Cancer screening inequities and people with intellectual disabilities—what should we do to close the gaps?

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Evidence from electronic health records is transforming what we know about the health inequalities experienced by people with disabilities. In *The Lancet Public Health*, Amina Banda and colleagues produced another excellent example of this approach, using large-scale data from the Netherlands to demonstrate that participation in cancer screening programmes is around 20% lower for people with intellectual disabilities than in the general population.[1] The inequities were remarkably similar across the breast, cervical, and colon cancer screening programmes, even though the programmes are different in terms of targeted age and gender, and the demands placed on the participant. The findings are also consistent with reports from elsewhere, despite the divergence in how the screening programmes operate and target participants in different countries.[2] This Article also adds a piece to the puzzle of explaining why people with intellectual disabilities are dying earlier than the general population.[3]

The power of data is to highlight where action is needed. It is fair to conclude that we now know that cancer screening programmes are failing to reach many people with intellectual disabilities. The important question remaining is what we should do to close these gaps. There are many reasons for the screening inequities observed, including lack of information and agency among people with intellectual disabilities, poor skills of health-care workers around disability, and inaccessible information and facilities.[4] Consequently, multifaceted interventions are needed to close these access gaps. Fortunately, there is growing evidence and a range of good practice examples that can help to guide action.

A key starting point is that services and information must be accessible for people with intellectual disabilities, for instance by providing easy-read invitation letters, information, and other support tools such as accessible videos. Reasonable adjustments are also important for improving understanding and participation for this group, such as offering longer or multiple appointments, pre-visits to screening sites, or other modifications such as providing information in visual formats.[5] Adding a reasonable adjustment digital flag in patient records will help ensure that health-care staff are aware of the needed accommodations. Training of health-care workers on intellectual disability is also important to aid the provision of adjustments, such as the National Health Service's Oliver McGowan mandatory training on learning disabilities and autism, in the UK.[6]

Another important concern is that the informed consent process is equitable and accessible for people with intellectual disabilities.[7] Achieving this ambition is complicated because people with disabilities might not have sufficient knowledge about their health needs, options, and rights, and there might be power imbalances between the clinician and the patient. True informed consent will therefore require a person-centred approach and effective communication tailored to individual needs (eg, use of simple language and communication aids), which might take extra time. Health professionals also need specific training to facilitate the informed consent process for individuals with intellectual disabilities, and to guide how decisions are made on capacity for decision making.

Additional support services might also help to improve uptake of cancer screening for people with intellectual disabilities. For instance, disability support staff might play an important part in promoting engagement, attending cancer screening appointments, and providing emotional support when needed.[8] Specific training programmes might also help people with intellectual disabilities. As an example, the *Women Be Healthy* programme in the USA is an 8 week course specifically designed for women with intellectual disabilities to enhance their understanding of and preparedness for cervical and breast cancer screenings.[9] Training is multimodal, and includes videos, engagement with hands-on models, activities, and relaxation exercises, and showed positive impacts in improving knowledge in some areas. Information sessions might also be needed for caregivers to let them know why and how they can support participation in cancer screening.

It might also be appropriate to consider alternative approaches to cancer screening for some people with intellectual disabilities. For instance, individuals who also have physical impairments (eg, due to underlying

cerebral palsy), might benefit from ultrasound screening rather than mammography screening for breast cancer,[10] and home-based screening for cervical cancer.

Overall, it is important that people with learning disabilities can engage with mainstream services and also to provide them with targeted care to close gaps, which is called the twin-track approach to disability inclusion. Importantly, whatever solution is implemented, it must be evidence based and developed together with people with intellectual disabilities to ensure that it is appropriate and acceptable and meets their needs.[7]

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