

An Australian Government Initiative

NDSS Helpline 1800 637 700 ndss.com.au

Effective communication with people living with diabetes and intellectual disability

A guide for health professionals



diabetes australia

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The Australian Diabetes Educators Association and Diabetes Australia take no responsibility for any adverse consequences that arise as a result of using the content of the guide for clinical purposes. Trainees and other health professionals need to consider the individual circumstances and needs of people with diabetes when they are applying the skills outlined in this resource in their clinical practice information.

Foreword

It is a great privilege to introduce you to this guide for health professionals, on communicating with people who have an intellectual disability about their diabetes.

This guide, in conjunction with the corresponding online training module, provides practice recommendations to health professionals to better support people living with intellectual disability and diabetes, as well as their families, carers and support workers.

This guide has been funded through the National Diabetes Services Scheme (NDSS) and developed by the Australian Diabetes Educators Association (ADEA). The NDSS is an initiative of the Australian Government, administered by Diabetes Australia. The NDSS aims to enhance the capacity of people with diabetes to understand and self-manage their life with diabetes. ADEA is the leading Australian organisation for health care professionals providing diabetes care and education. ADEA advocates for evidenced-based best-practice diabetes education to ensure optimal health and wellbeing for all people affected by, and at risk of, diabetes.

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If you require further information about this resource, please contact ADEA on **02 6287 4822** or email **admin@adea.com.au**.

Please refer people with diabetes to the NDSS Helpline on **1800 637 700** or **ndss.com.au** for information, self-management support or products.

Abbreviations

AAC	Augmentative and alternative communication
ABS	Australian Bureau of Statistics
ADEA	Australian Diabetes Educators Association
CDE	Credentialled Diabetes Educator
DSME	Diabetes self-management education
NDIS	National Disability Insurance Scheme
NDSS	National Diabetes Services Scheme
UK	United Kingdom
WHO	World Health Organization



Introduction to intellectual disability

Intellectual disability originates during the developmental period (before 22 years) and involves impairments in both intellectual functioning and adaptive behaviour.^{1,2}

Intellectual function refers to an individual's ability to learn, reason, and problem-solve.² Adaptive behaviour is the collection of conceptual, social, and practical skills that are learned and performed in everyday life.²

In the medical model of disability, intellectual disability is often categorised as mild, moderate, severe or profound, based on standardised intelligence testing and assessment of adaptive behaviour.³ This categorisation can be useful to indicate the level of disability and corresponding support an individual needs in their day-to-day functioning, cognitive function, and communication.³ However, all people with intellectual disability are unique and their experience of intellectual disability can vary within these classifications.

The impact of intellectual disability and the level of support a person may need will vary from one individual to the next.

The impact of intellectual disability and the level of support a person may need will vary from one individual to the next. It is also dependent on many factors, including their environment and level of family and community support. Most people living with intellectual disability are considered to have mild disability. With support, they can generally learn the skills to lead relatively independent adult lives. Individuals with moderate, severe or profound disability (according to the medical model) require more support and have increased complexity of care. An alternative to the medical model is the social model of disability, which distinguishes impairment from disability. In this model, disability is the restriction of activity resulting from an environment (physical and social) that fails to accommodate the needs of people with impairments.⁴ As a result, they are excluded from participating in mainstream social activities.

The social model of disability advocates for a more inclusive environment that enables people with a disability to participate on an equal basis to others. This encompasses not only environmental and structural changes but also addressing attitudinal barriers often faced by people with a disability. It has been argued that health professionals could improve their practice by learning more about this model and how it contrasts with the medical model of disability.^{4–6}

Australia's Disability Strategy 2021–2031 is based on the social model of disability. It recognises attitudes, practices, and structures can be disabling and act as barriers to people with disability, preventing them from fulfilling their potential and exercising their rights as equal members of the community.⁷



Intellectual disability and health inequities

In 2018, there were around 746,200 Australians (3.0%) with intellectual disability.⁸ Research has found individuals with intellectual disability not only have a higher prevalence of chronic health conditions, including diabetes, but they also receive significantly poorer management of these conditions.^{9,10}

In a research summary of health inequities and people with intellectual disability, the authors identify people with intellectual disability as a minority group with significant health inequality, highlighting a need for action.¹⁰ They conclude that Australians with intellectual disability:¹⁰

- » have extremely poor health status
- » have multiple barriers to timely, affordable, and appropriately equipped health services
- » experience a mismatch between health needs and accessible services, which has a major impact on their health
- have substantially elevated mortality rates above the general population (mean age of death 27 years earlier), including deaths from potentially avoidable causes.

