



Regular Access to Health Care

Practice Alert

December 2024



Key Points

- ◆ Participants have a right to maintain good physical, oral and mental health.
- ◆ People with disability can experience barriers to accessing health care which can result in poor health, chronic disease, mental health conditions and early death.
- ◆ Accessing health care services regularly can reduce health risks and poor health outcomes by preventing illness or diagnosing and treating problems early.
- ◆ Providers should monitor participants' health and wellbeing, and support participants to maintain their health. This includes supporting participants to access health care services and health checks.
- ◆ A Comprehensive Health Assessment Program (CHAP) identifies health issues and conditions that are preventable for people with intellectual disability. It enables management of health needs and reduces health risks and poor health outcomes. Fire safety risks for people with disability

Risk of poor health for people with disability

People with disability are at greater risk of poor health, chronic conditions, and developing health problems and mental health conditions.^{1,2,3,4} People with disability also have poorer access to health care services and inadequate attention to care needs compared to people without disability^{4,5} resulting in greater unmet health care needs.^{6,7,8,9} This can affect quality of life and increase severe illness and early death.^{8,9,10,11,12,13,14,15}

A person's individual social, medical and lifestyle factors can influence their health. People with disability can be at greater risk of health problems due to one or more of the following factors:

- ◆ **Social determinants of health** – non-medical factors can influence health outcomes such as income, education level, housing, unemployment and early childhood development.^{16,17}
- ◆ Access to health care services – people with disability experience difficulties accessing health care services due to

a variety of reasons such as lengthy waiting times, cost, inaccessible buildings, discrimination by health professionals, inaccessible communication and information, limited health literacy, lack of support, and lack of knowledge and understanding of disability from health care providers.^{4,5,6,18}

- ◆ Type of disability or other health conditions – people with intellectual disability, people with vision impairment and people with two or more chronic conditions or disabilities are at the greatest risk and experience greater unmet health needs.^{4,6,10,19}
- ◆ Diagnostic overshadowing – symptoms or changes in behaviour can be assumed as part of the person’s disability and not recognised as a sign of a health problem. This can cause health problems to go untreated.⁸ People with disability may communicate in ways that are specific to them and not understood by others. For example, people with intellectual disability may not be able to explain their symptoms or say they feel unwell.²⁰
- ◆ Lifestyle risk factors – some conditions and choices of a person can lead to developing health conditions or worsen existing ones for a variety of reasons such as poor diet and nutrition, lack of exercise, isolation, stress, smoking and alcohol intake.⁴ For more information on lifestyle risk factors and reducing risk, see [Practice Alert: Lifestyle Risk Factors](#).
- ◆ Barriers to maintaining health – certain barriers exist for people with disability to manage their own health or affect what

is in their control. For example, needing assistance to be physically active, or taking medication that increases appetite or affects behaviours.¹²

These factors can lead to a person with disability at increased risk of: ^{8,10,21,22,23}

- ◆ Having more than one chronic condition, often a mental health disorder such as depression or anxiety, and/or secondary disability
- ◆ Increased hospitalisation, longer hospital stays and post-surgery complications
- ◆ Reduced functional capacity or reduced physical functioning
- ◆ Increased psychological distress
- ◆ Increased use of multiple medications (polypharmacy)
- ◆ Misdiagnosis of symptoms
- ◆ Respiratory illness and cardiovascular diseases
- ◆ Diabetes
- ◆ Cancer
- ◆ Dental problems
- ◆ Early death

Many health problems experienced by people with disability can be prevented or reduced by managing health needs and accessing appropriate health care services regularly.

Regular access to health care services

Maintaining good physical and mental health is an important factor in a person’s quality of life and a way to maintain their

independence and ability to continue to participate in society.²⁴

Regular access to health care services is part of preventive health care. Preventive health care are actions aimed keep people healthy, and prevent the risk of poor health, illness, injury and early death.^{11,25,26} This can include regular and comprehensive health checks determined by their health professional. Health checks can include a physical exam, blood tests, cancer screening, vaccinations, swallowing tests and dental care.^{4,23,27} This can prevent health risks by finding and treating health and mental health conditions early before they become a problem or get worse,^{16,17,28} and support the management of health and chronic conditions.^{29,30}

Some people with disability may be eligible for specific health assessments under Medicare. A health professional will be able to determine eligibility. [See the Department of Health and Aged Care | MBS Health Assessments Items 701, 703, 705, 707 and 715](#) for further information.

