In this article...

- Training needs of nurses and health needs of people with a learning disability
- Key messages from people with a learning disability about healthcare
- Benefits of involving people with a learning disability in developing training resources

A training resource to educate students about learning disabilities

Key points

People with a learning disability are likely to have unmet health needs.

Healthcare services must make reasonable, person-centred adjustments to improve access to healthcare.

Nurses report having insufficient training and skills in supporting people with a learning disability.

Mandatory training is needed to ensure nurses understand the health and communication needs of people with a learning disability.

Involving people with a learning disability in developing training resources has benefits for both groups.

Children and adults who have a learning disability are more likely to experience health inequalities and unmet health needs than the general population (LeDeR, 2017; Oulton et al, 2018). This is in part due to reduced access to good-quality healthcare services, with one of the main barriers being the attitude, communication style and emotional reactions of health professionals (Howieson, 2015; Lewis and Stenfert-Kroese, 2010; Oulton et al, 2018). Disability Rights Commission research (2006) highlighted positive attitudes of health professionals as one of the most influential factors on the experience of people with a learning disability when accessing healthcare.

This article describes a project to create a training resource for student nurses, which was developed using the experiences, views and opinions of people with a learning disability. The resource was designed for student nurses across all four fields of nursing, as well as allied health professionals. The project enabled people with a learning disability to share their story, and they expressed a number of ways health professionals could adapt the way they support them to reduce health inequalities.

Training needs

The General Medical Council identified that discrimination against people with a learning disability happens because of health professionals’ attitudes and assumptions, and diagnostic overshadowing (when someone’s symptoms are incorrectly attributed to their learning disability). This discrimination leads to unmet health needs (GMC, 2016).

Health professionals need to have positive attitudes and increased engagement with this group, but this does not always happen. Staff have reported having insufficient skills and training to care for people with a learning disability, leading to avoidance of certain healthcare tasks with those patients. Lewis and Stenfert-Kroese (2010)
found that these tasks include:
- Invasive procedures;
- Personal care for which carers would be requested to remain with patients;
- Explaining interventions;
- Asking the person if they are in pain.
This demonstrates that health professionals need more training and supported contact time with this vulnerable group to reduce feelings of nervousness, fear and awkwardness, improve care and reduce preventable deaths.

A recent Department of Health and Social Care consultation (2019) recommended that health professionals have face-to-face education, involving people with a learning disability. This is to increase exposure to this group, as well as to accurately portray their opinions and lived experiences. Gumm et al (2017) have also shown that the use of films and other mediums can:
- Change health professionals’ attitudes;
- Increase their confidence in communicating with people who may have barriers in expressing themselves or comprehending speech.

This project to develop a training resource considered these needs and research when choosing a suitable medium to deliver vital messages to health professionals and identify future needs.

**Storytelling method**

Evidence shows that sharing real experiences can help engagement in the subject matter (Stone and Levett-Jones, 2014). Piryani (2016) emphasises the benefits of case-based stories including learning and applying knowledge to understanding ethical dimensions that support decision making.

The storytelling method has had greater prominence since the publication of the Francis (Department of Health, 2013a) and Berwick (Department of Health, 2013b) reports. These reports have provided evidence for a renewed effort to engage all health professionals in patient-safety education from the patient’s perspective – rather than the perspective of the professional or organisation. Kumgagai (2008) has indicated that patient stories could:
- Enable learners to empathise;
- Trigger an emotional response that reinforces learning and encourages better interpersonal skills.

This project aimed to make the training resource accessible to readers with no background knowledge in the care of people with a learning disability, while also offering academics a resource to prompt discussion and debate in a more formal educational environment.

“The aim was for the user to see the individual and read their narrative as spoken by them, to emotionally connect with people who have a learning disability”

**Developing the training resource**

People with a learning disability, learning disabilities student nurses and academics worked collaboratively to coproduce a training resource for student nurses and allied health professional students.

The group chose to create a photobook, containing real experiences of people with a learning disability. The aim was for the user to see the individual and read their narrative as spoken by them, to emotionally connect with people who have a learning disability and feel more confident when delivering care to this group in the future.

To create the photobook, the academics and student nurses interviewed 17 people with a learning disability who consented to have their words and photographs used in the book. Questions aimed to find out about their lived experiences and what they thought health professionals should know about people with a learning disability in order to improve care. The student nurses and academics reviewed all the questions to check they were easy to understand, in everyday language and free from medical jargon.
They also used pictures of healthcare services during the interviews to support understanding. All interviews took place at the participants’ day-service provider. This ensured they were comfortable with the environment and could seek support from regular staff if needed. The participants were all sent a letter using an easy-read format to tell them when and why the interviews were attending. This enabled them to:

- Consider if they would like to take part in the project;
- Think of any questions they wanted to ask;
- Decide how they would like to dress for the interview.

To help the participants feel more comfortable, the student nurses spent time with them before the interviews. They talked through what they would be discussing in the interviews, and helped with putting on make-up or grooming if people wanted.

The comments made by the participants during their interviews then formed the themes illustrated in the photobook, as outlined below.

“Invoking people with a learning disability in communications about their health will likely make them feel valued and respected”

Key themes
Getting to know the person and how they want to be treated

In previous research, people with a learning disability have reported being ignored, anxious or frustrated when attending acute hospitals (Howieson, 2015). Mencap’s Treat Me Well campaign identified that health professionals need to give them the time and opportunity to explain what will make them feel comfortable and safe (Mencap, 2017). The Nursing and Midwifery Council Code (2018) says that, to build trust and confidence between nurses and patients, they must:

- Treat patients with dignity, kindness and respect;
- Pay attention;
- Be compassionate towards them.

