabilities.
- Include the patient in all conversations and consultations.
- Respect the patient and their support staff/carer.



***“Treat us with respect.
Don’t talk about me behind my back.
I don’t like it. It hurts my feelings.”***



Buildings and equipment

- Use easy read signage.
- Provide staff/volunteers to show the way if needed.
- Alternative quiet waiting areas if someone is anxious.
- Calming music and sensory objects in waiting areas.
- Ensure individuals with physical disabilities have no physical barriers to accessing rooms and equipment. Provide equipment that will ensure equal access.
- Make sure individuals feel safe in waiting areas.
- Change the environment to reduce noise, lighting, or intimidating equipment if this is causing anxiety.



Systems

- Use fast track booking systems for patients with learning disabilities who may get distressed or have known medical conditions.
- Keep people informed of waiting times.
- Allow patients to choose best ways of making an appointment. Online and telephone communication can be very hard for some people.
- Remind people of their appointments verbally by telephone.
- Schedule appointments and treatments at beginning of day to lessen waiting times or in a slot which allows more time for the person.
- Try not to change dates of appointments or cancel as this is confusing and anxiety provoking.



Involvement in care planning and treatment

- Talk to the person not their carer.
- If someone has complex needs still talk to the person but involve the carer as part of the team.
- Use and share any communication or health tools that the person brings i.e communication book, hospital passport etc.
- The Mental Capacity Act (2005) requires staff to assume capacity and do all they can to support the person to understand and make informed choices and give consent. If it is determined that a person lacks capacity to make a decision, then a best interest decision would be made, and a referral made to an Independent Mental Capacity Advocate if there is no carer/family involvement.



Communication Needs

Communication should be appropriate to the person's level of understanding. Some people have extensive knowledge of their health conditions, others will have different levels of understanding. Some people with mild/moderate learning disabilities may be able to read but still find it helpful if information is presented in an accessible format.



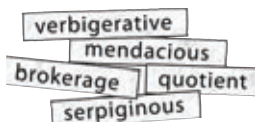
Verbal Communication

- Allow more time for communication.
- Do not use complex medical jargon or abbreviations, explain clearly and simply.
- Use everyday words.
- On the phone speak clearly and slowly.
- Make sure the person can hear and there are not distractions.
- Check understanding by asking open questions to see if the person has understood or you have understood the person correctly.
- Use short sentences.
- Use sentences that relate directly to the person e.g you will get a letter in the post for an appointment.
- Be specific, just give the information the person needs.
- Sentences that contain negatives can be confusing, e.g you won't, you can't, etc. Use positive language i.e you can bring your support worker into the room.
- Explain things in the order they will happen. This is easier for people to follow.
- Don't give too much information at once.
- Be aware that for some people talking about what is going to happen in the future is difficult and it may be clearer to deal with the present.
- If someone has a hearing impairment check that their hearing aid is working. Make sure you sit opposite and close to someone in quiet space.
- Record a consultation for person to play back at home.
- Use objects of reference, photos and images to explain information.



Written Communication

- Use easy read information or pictures to help the person understand (see useful resources and websites section).
- Use 16 point font as minimum in written information.
- Display easy read information in waiting areas, etc.
- Make your letters easy to understand by using large print and images.
- Send typed letter to explain test results, diagnosis and treatment options.



Tips for making easy read information

- Images on left, simple sentences alongside.
- Keep short and simple, no unnecessary information.
- Direct, positive language.
- Have white space around each point.
- No jargon, abbreviations, acronyms.
- Use photos or photo bank (www.photosymbols.com or www.changepeople.co.uk).
- Make sure the images show clearly what you are talking about.
- Use 16 point plain font e.g Arial where possible. 14 point as minimum.
- Provide on yellow paper if someone has a visual impairment.
- Make the images, contact details, as big as possible.