Providers should monitor participants' health, safety and wellbeing, and support participants to manage their health and access appropriate health care services under the Practice Standards of Provision of Supports Environment and Risk Management. Participants should be supported to regularly access health care services, take care of their health and improve their knowledge of health care. Providers should support participants in the following ways:

Monitor participants' health

Early detection of changes in a participant's health and wellbeing means that the participant can access health care services earlier and may prevent illness and health conditions from progressing. It is important to have good record keeping and knowledge of the participant's usual health so that observed changes can be noted. Changes to observe include:

- ◆ Unexpected weight loss or gain
- ◆ Sudden change in eating habits
- ◆ Sudden breathlessness
- ◆ Drop in activity due to fatigue
- ◆ Expressions of pain
- ◆ Changes in behaviour or functioning

Providers should ensure participants are supported to promptly access a doctor when participants are unwell or changes to their usual health are noticed.

Support participants to access health care services

People with disability have health care needs and require access to health care services to meet these needs. Health care services can range from different health professionals such as their regular doctors, specialists, and other health professionals. A person's care may require coordination between different health professionals.

- ◆ Consider the level of support and accessibility needs the participant has to make and attend the health appointment, or to have tests, scans or other procedures.

- ◆ Where appropriate schedule longer appointment times to give adequate time for participants to discuss concerns. Consider encouraging family members or supporters to attend appointments to support participants health needs.
- ◆ Time appointments on a day and time when it is likely to be less busy. Often Mondays and Fridays are very busy times. Talk to the office and make a time that works for both the participant and the doctor.
- ◆ Assist the participant to use their preferred method of communication during appointments.
- ◆ Bring along any important health history, such as support plans, health care plans, any written records of health issues affecting the individual and list of medications including over the counter supplements.
- ◆ Ensure that any information received from the health practitioner is provided to the participant in an accessible format.
- ◆ Support the participant to participate in the development of their health care plan.
- ◆ Work with the health practitioner to support the participant to understand their symptoms, treatment or health care plans and recommended changes.
- ◆ Ensure that any health care recommendations are documented, implemented with the participant and monitored.
- ◆ Support the participant to attend follow up and regular medical appointments including dental appointments.

Using the Comprehensive Health Assessment Program to promote comprehensive health assessments for people with intellectual disability

Having regular health assessments is a key strategy to reduce health inequalities experienced by people with intellectual disability.²³ Regular health assessments have been found to help identify previously unrecognised health needs, promote healthy lifestyles and reduce preventable emergency admissions.²³

The Comprehensive Health Assessment Program (CHAP) is a free evidence-based health assessment tool that can be used to effectively screen for health needs that are commonly unrecognised or poorly managed for people with intellectual disability.^{31,32}

The CHAP is a booklet that can be taken to the doctor to guide conversations and record and plan for health concerns. It involves the participant and doctor discussing and reviewing the participant's medical history, current health conditions, medications and any lifestyle risks. It is a two-part questionnaire to complete with the participant, their support person and their doctor.

1. Part one of the questionnaire asks about health history and is completed by the participant and/or

with a support person. This is shared with the participant's doctor.

2. Part two requires the doctor to fill in the rest of the questionnaire working with the participant and their support person. The doctor will perform an assessment of the participant's health.
3. On completion of the doctor's assessment, a health action plan can be made. This should be done in collaboration with the doctor, the participant and their support person.

It is important that providers support participants to follow their health care plan. This might include follow up appointments with other health professionals, changes to medication and additional tests.

The [CHAP](#) is available online and is free for use.

Support participants to understand their health needs and to make informed health decisions

- ◆ Work with health professionals to support participants to understand their health through the provision of accessible health information. See [Resources](#) below for ideas and tools.
- ◆ Support informed decision-making using the participant's preferred communication methods. Involve the participant's

family, other supporters, or guardian in the decision-making process, where appropriate.

- ◆ Encourage participants to let you know if they do not feel well using their preferred communication methods. Developing trust with a participant and knowing how they communicate will assist participants to tell you that they are unwell.
- ◆ If required, work with a speech pathologist to create or expand a personal communication system for the participant so that they have a way of communicating when they are unwell. This could include words, signs, symbols that can describe pain, nausea and fever, or anxiety, emotional distress.
- ◆ Support the participant to be involved in carrying out their health care plan and any health-related routines.

Provider obligations

NDIS Code of Conduct

Providers and workers must comply with the [NDIS Code of Conduct](#) when providing supports or services to NDIS participants.

