Improving public health and reducing health inequalities for people with learning disabilities

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Although each person’s life experience is different, research shows that variations in health and wellbeing can also happen because the opportunities one person has to manage their risk of developing some conditions is less than their peers (NHS England, 2021). For example, for conditions such as breast and cervical cancer, research indicates that people with a learning disability are less likely to access early identification services (Allen et al, 2018; NHS England, 2021). These people are therefore at risk of dying at a younger age than their peers, if diagnosis happens at an advanced stage of disease, and they are unable to maximise the benefits from prevention, early diagnosis, and treatment options (NHS England, 2021).

This article considers learning disability through the lens of health inequality. By exploring how learning disabilities can increase the likelihood of early death and prolonged illness, the article will outline why some people in society can access services for risk identification, prevention and treatment more easily than others and thereby remain healthier for longer.

What is a learning disability?

Learning disability is a lifelong condition for which there is no cure. Although different for everyone, the causes and implications are similar. The foundations of a learning disability are laid when brain development is disturbed. This disturbance can happen because of a condition or neurological disorder, including, Down syndrome, autism, meningitis, epilepsy or cerebral palsy. A learning disability can begin before or during birth, or in early childhood. The degree of disability may vary and can be classified as mild, moderate, severe, or profound (Department of Health and Social Care (DHSC), 2001). The existence of a learning disability makes it difficult for people to understand new or complex information, learn new skills and carry out daily life activities (DHSC, 2001). This means that many people with a learning disability are dependent on others to help them with both formal and informal interactions and activities in their daily life (DHSC, 2001).

The number of people living with a learning disability in England is approximately 1.5 million, of which more than 900,000 are adults (Public Health England (PHE), 2016a). Although the process was completed in 2016 it has not yet been repeated, so the number of people living with a learning disability in 2023 is likely to be much higher. This means that all health and care professionals, including nurses and midwives, are likely to engage with people with a learning disability during their daily practice.

What is the difference between a learning disability and a learning difficulty?

The term learning difficulty is sometimes conflated with learning disability. However, the terms have very different meanings. For example, a learning difficulty is associated with a specific form of learning. Conditions include dyslexia and dyspraxia, which are associated with reading and physical coordination difficulties, respectively. Although people with a learning difficulty can also have a learning disability, it is not associated with impaired brain development or function.

Why do people with a learning disability experience health inequality?

Life for people with a learning disability can present many challenges that may have a negative impact on their health and happiness. For example, we know that people with a learning disability are more likely than others to experience loneliness, social isolation, depression, and anxiety. We also know that they are likely to have fewer opportunities for education and employment than their peers (DHSC, 2001). Collectively, these issues mean that people with a learning disability are unable to benefit in the same way as others from the factors that influence health, collectively known as the social determinants (Allen et al, 2018).

In terms of physical health, people with a learning disability again experience inequality, because the likelihood of being affected by some conditions is much higher for them than others. For example, data derived from the annual Learning Disability Mortality Review (LeDeR), shows that people with a learning disability are more likely to suffer from conditions including respiratory, and cardiovascular disease, diabetes, obesity and constipation (NHS England, 2021). These facts indicate that people with a learning disability continue to experience limited opportunities for optimal health and are therefore likely to experience higher levels of morbidity and mortality than others in society.
In addition, the data highlight that, although physically present, some services are unavailable and inaccessible to people with a learning disability. This means that they cannot benefit from them. Services may be unavailable and inaccessible for several reasons. These include their physical location, which means that to use the service the person must travel long, often complex, and costly distances. Other services may not be designed to accommodate the needs of people with a learning disability. This means that even if the person were to travel, the delivery mechanisms mean they cannot use them. In these circumstances, modifications known as reasonable adjustments are needed. Reasonable adjustments include the provision of additional time, and the opportunity for the person with a learning disability to attend appointments with a family member or carer (NHS England/NHS Improvement, 2021).