The reasons for poorer health outcomes in people with intellectual disability are complex^{7,10} and health professionals face many challenges when working with individuals with intellectual disability, including:¹²

- » communication difficulties
- » inaccessible or incomplete medical history
- » lack of training in how to communicate with people with a disability
- » the complexity of care
- » inadequate professional support
- » fragmentation of disability support and health care services.

In 2022, The Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability released a report which makes 9 findings and 12 recommendations regarding the education and training of health professionals in relation to people with cognitive disability.¹¹ Key recommendations include:

- » A steering committee to develop a cognitive health capability framework that informs education and training for health professionals across all training stages
- » The inclusion of people or representatives of people with lived experience of cognitive disability on the steering committee
- » Specifying the core knowledge, skills and attributes required to provide quality health care for people with cognitive disability within the capability framework
- » The Australian Government and education providers take steps to ensure that continuing professional development programs address the health care of people with cognitive disability

One aim of Australia's National Roadmap for Improving the Health of People with Intellectual Disability is to provide more support for health professionals so they can deliver better care for people with intellectual disability.¹² The Roadmap aims to ensure that health professionals have the necessary knowledge, skills, and attitudes to provide high-quality, appropriate, and disability-informed health care for people with intellectual disability.¹² Australia's National Disability Strategy is also committed to improving access to and capabilities of health services to ensure they meet the needs of people with a disability.⁷

> Australia's National Disability Strategy is also committed to improving access to and capabilities of health services to ensure they meet the needs of people with a disability.

Intellectual disability and diabetes

The health inequities and challenges in providing optimal health care for people with intellectual disability are particularly relevant to the management of diabetes, a condition that requires intensive education and self-management.

Given studies suggest an increased prevalence of diabetes among people with intellectual disability, with one meta-analysis finding a 2.46 higher odds than age- and gender-matched controls,¹³ it is important for diabetes health professionals to understand how to best support people with intellectual disability living with diabetes.

However, the evidence on what this looks like is limited. A 2014 systematic review of the prevalence, incidence, and impact of diabetes in people with intellectual disability identified a lack of research evidence to establish what might constitute effective evidence-based practice, including self-management, for people with intellectual disability.¹⁴

A qualitative study exploring the perceptions and experiences of 29 UK-based health professionals working in diabetes and intellectual disability services identified three main themes relating to improving diabetes care in people with intellectual disability:¹⁵

- 1. Enabling access to services to meet diabetes-related care needs of people with intellectual disability.
- Communication and service improvements between staff, people with intellectual disability, and across services.
- Providing person-centred diabetes care and developing adapted resources to increase self-care.

Health professionals in this study reported feeling they lacked sufficient knowledge, access to resources and information, and time to enable person-centred care that adequately met care needs and addressed the challenges presented to services.¹⁵

Diabetes self-management education (DMSE) and intellectual disability

Diabetes self-management education (DSME) is an integral part of diabetes care for all individuals living with diabetes, including those with disabilities.¹⁶ However, individuals with intellectual disability may face barriers to accessing DSME and to the DSME process, making it more difficult to carry out necessary self-care tasks. Therefore, health professionals should consider the following three points when considering DSME for individuals with intellectual disability in their care.

