Acquired brain injury Disability Snapshot

SGP KP Publishing

Exported on 2024-10-18 03:09:18

Table of Contents

This Disability Snapshot provides general information about acquired brain injury to assist you in communicating effectively and supporting the participant in developing their goals in a planning meeting. Each person is an individual and will have their own needs, preferences and experiences that will impact on the planning process. This information has been prepared for NDIA staff and partners and is not intended for external distribution.

1 Peak body consulted

In developing this resource we consulted with Brain Injury Australia.

2 What is acquired brain injury?

Acquired brain injury (ABI) is a term used to describe multiple disabilities caused by damage to the brain after birth. An ABI can result in deterioration in a person's cognitive, physical, emotional or independent functioning.

An ABI can occur from:

- an accident
- stroke
- brain tumour
- head trauma
- infection (such as encephalitis or meningitis)
- poisoning (alcohol or other drug abuse)
- lack of oxygen (referred to as hypoxia or anoxia) or
- degenerative neurological diseases[1].

Some ABIs result in permanent physical disability, for example - paralysis, problems with balance and coordination, epilepsy, vision or hearing loss. Other significant impacts can be cognitive or behavioural, for example - challenging behaviour, poor short-term memory, reduced attention and concentration, difficulties with learning, planning and solving problems. Challenging behaviours may include irritability, social (sometimes sexual) disinhibition and verbal (sometimes physical) aggression.

3 Misconceptions about acquired brain injury

Some misconceptions about ABI include:

- ABI is an intellectual disability
- Recovery from an ABI doesn't continue beyond two years.
    - While the greatest improvement in function following an ABI occurs in the first two years, recovery can continue for at least five years following the injury.
- Everyone recovers from a mild traumatic brain injury.
    - Approximately one in four people who have concussion/s or mild TBIs do not make a full recovery within the expected timeframes. They can experience ongoing physical symptoms such as headaches and dizziness, impacts on cognition, and behaviour and/or mental illness. For some people, the impairment is permanent.

4 How is acquired brain injury diagnosed?

Participants who have a severe ABI will likely have one or more neuropsychological assessments. Assessments include an interview and standardised tests to determine the injury's effects on cognition and behaviour. Recommendations are then made for therapies to improve function.

The period of time in which the participant is unable to have continuous day-to-day memory (duration of post-traumatic amnesia) is currently the best single predictor of severity for the disability.

5 Language and terminology

Don't say	Instead say	Here's why
A participant "suffers from" or is a "victim of" brain injury.	A participant "sustained", "has" or is "living with" a brain injury.	Many people with an ABI or other disabilities would prefer not to be defined or described by their disability.
A participant is "brain-injured".	A participant "has" or is "living with" a brain injury.	Many people with an ABI or other disabilities would prefer not to be defined or described by their disability.
A participant is "wheelchair-bound" or "confined to a wheelchair".	A participant "uses a wheelchair" or is a "wheelchair user".	Use person-first language.
A participant has "behaviours of concern".	A participant has "challenging behaviours".	Use person-first language.

6 Enabling social and economic participation

The lived experience of a brain injury is usually very different from a lifelong developmental or intellectual disability. People with an ABI will likely remember what they were able to do before their injury. Their engagement with the NDIS may be affected by grief. Some participants may therefore have difficulty setting and achieving goals. They may also experience a breakdown in relationships with family and friends.

The circumstances of the participant's injury may also be associated with embarrassment or shame, especially when the injury was, or is perceived to be, the participant's fault. People with an ABI have a very high lifetime risk of mental illness, such as depression.

Help the participant adapt to their disability by reconnecting them to as much of their life before injury as possible. For example, exploring pre-injury employment, pursuits and pastimes.

It may be appropriate to explore ways for participants to go back to their previous career or profession with supports in place. For others, being supported through a vocational 'discovery' process to re-explore their strengths and interests in preparation for work could be useful. Volunteering to build confidence and connect with the community is another way to prepare for work.

While employers are required to make reasonable adjustments to accommodate needs in the workplace – supports that are above and beyond this could be funded under the NDIS. Participants may require NDIS funding for specialist disability assessment services to access external employment retention and support initiatives, such as the Work Assist program provided by Disability Employment Services.

