

Equity of access to healthcare for a patient with a severe intellectual disability

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My friend Dorothy (a pseudonym) is in her mid-40s. She loves parties and sharing good food with family and friends. She likes watching musicals and films, going to the ballet and the pantomime, to the pub and to church as well as expressing herself creatively. Whatever she is doing, she enjoys looking stylish and receiving compliments about her appearance.

It has not been possible for Dorothy to have a thorough dental examination in her adult life, nor blood pressure checks, women's health checks or any other preventative health checks. Why? Because she has a severe intellectual disability, and there are few services that provide the adjustments she would need to access preventative healthcare. It is also not possible for her to share her story because she has few clear words, and so I, a friend and former member of her care team, have worked with members of her family to write on her behalf.

Dorothy is very wary of unfamiliar situations and people and often finds transitions hard. She finds physical proximity and touch difficult. She is particularly nervous of medical professionals and environments and will strenuously resist any physical interventions or investigations. Because she has very little speech, it is difficult for her to express her needs and concerns. In her care home, where she lives with other adults with intellectual disabilities, she is supported day-to-day by assistants. In addition, she has a circle of support which meets quarterly, helping to ensure that decisions about her care and support are in her best interest, in accordance with the Mental Capacity Act.

The National Health Service functions for patients in many ways. It provides help when a patient seeks support for a specific health problem and screening to identify health conditions. It also provides health checks such as dental check-ups, and preventative health programmes, such as vaccinations. But what happens for someone like Dorothy, who faces barriers to accessing all of these services due to her disability?

It is very likely that if Dorothy develops a health problem, it will take a while for her care team to recognise it. Probably her behaviour will change, but these changes may be subtle or develop, so slowly that they go unnoticed for a long time, or are attributed to events in her daily life. Once the behaviour change has been observed, identifying that there is an underlying medical need will also probably take a while. At the same time, symptoms could be misinterpreted as behavioural challenges; this is of particular concern at the moment as we are aware she may soon develop symptoms of perimenopause. These things make disease prevention,

health screening and health check-ups even more important for Dorothy than for the general public, yet it is rare to find any service that she can easily access. And so: delay, delay, delay.

It is difficult to support Dorothy to brush her teeth and it is quite likely that her teeth have never been brushed to the same daily standard as most people do for themselves, so dental checks are really important. Even for a routine dental check-up, Dorothy needs specialist dentistry and requires sedation. We face similar challenges for all of Dorothy's health issues. For example, even though she is in the clinically vulnerable category for COVID-19, when she was due to receive her first vaccine in early 2021, it was not possible for her to give informed consent, nor to attend a normal vaccination clinic. After many months of negotiations, Dorothy was given a sedative medication to take at home, so that on arrival at the COVID-19 vaccination clinic, she was already relaxed and able to cope with the process. A private room, the company of an assistant, old friend and her sister, plus further sedation on arrival, enabled her to sleep through the vaccination and helped keep her calm and comfortable.

The barriers I have mentioned can seem insurmountable, and people die prematurely every year because of them. As a society, how can we provide people with intellectual disabilities with equitable care? Her family and I think there are three key issues. First, prioritising access to preventative care to reduce the risk of needing urgent surgery (eg, after developing tooth decay) or hospital intervention (eg, due to COVID-19 complications). Second, dealing with the issue of consent (eg, through a 'best interests' meeting) and third, by adapting services around an individual's needs. For preventive care, working towards obtaining consent tends to be a low priority—it requires time-consuming coordination between all parties involved—and adapting services requires extra funding and bold thinking. Healthcare providers may be cautious, for example, with using sedation for non-urgent procedures or checks.

Now that we know that solutions such as short-acting sedation are so straightforward and effective, what Dorothy really needs is for such opportunities to be utilised to the maximum. What else can be done while she is sedated? Blood tests for hormonal changes? Blood pressure checks? Optometry? Audiology? How can we coordinate and co-design care for her that support her health and well-being while minimising the impact on her life and comfort? Would it be possible to set up a regular multidisciplinary one-stop-shop?



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You might be thinking that such a multidisciplinary clinic would be expensive and unnecessary because not many people need sedation for routine procedures. We believe there may be a large unmet need throughout our country and many others. Dorothy and others like her cannot advocate for themselves, and the barriers they face are more complex than for many people with disabilities. Consider for yourself, if there are only a few people with intellectual disabilities using your services, maybe this is because the barriers to access the care you offer are too great. We need creative thinking to provide alternative routes to access care.

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