- » Have a good understanding of how the individual's intellectual disability impacts their ability to learn and communicate, so tailored education can be delivered to encourage self-management. This will help ensure DSME is delivered in a way that enables the individual achieve similar goals in implementing and sustaining the behaviors needed to self-manage their diabetes as those without a disability.¹⁶
- » Assume responsibility for learning about how the individual's disability impacts DSME and the resources available to support self-management for that individual.¹⁶ This includes understanding the NDIS supports available to assist the person with intellectual disability.
- » Ensure clear communication and shared* information across the multidisciplinary team caring for the individual. This will help enhance and coordinate the diabetes education provided, both at an individual level and in the overall DSME plan.¹⁷

^{*} Appropriate consent from the person with intellectual disability or their nominee must be obtained before sharing any information about that individual.

Communication matters

Challenges with communication between people with intellectual disability, their circle of support, and health professionals have been identified as major contributors to suboptimal health care for these individuals.¹⁷ In people with diabetes and intellectual disability, studies have consistently identified poor communication with healthcare professionals as a barrier to optimal diabetes management.¹⁷

A 2022 systematic review of the barriers and facilitators to managing diabetes with insulin in adults with intellectual disabilities highlighted the need for improvements in communication and the development of networks between the different services that support people with intellectual disabilities and diabetes.¹⁷

Other research suggests sharing health information in general practice care for people with intellectual disability could be improved by increasing medical consult duration, better record keeping and preparation for consults, and improving health professionals' knowledge and communication skills.¹⁸ One tool that can help with this is the Comprehensive Health Assessment Program (CHAP), an evidencebased tool for conducting annual health assessments for people with intellectual disability in Australia.¹⁸

Research has identified several barriers and enablers to exchanging health information with people with intellectual disability. These are summarised in the table below:^{17,19-23}

Barriers	Enablers
1. Difficulties in understanding and communication	1. Health professionals preparing for consultations
2. Insufficient health information provided by individuals and support people	2. The attendance of informed carers/support people during the consultation to provide relevant
3. Difficulties retaining information from	person with intellectual disability
individuals and support people	3. Tailored adjustments in communication by the
4. Insufficient information in records from support people regarding diagnosis, results, and management plans, and incomplete health histories	
	 Ongoing relationships between the individual with intellectual disability and health professionals
	5. Longer and more flexible consultation times
5. Time constraints and a mismatch between the	
working hours of support people and health professionals	 Provision of information in writing (hard copy or electronically) and requests for support people to record and share management plans
6. Lack of experience and training of health professionals regarding the healthcare needs of people with intellectual disability	
7. A shortage of tailored information and educationa	al contraction of the second se

resources for people with intellectual disability

Principles for effective communication with people with intellectual disability

- 1. People with intellectual disability are entitled to receive the same standard of health care as others, recognising the numerous barriers to care, including physical barriers, lack of knowledge by health professionals, stereotyping, or communication difficulties.^{7,12,24}
- 2. People with intellectual disability are entitled to be treated in the same way as those without disability, while also addressing their disability-related needs. ^{7,12,24}
- **3.** Each person with intellectual disability is unique and requires an individualised approach to meeting their healthcare needs.
- 4. People with intellectual disability vary greatly in their cognitive awareness and communication abilities. Additional skill, sensitivity, and time are therefore required to initiate and maintain effective health communication with people with intellectual disability.²⁵ However, it is important not to make assumptions about an individual's cognitive and communication abilities.
- 5. People with intellectual disability and diabetes experience enhanced health when they actively engage in their own health care. Health professionals can facilitate this by tailoring their communications to the needs of the individual and their circle of support.
- 6. People with intellectual disability should receive DSME in a way that enables them to achieve similar goals in self-managing their diabetes as those without disability.¹⁶





1.

Prepare for health care consultations

People with intellectual disability have diverse health needs. Managing and supporting them in their care can often be more complex and requires more time than for people without disability. Your preparation for consultations can help optimise the care, support, and health outcomes for people with intellectual disability.