Peer support from other people with ABIs can also be helpful to improve social and economic participation.

7 How can I tailor a meeting to suit a participant with an acquired brain injury?

A person with ABI may recover well physically their cognitive and/or behavioural disability can be significant. Their disability may not be obvious to someone meeting them for the first time and that is why ABI is often referred to as an “invisible disability”.

Participants can also lack insight into their disability and be unaware of their limitations, or may have unrealistic expectations of their recovery and/or set unrealistic goals. It is recommended, with participant consent, to check unmet support needs with significant others, family members, clinicians or allied health professionals.

Many people with an ABI experience tiredness and difficulties with attention and/or concentration and reduced information-processing speed. You can tailor a meeting to suit the participant by:

- asking their preferred meeting length and discussing any other adjustments that might assist when scheduling a meeting
- securing a meeting location free of competing background noise or distractions
- scheduling short meetings or taking breaks during longer meetings
- checking how they are feeling during the meeting
- communicating in short, simple, sentences using plain English
- checking for understanding without questioning the participant’s intelligence, ask “did that make sense?” rather than “do you understand what I’m saying?”.

8 Helpful links

- Brain Injury Australia (peak body)
- Stroke Foundation (national charity)
- Synapse (service provider)
- Ontario Neurotrauma Foundation (Canadian research and prevention organisation)

[1] Australian Institute of Health and Welfare *National Community Services Data Dictionary* (2014)

Autism spectrum disorder Disability Snapshot

SGP KP Publishing

Exported on 2024-10-18 03:09:45

Table of Contents

This Disability Snapshot provides general information about autism spectrum disorder to assist you in communicating effectively and supporting the participant in developing their goals in a planning meeting. Each person is an individual and will have their own needs, preferences and experiences that will impact on the planning process. This information has been prepared for NDIA staff and partners and is not intended for external distribution.

1 What is autism spectrum disorder

Autism spectrum disorder (ASD), referred to as “autism” in the remainder of this snapshot, is the collective term for a group of neurodevelopmental conditions affecting the brain’s growth and development. Autism can affect the way individuals interact with others and how they experience the world around them.

Autism is a life-long condition which can impact, to varying degrees, all areas of a person’s life, including social communication and social interaction.

The behavioural features of autism are often present before a person is three years of age but in others they may not be recognised until their school years or later in life. The developmental challenges, signs and/or symptoms can vary widely in nature and degree between individuals, and in the same individual over time – that is why the term “spectrum” is used.

Autism has a strong genetic base so there may be multiple diagnoses or related conditions within a single family and their extended family.

A person living with autism may experience:

- challenges with communication and interacting with others
- repetitive and different behaviours, moving their bodies in different ways
- strong interest in one topic or subject
- unusual reactions to what they see, hear, smell, touch or taste
- preference for routines and dislike of change.

2 How is autism spectrum disorder diagnosed?

Autism is diagnosed on the basis of behavioural presentation and developmental history. Careful developmental monitoring of social attention and communication behaviours in early life can lead to early identification and referral for a diagnosis. A reliable diagnosis is possible from as early as 18 to 24 months of age. Some people may be diagnosed in later childhood, adolescence or adulthood. Diagnosis is ideally undertaken by a multidisciplinary team with allied health and medical expertise. The DSM 5 is the most commonly used diagnostic criteria in Australia.

3 Language and terminology

Terminology can be a sensitive subject and reflects a range of personal perspectives.

Some families and individuals prefer “person first” language for example, “I am a person with autism”. Others prefer “identify first” language, for example, “I am autistic”.

You should let the participant take the lead in describing themselves, their disability and their preferred terminology. Use their preferred terminology consistently in all meetings and correspondence.

Common terms used include:

- DSM-5 - the Diagnostic and Statistical Manual of Mental Disorders Fifth Edition. It is published by the American Psychiatric Association and is the most commonly used tool across the world for diagnosing psychiatric conditions and disabilities
- neurodiversity - the concept that neurological differences are a natural part of human diversity. It highlights sensitivities to words like “disorder” and “cure”
- neurodivergent - is a broad term meaning atypical neurology; meaning there is a general functional difference
- neurologically typical (also referred to as NT) - a reference for people who are not on the autism spectrum.

