

An inclusive approach to people with disabilities in diabetes care and education



All people with disabilities deserve dedicated and equitable health care. The UN Convention on the Rights of Persons with Disability states that people with disabilities have the right to enjoy the highest attainable standard of health without discrimination.¹ People with learning and developmental disabilities have poorer health outcomes and greater health inequalities than the general population.² Some disabilities, such as learning difficulties, mental health disorders, and autistic spectrum disorder, might not be immediately apparent and could be considered as invisible disabilities. As a result, the barriers faced by people with these disabilities in accessing health care and education in a timely and appropriate manner can often go unrecognised.

Diabetes has been reported to be more prevalent in people with intellectual and developmental disabilities than in the general population,^{3,4} and people with intellectual or developmental disabilities are also more likely to be admitted to hospital for diabetes-related conditions.^{4,5} Research in this area is scarce, and many health providers do not have a strategy to address diabetes management in populations with diabetes and disabilities.

Self-management refers to daily activities done by an individual to manage and reduce the effect of disease on their health and wellbeing. Although different types of diabetes exist, effective self-management of blood glucose concentrations and dietary and healthy lifestyle changes are the mainstay goals to prevent chronic hyperglycaemia and to reduce the risks of long-term diabetes complications. Quality of diabetes care and education for individuals with all disabilities is often poor, and gaps in education on diabetes self-management in this population are attributed to reduced cognitive ability; short consultations; and communication difficulties, including inadequate communication by health-care professionals and poor communication skills in patients.^{6,7} In a qualitative study of 17 people with mild to moderate intellectual disabilities and diabetes who lived in the Netherlands, 12 people reported that they had had diabetes for about 5 years or longer, eight required insulin therapy, six were

on oral medications alone, and three people managed their diabetes by diet.⁸ The study reported that the main diabetes care was directed towards administration of medication and dietary management, with little focus on self-management behaviours. When participants received information about their diabetes, they reported that they could not understand the information provided, and 17 (71%) of the 24 respondents did not know what had caused their diabetes. Most respondents and their relatives also did not know whether the participant had type 1 or type 2 diabetes.⁸ Other qualitative research has shown that health-care professionals can hold strong and often erroneous views, controlling access to and deciding on who is able to understand and adopt new diabetes technologies and which people are most likely to benefit from these technologies.⁹ Such perception bias influences who will be offered advanced diabetes technologies and how health-care professionals present the benefits or burdens of the technology. It is imperative that health-care professionals are aware of their own implicit bias and help to reduce the stigma of negative attitudes that might exist towards people with disabilities. Additionally, health-care professionals should not make assumptions about a person's ability to understand diabetes technologies but should instead explore ways to deliver the required targeted health education.

Optimal diabetes management might include many daily decisions, such as changing dietary habits, checking blood glucose concentrations, counting carbohydrates, taking medications, and administering and calculating doses of insulin. These are complex decisions that are made by people with diabetes and their caregivers. For people with any type of disability, these daily decisions can pose additional challenges. Diabetes self-management in people with disabilities can be impeded by insufficient support, understanding, and motivation. In general, current support from health and social care providers is inadequate to meet the needs of people with disabilities and their caregivers. Additionally, health-care professionals often do not have the skills and expertise to educate and communicate with people with intellectual disabilities regarding effective



Lancet Diabetes Endocrinol 2022

Published Online

December 2, 2022

[https://doi.org/10.1016/](https://doi.org/10.1016/S2213-8587(22)00343-6)

[S2213-8587\(22\)00343-6](https://doi.org/10.1016/S2213-8587(22)00343-6)

self-management of diabetes and are often unable to tailor education and communication appropriately.^{6,7} In an interview of ten teams of diabetes specialists and 14 teams of intellectual disabilities specialists on their perceptions of caring for adults with intellectual disabilities and diabetes, all respondents identified the need for combined training in and awareness of both diabetes and intellectual disability. Common themes raised by respondents were the need to empower people with disabilities to effectively self-manage their diabetes and the need to develop diabetes information that is understandable by people with intellectual or developmental disabilities.⁷

For diabetes health-care professionals to deliver effective and equitable diabetes care, adequate care-giver and staff training on how to deliver educational programmes to support people with specific disabilities should be provided. Health-care systems and service providers should also be encouraged to make reasonable adjustments for people with learning disabilities, autism, or other developmental or physical disabilities. These adjustments might include visual aids, accessible information, and adapted resources about diabetes education aimed at the cognitive

ability of the person with the disability. Co-production of diabetes information together with people with disabilities is an important step towards engagement in self-management of diabetes, which is characterised by mutual trust, respect, and shared decision making in planning health goals. Adapted health information and resources that are person-centred and tailored to an individual's needs have a better chance of making a difference than generic resources. Raising awareness among the general public and health-care professionals that people with autism and people with intellectual or other developmental disabilities have more health needs than the general population is also crucial.

Developing multidisciplinary consultations between health-care professionals with expertise in diabetes and learning disabilities or autism practitioners to share knowledge and resources can improve the quality of care, thereby leading to improvement in diabetes self-management. A proactive approach to diabetes review clinics or health checks can reduce barriers to attending appointments by making health checks more person-centred (panel).

A large proportion of managing any type of diabetes effectively relies heavily on the individual making appropriate, health-conscious decisions on a day-to-day basis. Therefore, it is imperative that people with diabetes and disabilities, including intellectual disabilities, fully understand and are involved in their own condition and treatment. Positive and consistent engagement with health-care professionals in the education of diabetes self-management is associated with improved health outcomes, reduced diabetes complications, and improved quality of life.¹⁰ If there is no active commitment in managing the health of people with diabetes and disabilities from all parts of the health-care structure, the risk of serious and potentially fatal complications increase.

I declare no competing interests.

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Panel: Recommendations for diabetes review clinics and diabetes health checks in people with disabilities

- Consider a meet-and-greet first appointment with the health-care team as an initial step to get to know staff and provide photos of the health-care team
- For continuity of care, make reasonable adjustments so that the person is seen by the same doctor
- Allow extra consultation time for people with disabilities and their caregivers, and ensure reception staff offer double appointments where possible
- Ensure that the person is always accompanied by a caregiver or someone familiar to advocate for them during the consultation
- Build awareness of the disability with members of the health-care service, including the reception staff and nursing staff
- Use and adapt resources to provide education for various procedures, such as monitoring blood glucose, blood pressure, and height and weight. Such resources could include a story or an online video about a visit to the doctor or nurse
- Promote patient-centredness, mitigate barriers to booking follow-up appointments, reduce time spent in waiting rooms, improve accessibility of clinic rooms (especially for physical examinations), and adapt language when giving information

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