My name is Sally Britnell. I am a nurse, educator, and researcher who has a PhD in computing and also lives with a disability. I am deafblind and spend much of my spare time normalising disability in our society.

In the ever-advancing landscape of healthcare, integrating digital health technologies has become an undeniable reality. We, as nurses and midwives, consistently strive to provide holistic care, advocate for and with our patients, empower them, educate and foster learning, in other words, assist our patients to achieve the best possible health outcomes. However, amidst this, I paused and asked myself a crucial question: Are we getting it right when it comes to digital health and disability?

In the late 1990s, I recall a pivotal moment when I questioned the extent of my care. Did my role encompass all that I could offer patients, including the possibilities digital health offers? Regrettably, the answer at that time was a resounding "no." It began a personal commitment to infuse digital innovation and data utilisation into my nursing practice.

Fast-forward several decades, and I found myself grappling with a moral dilemma. Had my advocacy for digital health inadvertently contributed to the widening digital divide? By heavily relying on digital health solutions and data, were we unintentionally disadvantaging those without access?

My focus has since become how we provide digital health solutions for those with a disability, and I believe we still have a long way to go.

I thought it would be worth highlighting some common suggestions to improve digital health for those with disabilities. So, of course, I thought it would be advantageous to ask Google or ChatGPT how to improve digital health access for those with disabilities. Some of the ideas returned were:

1. Tailored digital health solutions and care
2. Remote monitoring
3. Accessible telehealth services
4. Tele-rehab
5. Accessible Educational Resources
6. Supportive communities
7. Accessible EHR
8. Close the feedback loops

These are valuable ideas, but these are all technical solutions that require retrofitting our existing systems. However, I believe that with a focus on technological solutions alone, we may be missing the impact of the social context surrounding the societal barriers that impede access. After realising all of the above ideas all had underlying constructs were at play, I asked myself how our society has contributed to the situation we find ourselves in and how the community can work to alleviate it.

At the Digital Health Leadership Summit in May, I was privileged to run a series of discussions on how digital health can improve access for those with disabilities and explore both the social and technical context. These provided a platform for critical discussions on how digital health can enhance access for individuals with disabilities. The resounding consensus was that we can do better the more challenging question was how to achieve this.

Where is the data and digital you may ask?

As context we need to look both backward and forward in time, the social model of health is underpinned by the notion that society disables people. However, the traditional medical model of health implies that the person with the disability needs to adapt to society's requirements. Changing a narrative so embedded in our history is not an easy task. The negative construct of disability has contributed to distrust in the health system and society.[1]

Rebuilding trust, nurturing empathy, and fostering respect between the disabled community, healthcare providers, and technology innovators stand as fundamental imperatives.

One of the first and most shared potential solutions during our discussion was the integration of co-design and universal design principles. These principles ensure that individuals with disabilities actively participate in designing accessible digital health solutions, transcending mere lip service. However, getting the right people at the table at the right time is paramount and with a lack of trust between the community who live with disability and service providers, how do we achieve this?

As a starting point education is a cornerstone in our journey towards improved digital health accessibility. This extends not only to educating healthcare professionals about disabilities but also embedding accessibility considerations into the training of those involved in designing and delivering healthcare technologies. Whaikaha, Ministry of Disabled People[4] encourages organisations to consider the depth and breadth of experience those with disabilities bring to society. It holds a database of its consumers, their qualifications and experience, and availability for governance positions.

In a literature review, I am partway through writing. There are pockets of guidelines that only work toward partial solutions, such as the WCAG[2] guidelines and Ministry of Health Accessibility Guidelines[3], both of which are for web-based solutions – what non-web-based or native solutions?

Much of what we achieve in using these guidelines is still retrofitting or adding workarounds to provide accessibility, often devaluing minorities by design. Would retrofitting to an existing system potentially compound the issue?

A personal passion of mine is the normalisation of disability within our society. With one in four individuals experiencing access needs at some point in their lives[5], this becomes a pressing concern. Recognising the value of individuals with access needs and fostering trust and empathy can pave the way for meaningful change.

As we venture further into the intersection of digital health and disability, I believe that true progress extends beyond the realm of technology. It encompasses a profound understanding of societal dynamics and a relentless commitment to inclusivity. Ultimately, it's about recognising each individual's potential and empathy's power to drive transformation.

A detailed report on the discussions at the How can data and digital improve access for those living with disability[6].

References

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