4 Enabling social and economic participation

A person's support needs for social and economic participation will vary depending on their strengths and level of function.

Data from the Australian Bureau of Statistics Survey of Disability, Ageing and Carers (2015) indicates people with autism experience poorer outcomes compared to other disability groups in relation to education, economic participation, social participation and independent living. Consider supports that reduce these barriers such as capacity building or support coordination. Planning for transitions from school to higher education or work is also important.

NDIS funding can support people with autism to build life skills, capabilities and independence. It can give them a greater understanding of what their interests are and what work might be suitable. It can assist them build specific work related skills which could support them to engage with other government services such as Disability Employment Services (DES).

Work adjustments or NDIS funding for specialist disability assessment services can help create opportunities for jobs to be adapted to meet the capabilities and strengths of the individual and to address access and lived challenge barriers as described below.

5 Barriers to achieving economic and social participation

Likely barriers to achieving similar levels of independent living, education, economic and social participation to other disability types were identified in the ABS Survey (2015) and are listed below.

NDIS supports can assist to address some of these barriers and improve access to social and economic participation for people with autism. Funding for capacity building can support participants build their planning, organisation and independent living.

Support coordination can connect participants with services and providers for assessment and support. For example, referral to a specialist providers such as an occupational therapist can help arrange adjustments to the physical environment for school, work or social activities.

Societal attitudes

- lack of public awareness and understanding regarding autism and how it impacts on daily living
- negative media portrayal of autism

Accessibility challenges

- access to timely and affordable assessments, including an understanding of the functional impact for the individual
- access to timely and appropriate supports and services following initial diagnosis and as needs change over time
- structures or physical features of the built environment, for instance lighting, noise, smells, colours, crowding
- mainstream and specialised supports and services not understanding autism or taking individualised approaches

Lived challenges

- cognitive and social differences
- difficulties with planning and organisation
- failure of agencies and services to work in partnership with the individual and their friends/family to understand and address needs
- experiencing bullying and harassment in schools, community settings and workplaces
- failure of mainstream and disability services to provide reasonable adjustments in education and work settings
- the specific characteristics of autism (difficulties in social interactions and communication, inflexible behaviours and routines, and executive function difficulties)

may lead to increased difficulty in relationships, completing education, gaining and maintaining employment, housing and health care

- failure of services to recognise other health conditions (comorbidities) such as anxiety, stress and depression.

6 How can I tailor a meeting to suit a participant with autism spectrum disorder?

Before a meeting

In preparation for a meeting:

- provide detailed information about how and where to present for a meeting and what the planning process will cover. Many people with autism find new events or tasks difficult and may need
- provide information at least five days before a meeting, where possible
- offer a choice of meeting options such as, face to face, phone, using written and/or verbal information
- inform the individual a support person can attend
- if the meeting needs to be re-scheduled or the Agency staff member attending changes, give as much advance notice and explain the reason for the change
- gather information about autism and the person you are meeting with. The participant and their support person are best placed to inform you about their needs and experience living with autism.

Communication during a meeting

When communicating during a meeting:

- anticipate the participant may not make eye contact
- consider the sensory environment, for example, sound, lights and invite the participant to use supports to stay calm, such as, fidgets
- simplify your language and use key words, natural gestures and pictures where appropriate. Be prepared that the individual's understanding of verbal communication could be very literal
- allow time for processing information if necessary. Pause periodically, to allow questions and check for understanding
- use positive statements as it is easier to understand positive sentences that say what to do, rather than what not to do
- sit side by side rather than face to face
- acknowledge anxiety. If the individual keeps coming back to a particular issue, be patient and allow time to answer the necessary questions to put their mind at ease
- make things as predictable as possible, including running the meeting to time
- allow for gender differences in the presentation of autism. Females in particular can be adept at masking their symptoms and tend to show less severe social and communicative symptoms. Be prepared to use gentle probing questions and draw on a range of evidence sources to identify their support needs

- consider many individuals view their autism as an important and valued part of their personal identity. They don't see their autism as a condition that needs to be "fixed or cured
- be aware that parents attending the meeting may also be highly stressed and anxious or may also be a person with autism.