The Royal College of Nursing (2017) has explained that, if dignity is absent, people feel devalued and lacking in comfort or control of the situation. This was demonstrated by a participant in this project, who felt some health professionals had a demeaning attitude towards people with a learning disability. They said they were rushed through appointments and that staff had not read their hospital passport (this contains important information about the person, so that health professionals can deliver person-centred care), repeating questions that other professionals had previously asked.

Building therapeutic relationships by getting to know patients promotes effective health outcomes. The hospital passport can support effective collaboration and coordination of care, by reducing communication barriers with the patient and highlighting different members of the multidisciplinary team who are involved in their care package. Nurses must work within their competence and ask for help when appropriate (NMC, 2018). Mencap (2017) has argued that, to get it right, health professionals need support and guidance; acute and primary learning disabilities liaison nurses are valuable roles for this additional support (MacArthur, 2015).

Communication

The Nursing and Midwifery Council Code requires nurses to communicate using a variety of methods (verbal and non-verbal) and to display sensitivity. To ensure they recognise and respect a patient’s contribution to their care, they must listen to and involve them at every stage (NMC, 2018).

People with a learning disability have reported that a lack of patience from health professionals has made them feel disrespected when discussing their needs during hospital visits. Deficiencies in the knowledge, attitude and communication style have been shown by health professionals (Howieson, 2015). This was also illustrated by participants in this project: one stated that staff should “know how to communicate. Some people use sign language, some people use normal talking. There is nothing to be afraid of. We are just like you guys – we are all different”.

Another said: “Talk in a normal way. Be polite – with respect, with patience and with a smiley face.”

Involving people with a learning disability in communications about their health will likely make them feel valued and respected. Mencap’s Treat Me Well document has shown that only one in four NHS hospital trusts routinely offers easy-read information to support people accessing healthcare. This information helps make communication easier and more understandable (Mencap, 2017).

It is important to communicate with patients about pain, because the experience of pain is subjective. Herr et al (2011) have said this means pain assessment must be logical and progressive by obtaining:

- A self-report;
- Potential causes;
- Observed behaviour;
- A proxy report from family members and carers.

Non-verbal cues can also help nurses pick up signs of pain. This is echoed in the words of one participant in the photobook, who stated, “look at the person’s expressions and how they are behaving”.

Overcoming fears
People with a learning disability may feel scared or intimidated when accessing health settings. This could be due to the lack of education and training staff members have in treating this group; Mencap’s Treat Me Well campaign highlighted that only one in four health professionals has had this training (Mencap, 2017). A key comment given during the interviews for this project was that “sometimes when doctors and nurses deal with someone with a learning disability it can be scary [for them], as they don’t know what to expect. But we also have nerves and butterflies beforehand”. This suggests the feelings of apprehension from both the staff member and the person with a learning disability could affect the experience and perceptions of care provided.

To ensure a patient with a learning disability feels safe, the care they receive should be person-centred for them as an individual. During the interviews for this project, many participants explained what makes them feel safe. One said it is for the staff member to “just tell me that they won’t hurt me and that they will stay with me and tell me what is happening”. This shows that making a person feel safe can affect their perceptions of the care they are getting.

Reasonable adjustments

Reasonable adjustments are modifications to the way services are delivered to help ensure people with a learning disability can use them as effectively as the general population (Public Health England, 2016). Under the Equality Act (2010), services and health professionals have a legal responsibility to make reasonable adjustments, where necessary, to help meet the needs of
Involving family and carers
The participants in this project said they wanted health professionals to listen to them, not only to their carers or family members. One person, who attends appointments with their parents, said, “listen to people and after talk to parents, as I am the patient”.

Dinsmore (2012) conducted semi-structured interviews that consistently found that families’ and carers’ knowledge was vital to make significant positive differences for the individual. However, families felt this information was seldom used in the planning and provision of healthcare. When working with patients with a learning disability, health professionals need to take the time to understand how best to communicate with them – as well as with their family and carers. This approach helps provide relationship-centred care that humanises and improves patient outcomes (Soklaridis et al, 2016).

How did people with a learning disability feel?
When people with a learning disability were asked to contribute to developing the training resource, they reported that they wanted to participate to make things in healthcare better for people with a learning disability. After the interviews, they said they had enjoyed the opportunity because:
• It was in a calm environment where they did not feel rushed;
• The student nurses had explained things to them simply and clearly.

When asked if they felt they had been able to express their true feelings about the healthcare system, one participant responded, “yes, it gave me a voice. I felt things I was saying was being listened to by those in healthcare – at last!”

Dissemination of the resource
A launch event was organised to gain feedback about the training resource and to publicise the project. Student nurses and academics from a range of healthcare disciplines who attended the event gave positive feedback about the resource, which was socially relevant and useful to improve knowledge and support assignment writing.

The resource has also been used as part of table-top simulations (scenario-based group exercises) for student nurses, organised for all four fields of nursing. The scenario used was about a patient with a learning disability who had fallen and banged their head.

Using the resource enabled the students to consider how they could improve their care, knowing the photobook was a true reflection of people’s lived experiences. It was observed that the students engaged with the material. They commented that they felt they had met with the service users pictured in the book, which appeared to increase their emotional connection with the messages.

The resource has been added to the reading list for nursing modules at the university, with copies held at the university library.

Conclusion and recommendations
The main objective of development of this resource was for people with a learning disability to have a positive experience when accessing healthcare. The participants all reported feeling a sense of empowerment, as they were given the opportunity to share their own experiences – both positive and negative – with health professionals, in support of this objective.

The cocreation of the resource highlighted the need for people with a learning disability to be included in training for health professionals, to ensure the barriers they face are portrayed in a credible and reliable way.

References


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