Key recommendations for health professionals to prepare for consultations: $^{\rm 25,26}$

- » Learn more about working with people with intellectual disability, including communication challenges and needs, particularly if new to working with this population. This includes working with the individual's circle of support.
- » Become familiar with methods of alternative communication for people with intellectual disability and how they are used (see page 14).
- » Where possible, obtain the person's medical history before the consultation (after obtaining appropriate consent), particularly if this is the first consultation with them.
- » Make appropriate use of the person's health records (including their My Health Record) to support good information exchange.
- Where possible, obtain information about the person's sensory requirements and how reasonable and necessary adjustments can be put in place.
- » Allocate a longer consultation time to accommodate the communication needs of the person with intellectual disability.

- » Send appointment reminders after finding out the individual's preferred format for reminders and their preferred contact if they have a support person help to organise their appointments.
- » Send additional information about what to expect at the appointment to ensure the person is prepared for the consultation, which may help to reduce anxiety. The Department of Health has sample letter templates available at health.gov. au/resources/collections/resources-for-healthprofessionals-managing-patients-with-intellectualdisability.
- » Avoid keeping the person waiting for long periods by scheduling appointments at less busy times and/or calling them if long delays are anticipated.
- Encourage individuals and support persons to be prepared with a list of questions to ask, an up-to-date medical history, and relevant observations and records that will assist with the consultation. This could include asking them to complete a health/medical history form with relevant information and send this back before the appointment or bring it on the day.

NDSS registration

People with intellectual disability may require more support to register for the NDSS. Check the person is registered and knows how to access the scheme.

Registration with NDSS is free and open to all Australians who are diagnosed with diabetes. It is important that people with diabetes register with the NDSS so they can access information, support services and subsidised diabetes products.

More information can be found on the NDSS website at **ndss.com.au/registration.**

2. Consider the consultation environment

The environment in which health care consultations occur plays an important part in facilitating good communication and should be considered alongside improving the communication skills of individual practitioners.

Key recommendations for health professionals to optimise the consultation environment:^{25–27}

- » Locate diabetes services in a wheelchair accessible location.
- » Provide a space for communication, which is quiet and free from distractions.
- Where possible, have the person with intellectual disability see the same health professional at each visit. This allows the health professional and individual to get to know each other well and to better understand their nonverbal communication and other cues.

- » Provide suitable waiting room activities or an alternate room for waiting, if required. Consider asking people to bring their own familiar activities.
- Find out if the person wishes their support person to stay for the consultation, and if they are happy for them to speak on their behalf. If they stay in the consultation, seating should be arranged to ensure that the health professional focuses on the client rather than the support person.
- » If the person uses a communication device, ensure they have access to it during the consultation and find out how it is used.
- » Arrange a translator, if required, for people with intellectual disability who are deaf and communicate with sign language.



3.

Tailor communication to the individual

Many people with intellectual disability have communication challenges, particularly those whose disabilities affect speech, hearing, or sight. However, every person is unique and the extent of their ability to communicate and the best way to address this will vary. Consider the following general recommendations, but tailor communication to the needs of each individual.

Key recommendations for health professionals to tailor their communication to the individual:^{25–28}

- Find out how the person communicates before asking questions (e.g. how they indicate 'yes' or 'no') and endeavour to use this to improve communication during the appointment.
- » Speak directly to the person with a disability, rather than a support person, regardless of the extent of their disability and their degree of comprehension.
- » Ask for permission to direct questions and conversation to their support person if there are difficulties communicating with the person. Encourage the person to be actively involved in the communication, either verbally or nonverbally, to help them feel engaged.
- » Gain the person's attention and eye contact before speaking, if possible, recognising that this may be challenging for some people.
- » Explain what will happen in the consultation in simple terms, including telling the person what will be done and why, if you need to examine them.
- » Use age-appropriate language i.e. avoid talking to an adult as if they were a child.
- » Use short, simple sentences and plain language. Speak slowly and clearly and pause frequently, so as not to overload the person with information. Ask one question at a time, avoiding doublebarreled questions.
- » Use a normal tone of voice and do not raise your voice or shout, unless required (e.g. due to hearing difficulty).
- » Be aware of and responsive to the emotional needs of the person, along with any fears or negative reactions they may feel, including those linked with previous negative health system experiences.