Planning considerations

Things to consider when developing or reviewing a participant's plan:

- focus on the functional impact of the diagnosis. Verifying the diagnosis or interpreting reports made by health professionals can be frustrating for families and individuals who have undergone an extensive (and costly) diagnostic process
- include support coordination where there are complex needs or other health conditions (comorbidities) that cross health, disability, community, housing and/or employment sectors
- consider and plan for life stage transitions, such as primary to high school or school to work
- remember people with autism have individual and unique needs which can change throughout their life. It is best not to make assumptions based on your existing knowledge and experience of autism.

7 Peak body consulted

In developing this resource we consulted with the Australian Autism Alliance, who consulted with the following partners and supporters:

- AEIOU Foundation
- Amaze
- Autistic Self Advocacy Network (ASAN AUNZ)
- Australasian Society for Autism Research (ASfAR)
- Autism Asperger Advocacy Australia (A4)
- Autism Association of Western Australia
- Autism Co-operative Research Centre (CRC)
- Autism Queensland
- Autism SA
- Autism Spectrum Australia (Aspect)
- Autism Tasmania
- I CAN; and
- Autism Awareness Australia.

8 Helpful links

For further information refer to:

- Australian Autism Alliance
- Raising Children
- Autistic Self Advocacy Network
- Autism Aspergers Advocacy Australia
- I Can Network

See also, service providers who are partners of the Australian Autism Alliance:

- Amaze
- Autism Spectrum Australia
- AEIOU Foundation for Children with Autism
- Autism Queensland
- Autism South Australia
- Autism Tasmania
- Autism Association of Western Australia
- Other Autism Organisations

Blindness and vision impairment Disability Snapshot

SGP KP Publishing

Exported on 2024-10-18 03:09:59

Table of Contents

This Disability Snapshot provides general information about blindness and vision impairment. It will assist you in communicating effectively and supporting the participant in developing their goals in a planning meeting. Each person is an individual and will have their own needs, preferences and experiences that will impact on the planning process. This information has been prepared for NDIA staff and partners and is not intended for external distribution.

1 Peak body consulted

In developing this resource we consulted with Blind Citizens Australia.

2 What is blindness and vision impairment?

Blindness and vision impairment is a sensory disability that affects a person's access to social, economic and physical participation. It reduces access to information, in particular written information. This affects the person's ability to independently work, socialise and safely go about their lives in the community.

While more than 453,000 Australians are blind or vision impaired, the number of people eligible for the NDIS based on the primary disability of blindness or vision impairment is much smaller. This is because blindness and vision impairment is primarily associated with the ageing process.

3 How is blindness and vision impairment diagnosed?

Some people are born blind or with a vision impairment. Others may acquire it later in life, through a genetic eye condition or accident. Some conditions are degenerative and get worse over time.

Eye specialists such as optometrists and ophthalmologists diagnose vision impairments.

Orientation and mobility specialists train people who are blind or vision impaired to use mobility aids and assistive technologies. Occupational therapists provide training and advice with independent living skills.

4 Language and terminology

Language shapes the way we view the world. The words we use can have a powerful effect. How we write and refer to people with disability can affect the way they are viewed by the community. Some words can degrade and diminish people with a disability.

Person-first language places the person first and the impairment second. Person-first language is used to acknowledge that a disability is not as important as the person's individuality or humanity.

Persons with disability or people with disability are the most commonly used terms in Australia. If you are not sure of the correct words to use, don't be afraid to ask. Focus on the person, rather than their disability. Offer an apology if you feel you've said the wrong thing and always be willing to communicate.