Enhancing knowledge and action about learning disability

To support all nurses, midwives and the wider health and care workforce to enhance their knowledge and, more importantly, to take greater action on key public health issues such as learning disability, free online e-learning resources have been published as part of the programme entitled ‘All Our Health’ (Health Education England e-Learning for Healthcare, 2022). The learning disabilities e-learning resource aims to support professionals to:

- Provide better access to health and care services and promote wellbeing as part of their everyday practice
- Address the impact of learning disabilities when they work with individuals, families, and communities.

Conclusion

Although several factors can increase the potential for inequalities in health, research shows us the measures that can mitigate the risks. The case study illustrates the ways in which nurses work with the person and not the diagnosis. In this case, by prioritising people, the district nurse, advocated for Clara and put her needs at the centre of her thinking. She also worked alongside Clara’s family and the multiprofessional team to ensure the care provided resolved the presenting problem and prevented future recurrence.

CASE STUDY: the impact of a learning disability on a person’s health

Although they share the same diagnosis, it is important to remember that people with a learning disability will present in different ways. Each person should be considered holistically as an individual and their care planned and provided accordingly.

Clara (not her real name) is 21 years old and has Down Syndrome. A condition that causes her to speak and process information much more slowly than her peers. Although this is not usually a problem when engaging with health services in her home town, it can affect her access to care when people do not know her and have not taken the time to identify her needs. Clara’s GP practice has organised the service so Clara can see the same nurse and doctor whenever she attends. The reception team will always arrange for her to have a longer appointment.

In the past 6 months Clara has suffered with constipation. Although this has been treated with medication, her preference for sweets and cakes over fruit and vegetables means that the condition can recur if not carefully managed.

Clara has been happy in her home, a supported living placement. Her parents live nearby, and she has a supportive carer who has helped her achieve some independence. However, the placement was only temporary, and now a permanent placement has become available, and Clara must leave. She no longer has a personal carer, and it is also further away, which means her parents must complete a round trip of 200 miles to visit her. Although her care needs and aspirations have been clearly documented, since her arrival no one in the new facility has managed to read them or take the time to listen to Clara.

Clara began to feel unwell within the first month of arriving in the placement. As the district nurse you have been asked to make a home visit to see her. You are told that she is refusing to get out of bed, is aggressive and has stopped eating and drinking. Having recently completed the e-learning module about learning disability, you plan to allow more time for the visit and on arrival you ask to see the written plan outlining information specific to Clara’s needs. Prior to the visit, you contacted Clara’s mother who alerted you to her history of constipation.

Although quiet at first, with time, active listening and careful prompting, Clara tells you about the pain in her tummy and that she had not ‘been to the toilet’ for a long time. Her tummy feels hard, and you notice that she doesn’t like it to be touched. Although the staff provide three meals a day, no one can tell you if Clara has eaten or the foods she likes to eat. You cannot see any drinking water in her room.

Knowing that Down Syndrome will present in different ways, you contact her previous GP for information about her usual treatment (PhE, 2016b). After treating the acute episode of constipation, you work with Clara and the staff to agree a weekly plan for her meals, which includes the fruits and vegetables she likes to eat. She tells you that she likes drinking cold water, but dislikes it when it is warm. You negotiate with the staff and agree a plan to help Clara get fresh cold water during the day from the water fountain in the living room. Exercise is also important and although Clara has limited physical ability, the staff agreed to walk with her around the garden each day. Helping her to plant a rose of her own in the far corner of the garden means she has a greater incentive to make the daily trip.

Spending time with Clara, and listening to her, has shown you the importance of focusing on the person, not the diagnosis. Although, as a community nurse prescriber, you manage the care for many patients with constipation, the care you planned for Clara was different. Rather than merely considering the most appropriate medication, you also planned elements of care to address her psychosocial needs. On reflection, you can see that merely knowing how to recognise and treat this medical condition was insufficient when deciding how to best care for Clara. Practical actions such as these have thereby positively impacted on the healthcare available to Clara and the impact it can have on her health and wellbeing (Allen et al., 2013).