Getting it Right for People with Learning Disabilities

A Guide for LCH staff

March 2012
Introduction

The Department of Health defines a learning disability as the presence of a significantly reduced ability to understand new or complex information or to learn new skills, coupled with a reduced ability to cope independently that began before adult and has had a lasting effect on development. These difficulties mean that individuals may need support in new environments, such as health centres, and may not understand information relating to their healthy needs if it is not presented to them in an accessible manner.

People with learning disabilities have greater and more complex health needs than the general population, many of which remain unrecognised and unmet. A fundamental aspect of care is to “treat everyone with dignity and humanity and to understand their individual needs, show compassion and sensitivity and provide care in a way that respects all people equally”. This guide is based around that principle and aims to provide practical examples of how all staff can improve access to our service and the experience and healthcare outcomes for people with learning disabilities.

Delivering Dignity in Healthcare

Dignity for people with learning disabilities often involves what other people may take for granted – asking the person what they want, what support they need and including the individual at all stages of the care planning process. This may take more thought and time to prepare; it may involve using alternative methods of communication.

Staff can promote dignity by recognising each person as an individual with a unique personality, history and range of abilities. Do not make assumptions about the person. You need to take time to establish what their abilities are and what they need support for. Ask the person what they can do for themselves, what support they need and how that support is given.

It is important that people with learning disabilities do not feel disempowered. It may be frustrating for the clinician to watch an individual seemingly struggle with a task and it may seem easier to do it for them. It may take the person longer to complete certain tasks but giving them the opportunity to work through it themselves will enhance feelings of self-worth and achievement, thus promoting their dignity.

Healthcare can be an anxiety provoking experience for anyone. Having learning disabilities may increase this anxiety, as the individual may not understand why they are there or what to expect.

Reasonable Adjustments

The Equality Act (2010) states that providers and commissioners of healthcare must make reasonable adjustments that will reduced or remove barriers to healthcare services for disabled people. This guide contains
practical examples of reasonable adjustments that can be made for a person with a learning disability. However, everyone who has a learning disability will have very different needs and it is important to recognize that one size does not fit all and staff should continue to treat patients as individuals.

Respecting Patients

- Ask the patient how they wish to be addressed and use the term consistently (for example, Mr, Miss or by their first name or nickname)
- Understand that people with learning disabilities are all different and should be treated as individuals
- If patients are adults they should be treated as adults
- Do not use out of date terms that may cause offense, such as mental handicap, mental retardation or mental sub normality. Some individuals may prefer to use the term learning difficulties.
- People with learning disabilities have the same right to privacy as everyone else but they may need support in putting it into practice (like being shown how to close the curtains or lock a door)
- Before entering a room always knock first, even if you know the patient is unable to answer you.
- Staff should find out what the patient can do for themselves before offering support

Effective Communication

- Keep communication clear, using simple everyday language
- Before meeting the person try to think of easier ways of saying a word, for example sad rather than depressed
- Check if the person has had a speech and language assessment and if there are any recommendations from that
- Avoid abstract words or concepts and use concrete term where possible. For example, I will come back at 10, o’clock, rather than I’ll be back in a minute.
- Consider using alternative methods of communication such as pictures and signs. The LCH Communication for All Guidelines contains advice on communication methods such as Makaton and instructions on how to develop picture boards.
- When talking to the patient always talk to them directly and do not ask the carer questions first. With the patient’s consent, you may ask the carer questions
- Give them information about their treatment in a format that they will understand. There is a learning disability resource on the web pages that has examples of information in easy read or contact the Equality & Patient Experience Team for help to develop your own.
Making Appointments

- Consider booking a double appointment
- Find out about the patient’s support needs. Does noise and busy environments upset them? Would they prefer an appointment at a quieter time of the day? Would they prefer to wait in a side room?
- Explain what will happen at the appointment
- Ensure that the patient and/or carer has a named contact to discuss the appointment with

The Role of Carers

Carers are often family carers who have been caring for the person over a long period of time and are experts at knowing how the person feels and what they need. It is essential that staff involve carers fully in the persons care.

Care Plans

When a person’s likes and dislikes are known, these should be documented in their notes along with all the things that make them feel safe and comfortable in a healthcare setting. For example, is the gender of the clinician important? Are they needle phobic? What communication methods are preferred?

Hospital/Care Passports

Many people with learning disabilities will have a document, often referred to as a passport or personal profile. Find out of the person has one as they will detail their health and support needs along with personal information that may help you to care for the person, such as their favourite music.

Challenging Behaviour

Some people with learning disabilities may engage in behaviour that is considered challenging. This is often associated with environmental issues like noise levels, boredom and communication difficulties such as not being understood.

Consent

The Mental Capacity Act 2005 indicates that it should not be assumed that people lack the capacity to consent just because they have particular conditions. Instead, there should be an assumption of capacity and an
assessment should take place to determine whether the individual has the
capacity to consent.
To have capacity, individuals must be able to understand and retain relevant
information, use it to make decisions and then communicate those decisions
to the relevant people. The act recognises that the way in which information
is presented may influence understanding, retention and use of that
information and that the way in which patients communicate their decisions
may vary. Therefore we must provide the right support for an individual to
make and communicate decisions about their care.