Support needs around care and treatment



- Allow enough time. Someone with a learning disability may need more time for personal care, discussion about treatment or any medical intervention.
- People with learning disabilities may need more appointments than is standard.
- Some people may experience high levels of anxiety. Find ways to support them e.g reassurance, more time, more preparation, seeing what will happen from pictures or going to look at the equipment.
- Consistency in staff supporting an individual will build trust and develop understanding of that individual's support needs.
- Accommodate peoples' preferences where possible i.e for same gender health staff, and explain reasons if it is not possible.
- For people visiting clinics regularly a named key clinic nurse for the person will provide continuity and understanding.

Feedback from patients



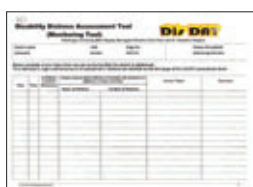
- Ask the person with a learning disability for feedback about their experience of being a patient..
- Accessible feedback systems should be in place.
- If someone is not happy with their treatment inform them of their choices to make a complaint i.e PALS, ICAS.
- Inform patients of local advocacy service that can help the patient to give feedback or make a complaint.
- Ensure quick and accessible response to feedback and complaints.

ADDITIONAL GUIDANCE JUST FOR HOSPITAL SETTINGS



Systems in Hospitals

- Fast track systems for patients with learning disabilities who may get distressed in hospital or have known medical conditions. Particularly addressing needs of people with learning disabilities with autism, profound and multiple learning disabilities and mental health issues in accessing emergency care.
- Don't move people around too much to different waiting areas as this can cause anxiety.
- Ensure when planning hospital stays that people understand what equipment they need to bring and what will be available.



Involvement in Care Planning and Treatment

- Use tools that the person brings i.e Hospital Passport, DisDat or Communication Book.



Support needs around care and treatment in hospital

- Staff to share information during hospital stay about the individual's preferences around care and support – use the Hospital Passport to facilitate this.
- Some people with learning disabilities may experience loneliness or confusion and anxiety during hospital stay. Ensure that if they do not have a carer or support worker present there are health staff who can spend time with them.
- Involve the learning disability liaison team to support good practice when people are accessing hospital clinics/in-patient stays e.g. help with preparation for appointments/treatment, help with communication.
- In preparing people for surgery check with patient if they want support worker in anaesthetic room/recovery room (when this is possible).
- Check previous experience of medical intervention to inform support needed.
- Have named nurse on ward for the individual when admitted.
- In care planning, take into account the individual's physical, psychological, social and cultural needs when someone is admitted to hospital.
- Find out what the person is usually like before becoming ill.
- Ensure all staff have training in postural equipment, and positioning. Make sure people who have postural issues are repositioned regularly.





- In making a care plan for someone with profound and multiple learning disabilities, include information on positioning, sensory stimulation and feeding requirements.
- Ensure staff are trained in PEG feeding when supporting someone with complex needs.
- A person with a learning disability may not be able to communicate levels of pain or ask for pain relief. Hospital passport, DisDat or talking to the person or the carer about how they show pain will give information on this.
- During the length of a hospital stay check with the individual for changing care needs.



What people with learning disabilities want from their doctors, nurses, health care assistants and other health professionals

- Your doctor should get to know you.
- They should understand about your health.
- They should understand about your mental health.
- Receptionists, doctors, nurses should ask you what would make it easier for you at your GP surgery.
- They should be relaxed and patient.
- They should give you enough time. 'I didn't know about a double appointment'.
- I want kind and friendly doctors and nurses. They should care about helping you get better.
- They should be really good at listening and helping you to talk about what's wrong.
- They should talk to me, not my carer.
- Some people don't speak, they should find ways to communicate with them.
- No difficult words.
- Give us easy read information.
- Doctors and nurses should make you feel safe.
- You can trust them.
- Doctors and nurses should make sure your information is confidential. They should ask you if it is ok to share information with someone and tell you why.
- Be clear about what is going to happen next.
- Help us to feel better if we are worried.
- We should be able to ask questions about things like medicines.
- Help us if it is hard to speak up. Help us if we are anxious.
- Forms are really difficult. Lots of people with learning disabilities can't read. Fill out information for us.
- When they send us to other services, doctors should tell them what makes it easy for us.