- » Be sensitive to nonverbal cues.
- » Become comfortable with silence. Many individuals need extra time to process questions and/or formulate a response. Talking while they are doing this could distract them.
- » Be aware that some people may have difficulties speaking but still be able to understand what is said to them, while other people's expressive speech may give the impression that they understand more than they actually do.
- » Check the understanding of what the person has said by repeating key points back to them and asking for confirmation or correction. Don't pretend to understand what they said.
- » Provide clear explanations and always check that the person has understood what was said by asking them to repeat it back in their own words.

Communication preferences of people with intellectual disability

In a small qualitative study, individuals with a mild or moderate intellectual disability formulated their preferences for communication with their doctors¹².These preferences can be summarised using the acronym LANGUAGE:

- 1. Listen carefully to me
- **2. Allow** me to tell you about my symptoms
- 3. Need to take me seriously
- 4. Give sufficient time to the consultation
- 5. Understand and show consideration for what I want
- 6. Ask questions about my symptoms
- 7. Gain permission before talking to my support worker about me
- 8. Explain and demonstrate before starting a physical examination

4.

Consider language use

The words we choose, and the way we use them, influence, persuade and affect how people view the world.²⁹ Words can create a culture in which people feel valued, understood, and supported, or one in which people feel misunderstood, undermined, stigmatised, and excluded.²⁹ Words can also express conscious or unconscious bias.²⁹

Key recommendations for health professionals regarding language use:^{29,30}

- » Treat each person with respect and dignity.
- » Be aware of the impact of the language they use when speaking to and about people with intellectual disability and diabetes.
- » Use language that engages people with intellectual disability and diabetes and supports their daily self-care efforts.
- Avoid language that is patronising, that de-motivates or that induces fear, guilt, or distress. This includes language that is derogatory, abusive, or negative about disability.
- » Understand that each person is different and will have their own preferences for language use, so ask the person what works for them, and respect their wishes. If in doubt, use person-first rather than identity-first language.
- » Most importantly, focus on the person and ability, not the disability.

"The language (words and phrases) that people use about people with disability has an impact on the social narrative about people with disability, how we are perceived and treated by the general public, which affects the systemic structures in society. It also has an impact on our sense of self, how we feel about ourselves, how we navigate society, and interact with other people. It is important that there is awareness of the meaning behind the words that are used when talking to, referring to, or working with people with disability."

PWDA Language Guide: A guide to language about disability. People with Disability Australia (PWDA), 2021

Diabetes Australia has similar guidelines on recommended language use when communicating with or about people with diabetes, which should be used alongside the recommendations above.²⁹ The full position paper can be accessed at www.diabetesaustralia.com.au/position-statements.

Terms to avoid	Terms to use instead	Rationale	
People living with disability, the disabled Intellectually challenged, mentally retarded, mentally disabled, handicapped, simple	People/women/children with disability	Focus on the person, not the disability.	
	Has intellectual disability or cognitive disability	Use the word disability as an uncountable noun (e.g. person or people with disability, rather than person with a disability or people with disabilities.	
Suffers from, victim of, crippled by,	Has a chronic health condition	These terms imply a person with disability is	
incapacitated by, afflicted by	Has intellectual disability or cognitive disability	suffering or has a reduced quality of life. Use neutral language, instead.	
Able-bodied, abled, healthy, normal	Person without disability or non-disabled person	Some people with disability reject the term 'able-bodied' because it implies people with disability lack able bodies.	
Wheelchair-bound, confined to a wheelchair	Uses a wheelchair or mobility device	A person who uses a wheelchair is not bound by the chair; they are enabled and liberated by it.	

Table 2: Examples of recommended language from People with Disability Australia³⁰

Use appropriate communication tools and resources

Communication difficulties in people with intellectual disability can make the exchange of health information more challenging, leading to less effective consultations and suboptimal health care.¹⁷

5.

The use of appropriate tools and resources can help to aid communication and optimise health outcomes.