The NDIS Code of Conduct requires all NDIS providers and workers who provide NDIS supports or services to NDIS participants to, among other things:

- ◆ Act with respect for individual rights to freedom of expression, self-determination and decision-making in accordance with applicable laws and conventions.
- ◆ Provide supports and services in a safe and competent manner with care and skill.

- ◆ Promptly take steps to raise and act on concerns about matters that may impact the quality and safety of supports and services provided to people with disability.

NDIS Practice Standards

If you are a registered NDIS provider, you must comply with the NDIS Practice Standards contained in the [National Disability Insurance Scheme \(Provider Registration and Practice Standards\) Rules 2018](#) as part of your conditions of registration. The NDIS Practice Standards relate to the delivery of safe, quality supports and services, and the management of risks associated with the supports you provide to NDIS participants.

To achieve compliance with the NDIS Practice Standards, providers should demonstrate compliance with the [National Disability Insurance Scheme \(Quality Indicators for NDIS Practice Standards\) Guidelines 2018](#). The NDIS Commission's guidance on the [NDIS Practice Standards and Quality Indicators](#) provides a further resource to assist registered NDIS providers to understand their obligations in relation to participants.

The NDIS Practice Standards that are most relevant to this alert include:

- ◆ **Support planning:** each participant is actively involved in the development of their support plans. Support plans reflect participant needs, requirements, preferences, strengths, and goals, and are regularly reviewed.
- ◆ **Access to supports:** each participant accesses the most appropriate supports that meet their needs, goals and preferences.
- ◆ **Responsive Support Provision:** Each participant accesses responsive, timely, competent and appropriate supports to meet their needs, desired outcomes and goals.
- ◆ **Incident Management:** Each participant is safeguarded by the provider's incident management system, ensuring that incidents are acknowledged, responded to, well-managed and learned from.
- ◆ **Information Management:** Each participant's information is managed to ensure that it is identifiable, accurately recorded, current and confidential. Each participant's information is easily accessible to the participant and appropriately utilised by relevant workers.
- ◆ **Safe Environment:** Each participant accesses supports in a safe environment that is appropriate to their needs.
- ◆ **Risk Management:** Risks to participants, workers and the provider are identified and managed.

Worker Capability

Providers should consider how to increase NDIS workers' training and skills in line with the [NDIS Workforce Capability Framework](#).

Resources

About health and health care services

These websites have information about staying healthy and getting a health or mental health assessment. There is also information on rights and ways to access health care.

Mental Health

- ◆ [Resources | Department of Developmental Disability Neuropsychiatry \(3DN\) \(unsw.edu.au\)](https://www.unsw.edu.au) has tools and training resources for all audiences, including resources [for people with lived experience of disability](#) and Easy Read fact sheets on [getting help with your mental health](#).

Mental Health - Easy Read Information

- ◆ [Preventive healthcare for people with intellectual disability | Department of Developmental Disability Neuropsychiatry \(3DN\) \(unsw.edu.au\)](#) contains a 4-part Easy Read series on preventative health.
- ◆ [Mental health - Council for Intellectual Disability \(cid.org.au\)](#) and [Tips to help mental health - Council for Intellectual Disability \(cid.org.au\)](#) are Easy Read information about what mental health is, and tips for good mental health.

General Health Checks

- ◆ [Annual Health Assessments – Inclusion Australia \(https://www.inclusionaustralia.org.au/project/annual-health-assessments/\)](https://www.inclusionaustralia.org.au/project/annual-health-assessments/) has information and resources for people with intellectual disability, families, GPs and clinic staff, service providers and others to help people with intellectual disability get their yearly health check.
- ◆ [Our health fact sheets - Council for Intellectual Disability \(cid.org.au\)](#) covers 30 topics in Easy Read about health and health services for people with intellectual

disability. You can download the topics that interest you.

- ◆ [Resources & Links – CDDH \(monashhealth.org\)](https://monashhealth.org) contains health resources for people with an intellectual disability, families, carers, providers and health practitioners.
- ◆ [Health Care Guide \(notredame.edu.au\)](https://notredame.edu.au) is a comprehensive guide for families, carers, providers and health practitioners to better understand and meet the healthcare needs of people with cognitive impairment or intellectual disability.
- ◆ [IDEAS](#) provides independent information for people with disability, family, carers and workers. This links to health resources.
- ◆ [Find a health service | healthdirect](#) is the national virtual public health information service with a web-based health directory.
- ◆ [Your local Primary Health Network | Australian Government Department of Health and Aged Care](#) can help participants, families and providers seek advice and assistance with information about health services, special interests and languages spoken.
- ◆ [Understanding your rights | Australian Commission on Safety and Quality in Health Care](#) information about your health care rights and [high quality standards of care](#).
- ◆ [Department of Health and Aged Care | Medicare Benefits Schedule \(MBS\) Health assessment for people with an intellectual disability](#) factsheet. The Medicare Benefits Schedule allows for brief, standard, long or prolonged consultation times with the doctor.

