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Editorial

“It is up to healthcare professionals to talk to us in a way that we can understand”: Informed consent processes in people with an intellectual disability

People with an intellectual disability form a sizeable minority group. Estimates of prevalence vary, depending on criteria used, but it is thought that intellectual disability affects around 1-2% of the world population [1,2]. Intellectual disability is present when the following three criteria are met: a significantly reduced ability to understand new or complex information, or to learn and apply new skills (impaired intelligence); a reduced ability to cope independently (impaired social functioning); and beginning before adulthood, with a lasting effect on development [3,4].

Health inequities

People with an intellectual disability experience stark health inequities. Understanding the causes of these inequities is important in making steps towards addressing them. The LeDeR programme (*“Learning from Lives and Deaths”*), which has investigated deaths of people with an intellectual disability and autistic people in England since 2016 [5], contributes towards achieving such understanding. The latest LeDeR report [6] includes data on 3,648 people who died in 2022, finding that the median age at death for adults with an intellectual disability was 62.9 years. Women with an intellectual disability died, on average, 23 years earlier than women in the general population, whilst males with an intellectual disability died on average 20 years earlier. People with an intellectual disability were almost twice as likely to die from an avoidable cause of death than people in the general population (42% vs 22%). Avoidable mortality includes deaths that resulted from conditions or diseases which could have been avoided with current, effective methods of prevention and/or treatment [7].

The importance of reasonable adjustments

Avoidable deaths are less likely if reasonable adjustments are provided, such as adopting someone’s preferred method of communication, increasing the time available for decision-making, or engaging in desensitisation to anxiety-inducing medical procedures, environments or personnel. The LeDeR data showed that often, reasonable adjustments were not made when they should have been; this was the case in roughly one third of the deaths that occurred in England in 2021 and a quarter of deaths that occurred in 2022 [6]. Previous research has supported the finding that there is a lack of provision of reasonable adjustments within health services [8] and called for the delivery of reasonable adjustments to be tracked, to ensure compliance with the Equality Act [9].

There is an onus on healthcare professionals to ensure that the information they provide to patients with an intellectual disability is in a format that they can understand. The Mental Capacity Act (2005) [10] stipulates that informed consent can only be provided if the person can understand the information that is being communicated, if they have not been coerced and if the person has the capacity to make the decision. A worrying 25% of people with an intellectual disability who died in England in 2022 did not receive a Mental Capacity Assessment that was required as part of their treatment [6]. The potential for improvements in communication between medical practitioners and patients with an intellectual disability has been emphasised in the literature [11,12]. Much of the

efforts to making health information accessible focus on producing information in “Easy Read” format, which consists of short, simple sentences with accompanying pictures. However, there is a lack of high-quality research evaluating the effectiveness of Easy Read information, despite the frequency of its use [12-14].

Barriers and enablers to engagement in decision-making about health

The paper by Dunn and colleagues [15] in this issue of *BMJ Quality & Safety*, is a welcome new contribution to the literature, furthering our understanding of how to make the process of obtaining healthcare consent for people with an intellectual disability more equitable and accessible. The authors identified the barriers and enablers to obtaining healthcare consent by analysing 23 studies in a systematic review of the literature. Barriers were healthcare professionals’ attitudes and lack of education, inadequate provision of accessible health information, and systemic constraints (e.g. time restraints and inflexible models of consent). Enablers were person-centred informed consent, and effective communication between healthcare professionals and patients. The involvement of support people was both a barrier and an enabler to healthcare consent processes. Support people may act as an enabler by facilitating communication with health professionals. They may also act as a barrier by preventing the person with an intellectual disability from making their own choice. The authors suggest that healthcare professionals require more training in informed consent processes for people with an intellectual disability, with a focus on establishing effective communication, reasonable adjustments and trauma-informed care so that people with an intellectual disability can provide consent themselves. They also recommend that people with an intellectual disability are fully involved in making accessible information for people with an intellectual disability and future research in this area.

The perspectives of a co-researcher with an intellectual disability

One of the strengths of the paper by Dunn and colleagues is including the perspectives of two co-researchers with an intellectual disability, and the inclusion of a co-created Easy Read summary. The authors of this editorial include a researcher with an intellectual disability (Keagan-Bull). When Dunn’s paper was discussed with the author team, Keagan-Bull identified the issues that were most important to him. These are his reflections:

“They could do CPR when I might not want it! It is our future that could be affected; it is our bodies that we are making decisions about. People with an intellectual disability are the experts. My carers could get it wrong and may worry about the responsibility. It is important that healthcare professionals talk to us. We know what we want. It is up to healthcare professionals to talk to us in a way that we can understand. One person might understand one way of communicating and another person might not. It is sad that policies aren’t being followed, that people are not seeing the bigger picture. People are being disrespected; people are being forgotten. Being involved in making decisions can make you feel important. Things are changing, but you have to use a magnifying glass to see the changes.”

We underline the importance of listening to the perspectives of people with an intellectual disability, and the importance of co-production. That includes involving people in service development and staff training initiatives, such as the now mandatory training on intellectual disability and autism for all health and social care staff in the UK [16]. It also means involving people with an intellectual disability in all stages of research that is relevant to them. The authors of this editorial lead the co-production team of ten people with an intellectual disability who support the work of the LeDeR programme [17]. In the words of Keagan-Bull: “We can really improve your work. For example,

research participants are often more comfortable talking to someone with an intellectual disability, because I have seen the doors shut before, they have shut in my face too. If you are going to do research in this area, try to include people with an intellectual disability where possible.”

Implications

It is important that we improve informed consent processes for people with an intellectual disability. Clinicians may benefit from the production of guidance that specifically addresses informed consent in people with an intellectual disability and more training in accessible communication, reasonable adjustments, advocacy and relationship dynamics between people and their carers. Research is needed to identify more effective ways of communicating with people with intellectual disabilities in healthcare settings and should evaluate the effectiveness of different types of resources used to facilitate communication (e.g. picture stories and videos). Research should also focus on areas where informed consent is most vital (e.g. for invasive and life changing procedures) and should explore the experiences of sub-groups of people with an intellectual disability, such as children and young adults, people from minority ethnic backgrounds and people with severe disabilities, to further our understanding of how to improve consent processes.

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