5 Communicating with people who are blind or vision impaired

How to communicate	How not to communicate
Use person-first language such as 'person who is blind.'	Don't use collective nouns to describe a group – don't use "the blind", or "the disabled". Use "people who are blind" instead.
Speak directly to the person in a normal tone of voice.	Don't shout! Vision impairment and deafness are not related.
When speaking with the person, identify yourself and the others with you.	Don't presume a person cannot see anything. If appropriate, ask what they can see.
Check what format, the person requires their information to be provided in. When preparing printed information use large print formats. Use a minimum of 16 point Helvetica font, bold for emphasis. Don't use italics or underline.	Avoid using coloured paper when printing because the lack of colour contrast between paper and print can be a barrier. Ask the person what works best for them. When you are writing by hand, write in large print and use a heavy-duty pencil or pen.
Make sure there is adequate lighting in the meeting room.	Avoid dim or very bright lighting as this makes it more difficult to see for people with vision impairment.
Be specific when giving verbal directions and give approximate distances where appropriate 'the chair is 1 metre to your left'.	Never give directions such as 'over there'.
If guiding a person, walk alongside and slightly ahead of them.	Don't hold onto the person's arm. Allow the person to take your arm if they need to. Ask how they would like to be guided.
When assisting the person to sit down, put the person's hand on the back of the chair.	Never leave a person with vision impairment in an open area or without saying you are leaving. When you leave, lead a person to a landmark so he or she can get a sense of direction.

6 Enabling social and economic participation

Busy, cluttered and visually oriented environments can be a major barrier to participation in normal life, like; going to the shops, going for a walk in the park, going to work, looking for work or simply socialising.

Work enables an individual to establish greater financial security, develop a sense of productivity, purpose and make new connections with people in their community.

People who are blind or vision impaired can come up against attitudinal barriers which compromise their dignity and independence. For example, some employers' negative attitudes or lack of knowledge contribute to the high rate of unemployment amongst people who are blind or vision impaired–a rate which is four times the national average. This has a dramatic impact on the inclusion and participation of people who are blind or vision impaired.

Assistive technology may also be required to support participation in work. To enable and maintain work, ongoing supports or adjustments at work may be needed. This might require NDIS funding for specialist disability or employment related assessment services. Alternatively the person can access external employment retention and support initiatives such as Work Assist provided by the Disability Employment Services (DES) program.

7 How can I tailor a meeting to suit a participant with blindness and vision impairment?

When meeting someone who is blind or vision impaired for the first time, they may not see your extended hand to shake hands in greeting. Telling someone that you would like to shake their hand is appropriate. Otherwise a friendly verbal greeting is okay.

Glossy brochures will not attract or be useful to people who are blind or have minimal usable vision. Think about other ways to share information such as information on a website (which meets web accessibility standards, W3C), large print information with good contrast, audio format, braille or information over the phone.

Prior to a meeting, it is important to ask the person their preferred format for accessing information. That way the planner can organise material in their preferred format.

During telephone conversations, especially when organising planning meetings or other information, encourage the person who is blind or vision impaired to make note of any times, dates and contact information. Ask if they would like the details for the meeting and contact information sent to them or a reminder call the day before. It is important this information is provided in the person's preferred communication format.

When you are planning the meeting, discuss if it will be held at their home or another location. If another location, ask if they will be bringing a support person along with them. Ask what they need from you to create an accessible environment, for example, meeting them at the entrance. Keep in mind each person's requirements may differ.

Verbal communication

- No matter how well you know a person who is blind or vision impaired, it is good practice to introduce yourself when you approach the person, particularly if you are both away from your usual environment. A simple 'Hi Sarah, it's John' can help a person who is blind or vision impaired know who has approached.
- It's okay to use the word 'see' 'see you later' and 'look' 'do you mind taking a look at this?' People who are blind or vision impaired use these words too.
- Talk to the person, not their guide dog.

Written communication

- Not all people who are blind read braille. Some use braille for reading, labelling, identifying items or to read signs. Some don't use braille at all.
- How people read information can come down to personal choice, convenience and ease. Some people with usable functional vision might use standard print or large print (san serif font like 'Arial' in size 16 or greater), audio format, electronic formats (such as word documents, html, or rtf), braille or a number of these formats depending on the task they are working on.

- Pictures, symbols, tables and a host of other marketing tools can be inaccessible, depending on the technology the person is using. Therefore it's important to check with the person what works best.
- Word documents, html and rtf formats are a lot easier to read for people who use screen-reading software.
- When offering information in accessible formats, offer large print, braille, audio, or electronic versions. Refer to Round Table Guidelines for producing information in accessible formats.