General Health Checks - Easy Read Information

- ◆ [Yearly Health Check fact sheet - Council for Intellectual Disability \(cid.org.au\)](#) tells you about yearly health checks at the doctors to help people with disability stay healthy in Easy Read.
- ◆ [Types of Health Checks fact sheet - Council for Intellectual Disability \(cid.org.au\)](#) tells you about the different types of health checks in Easy Read.
- ◆ [Goals of Care - Easy English | Australian Commission on Safety and Quality in Health Care](#) Easy Read information about your goals of health care.

Health assessment tools and resources

The following websites provide a variety of tools, easy read documents and resources to assist participants, families and NDIS workers with health appointments and procedures.

Participants, families and workers

- ◆ [Adult Comprehensive Health Assessment Program \(CHAP\) – Annual Health Assessment for People with Intellectual Disability | Australian Government Department of Health and Aged Care](#) is a validated tool to assist the participant and/or support person to gather information for a comprehensive health assessment for people with intellectual disability. Workers can assist the participant to gather information and provide it to the doctor for review.
- ◆ [Health Screening Tool – Down Syndrome Australia](#) provides information about additional health screenings that should be available to people with Down syndrome.
- ◆ [My Health Matters folder - Council for Intellectual Disability \(cid.org.au\)](#) is an Easy Read folder created to improve communication between people with an intellectual disability and their healthcare providers and can be used to collect all of a person's important health information.
- ◆ [Microsoft Word - hc_symptoms worksheet.doc \(autismandhealth.org\)](#) is a worksheet to help you better describe your symptoms to talk to your healthcare providers.
- ◆ [Say less show more | Agency for Clinical Innovation \(nsw.gov.au\)](#) is a collection of Easy Read and photo story resources explaining the steps involved in common medical procedures.
- ◆ [Carers and Family – Intellectual Disability Health Education by 3DN \(idhealtheducation.edu.au\)](#) is an e-Learning resource for carers on intellectual disability mental health.
- ◆ [Communication Hub - Home](#) highlights the importance of communication in everyday life and provides information for those with communication difficulties to empower themselves and others.
- ◆ [Medical Encounter Communication Board \(patientprovidercommunication.org\)](#) is a free downloadable communication sheet with images, simple questions and statements that may help communicating with health practitioners.

Providers

- ◆ [ABLEx Series - Queensland Centre for Intellectual and Developmental Disability - University of Queensland \(uq.edu.au\)](#) is a self-paced learning series to improve the physical and mental health of people with intellectual disability.
- ◆ [E-Learning | Department of Developmental Disability Neuropsychiatry \(3DN\) \(unsw.edu.au\)](#) is a health and mental health e-learning resource for workers and health professionals.
- ◆ [Working with people with intellectual disabilities \(monashhealth.org\)](#) is an information sheet on working with people with intellectual disabilities in healthcare settings.
- ◆ [Intellectual Disability Resources | Agency for Clinical Innovation \(nsw.gov.au\)](#) contains resources to support the healthcare of people with an intellectual disability.
- ◆ [Support My Decision – The A.C.T. Disability, Aged and Carer Advocacy Service \(support-my-decision.org.au\)](#) contains information and questions that may help you make decisions and support decisions.
- ◆ [Supported decision-making and capacity | NSW Trustee and Guardian](#) is a tool kit to assist people with disability, families, carers and providers to understand the need for supported decision-making.
- ◆ [IDEAS](#) provides independent for information for people with disability, family, carers and workers. This links to supported decision-making resources.

Supported decision-making resources

The resources below are supported decision-making tool kits to assist participants and their families, guardians and providers learn about decision-making and choice.

- ◆ [It's my Choice Toolkit! - Inclusion Melbourne](#) is a five-booklet toolkit to assist people with a disability make choices about their life.
- ◆ [Supported Decision Making | WA's Individualised Services \(waindividualisedservices.org.au\)](#) is a resource about understanding and doing supported decision-making.

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