USEFUL RESOURCES AND WEBSITES

National



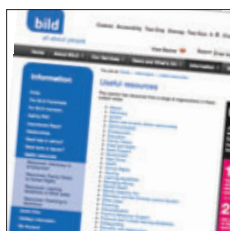
Working Together 2: Easy Steps To Improve Support For People With Learning Disabilities In Hospital (Public Health England), available on www.improvinghealthandlives.org.uk

Supporting And Meeting The Needs of People With Profound And Multiple Learning Disabilities - Top Tips (NHS England)

Easy Health – website with many free accessible resources to download www.easyhealth.org.uk

Foundation For People With A Learning Disability – national organisation, website provides a range of information and resources. www.learningdisabilities.org.uk

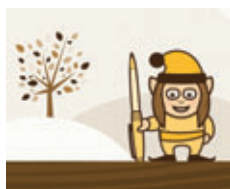
Mencap – national campaigning organisation web site provides a range of information and resources for people with a learning disability, carers and professionals. www.mencap.org.uk



British Institute of Learning Disability (BILD) – organisation working to improve the lives of people with a learning disability and family carers – range of information and resources on web site. www.bild.org.uk

Improving Health And Lives Public Health Observatory For Learning Disability – publishes many reports and good practice guidance documents. www.improvinghealthandlives.org.uk/

NHS England – information on accessible information standard www.england.nhs.uk/ourwork/patients/accessibleinfo-2/



The Learning Disabilities Elf – blog highlighting the latest learning disabilities evidence published each week, relevant to health and social care professionals with an interest in learning disabilities. www.thelearningdisabilitieself.net

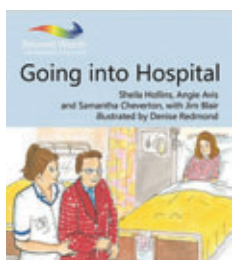
National Autistic Society (UK) – organisation that champions the rights and interests of people with autism. www.nas.org.uk/

Royal College Psychiatry, Learning Disability pages – range of information and resources, including easy read information on medications and conditions. www.rcpsych.ac.uk/healthadvice/problemsdisorders/learningdisabilities.aspx



GMC, Learning Disability pages – aims to help doctors provide better care for people with learning disabilities, includes interactive learning. www.gmc-uk.org/learningdisabilities/default.aspx

RCN, Learning Disability pages – information and resources including guidance and good practice in relation to supporting people with a learning disability. www.rcn.org.uk/development/practice/social_inclusion/learning_disabilities



Beyond Words – books and other resources developed using pictures on a range of topics including health, relationships, death and bereavement and crime. As well as a story told in pictures, each Books Beyond Words title has written information, guidelines and resources for readers, families, supporters and professionals. www.booksbeyondwords.co.uk

www.photosymbols.com – provide health picture banks.

www.changepeople.com – provide specialist health picture banks and health information.

Local



Coming to Hospital, A Guide For People With Learning Disabilities (Brighton and Sussex University Hospitals NHS Trust document).

Brighton and Hove Learning Disability Services – for more information about learning disability services including eligibility, service charges, advocacy etc, please see Brighton & Hove City Council 'learning disabilities' pages. www.brighton-hove.gov.uk

Health Promotion Library – Brighton & Hove Health Promotion Library has a range of resources suitable for use with people who have a learning disability. Based at Audrey Emerton Building, Royal Sussex County Hospital, Eastern Road, Brighton.
Tel: 01273 523300 Email: library.services@bsuh.nhs.uk



Brighton and Hove Learning Disability Partnership Board – range of information about local initiatives. See 'Total Communication' pages for information on making information easy to understand. www.brightpart.org

Sussex Partnership NHS Foundation Trust – Sussex wide NHS Trust providing mental health, and learning disability services. www.sussexpartnership.nhs.uk



GUIDANCE ON GOOD SUPPORT CREATED BY BRIGHTON AND HOVE SPEAK OUT ADVOCACY



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THE WAITING ROOM FILM WAS CREATED WITH CAROUSEL ARTISTS, FILMMAKERS AND ACTORS



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