Key recommendations for health professionals to improve how they communicate health information: ^{26,28}

- » Become familiar with the various communication tools used by people with intellectual disability and how they are used. Known as augmentative and alternative communication (AAC) systems, these can be formal or informal and aided or unaided (Refer to text box Communication tools commonly used by people with intellectual disability).
- » Identify an individual's preferred form of learning before or at the start of the consultation and personalise education accordingly.
- » Be aware that some people may have difficulty expressing their feelings and describing symptoms. In this case, involving a support person who knows them well may help. Also, consider using resources such as picture boards to support people in talking about their body and symptoms.
- » Provide information and education resources that are tailored to the needs and learning styles of the person with intellectual disability. This might include information written in easy read, a style of writing that uses simple sentences and images, or videos. Some examples can be found at: https:// www.gcidd.com.au/diabetes



Communication tools commonly used by people with intellectual disability^{22, 23}

- 1. Communication books and boards use pictures, symbols and/or the alphabet to communicate specific messages.
- 2. Electronic devices vary in complexity from those with a limited number of messages to those which allow the user to construct longer messages by typing words or accessing picture symbols.
- 3. Key word signing such as Makaton vocabulary which uses signs to indicate needs and wants or to formulate other messages.
- 4. Informal communication such as facial expressions, gestures, body language, vocalisations or eye contact.
- 5. Auslan for those who are hearing impaired.

Understand the NDIS and diabetes care

The National Disability Insurance Scheme (NDIS) supports over 500,000 Australians with a permanent and significant disability to access the services and supports they need.³¹ The aim of the NDIS is to help individuals with a disability gain greater independence, develop new skills, apply for jobs, or volunteer in their community, contributing to an improved quality of life.³¹ It also connects people with a disability to services in their community.³¹

6.

The NDIS can't provide health services for diabetes management that are provided through the Australian health system. However, they will fund diabetes supports (called diabetes management supports) if they are related to the person's disability or if someone has trouble managing their diabetes on their own because of their disability.

It is recommended that diabetes health professionals develop and maintain their knowledge of NDIS funding available to support people with diabetes and intellectual disability. They can also increase awareness of the available funding for diabetes management support by asking people with intellectual disability whether they have this included in their NDIS plan. If they don't and it is required, health professionals can also provide a letter of support for relevant disability-related diabetes supports. It is important for this letter of support to focus on why their disability requires them to have additional help in order to achieve their diabetes self-care. **More information** can be found by visiting: ourguidelines.ndis.gov.au/supports-you-can-accessmenu/diabetes-management-supports/what-typesdiabetes-management-supports-do-we-fund.

The diabetes management supports that may be funded by the NDIS include:

- 1. A nurse to create and review a disabilityrelated diabetes management plan
- 2. Training for support workers to assist someone with their diabetes management needs
- 3. A support worker to monitor glucose levels and give insulin or other diabetes medication
- 4. A nurse to monitor glucose levels and give insulin if someone has diabetes which is difficult to manage or more complex disability needs
- 5. Assistive technology to help the person manage their diabetes if they can't access these through the health care system.



Work with support people

Many people with intellectual disability rely on the help of others to support them to live and actively participate in their community. This may include family members and/or formal support workers, collectively referred to as support people in this document.

According to the Australian Bureau of Statistics (ABS), in 2018 approximately 81% (4 in 5) people living with intellectual disability under the age of 65 years received assistance with activities of daily living.³³ The most common form of assistance is help with cognitive or emotional tasks, followed by mobility, health care, oral communication, self-care and reading or writing.³³

Support people play a key role in facilitating communication between the person with intellectual disability and their health professionals. They also play an important role in helping the person with intellectual disability manage their diabetes. However, several studies have identified the need for better education of support people, to enable them to perform this role.^{15,32,34}

Collaboration between people with intellectual disability and diabetes, their circle of support and health professionals has been identified as an important facilitator of optimal person-centred diabetes care.¹⁷

Key recommendations for health professionals to work with support people:^{22,32}

- » Establish good communication with the support people of individuals with intellectual disability, to obtain relevant health information and to implement treatment/management recommendations.
- » Provide the education and support (initial and ongoing) to support people to enable them to provide best-practice diabetes care and/ or to facilitate and encourage diabetes selfmanagement in the individuals with intellectual disability who they support.
- » Facilitate the sharing of information (where there are multiple support people) by providing written guidelines (hard copy or electronic) and encouraging the use of communication books.