8 Helpful links

- Blind Citizens Australia (BCA)
- Video featuring Graeme Innes AM from the NSW Government's 2015 Don't Dis my Ability campaign.
- Blog post: A day in the life with Stargardts disease, Matt De Gruchy.
- Blog site, Where's Your Dog? Article: My Roommate is Blind – Help!
- Dialogue in the Dark – an experiential awareness raising tour, led by people who are blind or vision impaired.

Carers Disability Snapshot

SGP KP Publishing

Exported on 2024-10-18 03:10:11

Table of Contents

This Disability Snapshot provides general information about carers to assist you in communicating effectively and supporting the participant in developing their goals in a planning meeting. Each person is an individual and will have their own needs, preferences and experiences that will impact on the planning process. This information has been prepared for NDIA staff and partners and is not intended for external distribution.

1 Peak body consulted

In developing this resource we consulted with Carers Australia, the national peak body representing Australia's unpaid carers.

2 About carers

The sustainability of the National Disability Insurance Scheme (NDIS) depends on the capacity and willingness of family and friend carers to provide informal supports and unpaid care.

Australian Bureau of Statistics' data from 2015 revealed that:

- 26% of primary carers (who provide the most substantial care for someone with disability, chronic illness, mental health condition or is frail or aged) had been caring for between 5 and 9 years and 28% had been caring for between 10 and 24 years
- 33% of carers were providing care for 40 hours or more per week and in many cases, substantially more
- 50% of primary carers identified that caring had one or more negative impacts on their physical or emotional wellbeing
- 36% indicated they were weary and lacked energy
- 12% said they frequently felt angry and resentful
- 48% reported interrupted sleep
- 12% had been diagnosed with a stress related illness.

3 Carers and the NDIS

Families and carers make a valuable contribution to supporting participants. It is important to take the time to listen to carers and support them in their role. They are often the greatest advocates for participants.

The participant statement in a participant's plan contains important information about the participant's life, their living arrangements, relationships and plan goals. As part of the discussion to complete the participant statement, consider what may be required to strengthen and build the capacity of those providing informal support.

The family questionnaire, usually completed during a planning meeting is an opportunity to capture the experience of the family or care giver and discuss whether they have sufficient support to provide care. A number of organisations have developed pre-planning guidance for families and carers to assist them identify their own caring role. If they choose to, a carer can also provide a carer statement. To access the Carers Australia Carers Checklist refer to the Helpful links section below.

4 Why respite is important

While families and carers take pleasure and satisfaction in supporting their loved ones, they may experience stress from caring. Carers often need support and relief. They may need to take a break from time-to-time to sustain their own wellbeing, their relationships with others and their capacity to continue caring.

Respite can reduce carers' stress and give them an opportunity to recharge their batteries. It can also assist them in continuing to provide quality care.

Respite can also assist participants. A period in short-term accommodation or participation in community activities can provide opportunities to experience new environments, make new social connections and in some cases, develop new skills.

5 Can a plan include NDIS funding for respite?

Funding for respite is available under the NDIS. Respite aims to support ongoing caring arrangements between participants and their carers by providing carers with short term breaks from their caring responsibilities.

Participants can purchase a number of supports through their NDIS plan for respite arrangements including:

- short-term accommodation
- temporary periods of extra personal supports so that the participant can remain at home when families and/or carers are not available
- support to participate in community activities, resulting in a break for carers.

The NDIS funds reasonable and necessary supports that facilitate respite and build independence, offer time away from the home or provide supports in the home. Examples are provided in the case studies below. These supports can reduce the demand on carers and give them a break from caring responsibilities.

6 How can I help carers to sustain their capacity to provide informal supports?

Let carers know that, while the NDIS supports the goals and aspirations of the participant(s) they are caring for, it recognises that supporting family and friend carers in their caring role is also important.

Allow carers to explain to you the type of care and amount of care they provide. Carers should feel comfortable to be able share any concerns they have about their capacity to continue providing their current level of care. If they are unwilling to raise these issues in the presence of the person they care for, a written carer statement can be provided. Refer to the Helpful links section below for examples.

Explain to carers how the participant's plan can be used to purchase supports like short term accommodation which offers value for the participant and a break for carers.