Collaboration between people with intellectual disability and diabetes, their circle of support and health professionals has been identified as an important facilitator.

Summary

Good communication is everyone's responsibility. Good communication between health professionals and people with intellectual disability and their support people is essential for optimising health outcomes for these individuals.

This is particularly the case for people with intellectual disability and diabetes, due to the important role of self-management in diabetes care. Improving a health professional's understanding of the needs of people with intellectual disability and diabetes will help them deliver the best diabetes care and self-management education possible. Effective communication also helps the health professional make their care individualised and person-centred.



Further information

Diabetes Australia Position Statement. Our Language Matters: improving communication with and about people with diabetes

diabetesaustralia.com.au/position-statements

National Disability Services nds.org.au

Australian Disability Network. australiandisabilitynetwork.org.au

Australia's Disability Strategy 2021-2031

dss.gov.au/disability-and-australias-disability-strategy-2021-2031

National Roadmap for Improving the Health of People with Intellectual Disability health.gov.au/our-work/national-roadmap-for-improving-the-health-of-people-with-intellectual-disability

National Centre of Excellence in Intellectual Disability Health health.gov.au/our-work/national-centre-of-excellence-in-intellectual-disability-health

Adult Comprehensive Health Assessment Program (CHAP) health.gov.au/resources/publications/chap-adult-standard

NDIS: Diabetes management supports

ourguidelines.ndis.gov.au/supports-you-can-access-menu/diabetes-management-supports

Queensland Centre for Intellectual and Developmental Disability (QCIDD): Living with Diabetes www.qcidd.com.au/home/individuals-2/diabetes-to-the-point/diabetes/

Department of Health and Aged Care: Resources for health professionals managing patients with intellectual disability

health.gov.au/resources/collections/resources-for-health-professionals-managing-patients-with-intellectual-disability

United Nations Convention on the Rights of Persons with Disabilities (UNCRP humanrights/gov.au/our-work/disability-rights/united-nations-convention-rights-persons-disabilities-uncrpd

Development of this document

This guide was developed to assist health professionals in improving their communication with individuals with intellectual disability and diabetes and/or their support people.

This document was originally published in 2020 and was written following a review of the current literature; a survey of health professionals, people with diabetes and intellectual disability, and support people of people with diabetes and intellectual disability; and with input from an expert reference group. The document was updated in 2024 based on feedback from a second expert reference group and a review of recent research.

This document provides information for health professionals to improve their understanding of the health care challenges and needs of individuals with intellectual disability and diabetes, particularly regarding the communication of health care information. It also encourages all health professionals and their health service management to advocate for health organisations to consider and accommodate the needs of people with intellectual disability and diabetes, along with their support people.

The document has been developed for the range of health professionals who may work with people with intellectual disability and diabetes, including medical practitioners, nurses, and allied health professionals.

If you require further information about this resource, please contact ADEA on 02 6173 1000 or email inquiries@adea.com.au.

Please refer people with diabetes to the NDSS Helpline on 1800 637 700 or ndss.com.au for information, self-management support or products. Many thanks to the following people for generously providing their expertise to this project:

Expert Reference Group:

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- » Anthea Gellie, Policy & Project Officer, National Disability Services
- » Angelina Atita Tapim, Carer (Carers Australia)
- » Jayne Lehmann, Registered Nurse (RN)/ Credentialled Diabetes Educator (CDE), Ed Health Australia
- » Kaye Powell, Consumer Representative Health Care Consumer Association (HCCA)
- » Noela Baglot, Consumer Representative Health Care Forum (HCF)
- » Ruth Went, Clinical Nurse, The Disability Trust
- Associate Professor Roy Rasalam, University of Melbourne (Medicine); Alfred Health (Endocrinology & Diabetes)
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Notes

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