7 Case study examples of respite supports

Taking the time to listen to families and carers may identify innovative supports that facilitate respite. Several examples are included in the case studies below to demonstrate different arrangements.

7.1 Short-term accommodation for Peter

Carl, aged 64, and Sophie, aged 59, care for their adult son, Peter, who has cerebral palsy, poorly controlled epilepsy, an intellectual impairment and respiratory problems. Carl and Sophie immigrated to Australia in 1990 and would like to travel to their home country to visit their elderly parents and catch up with other family and friends. They plan to spend three weeks overseas. They don't believe they can manage taking Peter with them. Carl and Sophie have no friends or family members able to provide care in their absence so they will need to explore alternative accommodation options for Peter while they are overseas.

In this situation funding for short-term accommodation in Peter's plan will allow his parents to take a break from their caring role. It will also benefit Peter by having some experience with other carers and environments. This is important preparation for when Carl and Sophie won't be able to care for Peter at home because his parents are getting older. Peter supports his parents' request.

7.2 Short-term accommodation for Henry

Henry, aged 9, has severe autism and regularly has difficulty controlling his behaviour which includes physical and emotional aggression. This behaviour often occurs for several hours at a time and typically at night. Despite therapeutic interventions these behaviours are still occurring and employment of an in-home support worker is not suitable.

Henry's parents are constantly hyper-vigilant and preoccupied with attempts to reduce behavioural outbursts. They find it difficult to find the time and energy to give enough attention to their other two children or to each other. The situation is taking a significant toll on Henry's family members and their relationships.

The family would like to include funding in Henry's plan for regular short-term accommodation. This will allow his parents and siblings to strengthen their resilience and bond as a family by spending time together. It is also intended to give Henry the opportunity to undertake new activities and interact with other children guided by specialised professional carers.

7.3 Access to the community for Jordan

Jordan, aged 13, lives with his parents and sister in a regional area. He has severe intellectual and language delays and attention deficit hyperactivity disorder. He is unable to talk, has behavioural concerns and needs constant supervision and help with daily living activities. Each Saturday Jordan participates in a three-hour group activity that allows him to access the community with his friends, develop social skills and independence. The group meets in a town that is one and a half hours' drive from home.

Jordan's parents have asked that the transport costs and a support worker to accompany him to each group session be included in his plan. This will enable them to have respite and to spend time together and with their other child.

Without this support, one parent would need to drive Jordan to the activity and stay in the town while he is participating. The NDIS planner could consider that the transport of this distance to a community activity exceeds ordinary parental responsibilities, provides Jordan with an opportunity to meet his goals and objectives while providing a break for his parents.

7.4 In home supports and personal care for Sami

Sami, aged 18, is the sole family carer for her mother, Sara, who has advanced multiple sclerosis and suffers from severe depression. Sami manages the household duties, including looking after her 10 year old brother, as her mother cannot. While Sara receives paid personal care and some household assistance during the day until Sami comes home from school, she is very often in pain and in need of assistance throughout the night. This seriously interferes with Sami's sleep. Sara feels very guilty about the situation and the negative affect it is having on Sami. This compounds her depression.

As well as paid carer support between the hours of 8.30am and 3.30pm on school days, Sara would like funding in her NDIS plan for some over-night support during the week. This will relieve Sami from providing overnight care, improve her general wellbeing, and her capacity to engage in education. This would also have a positive effect for Sara and her ongoing well-being.

7.5 In home supports and personal care for Eleesha

Katerina is the primary carer of her three year old daughter Eleesha, who has a congenital heart disease, stroke and developmental delay. Complications from her medical conditions have resulted in the loss of a kidney, damage to her spleen and a reduced ability to fight infections.

Because of Eleesha's susceptibility to infections she is becoming increasingly isolated with little interaction with anyone other than her parents. Katerina is also feeling isolated. However, while

Eleesha would benefit from the opportunity to develop independence and social skills ordinarily provided by attending child care, she is unable to attend a child care centre because contact with other children increases her risk of infection.

Katerina would like Eleesha's NDIS plan to include funding for regular in-home support. This would have the benefit of providing Eleesha with the opportunity to interact with people other than her parents and develop social skills, as well as enabling Katerina to have some time for herself. Katerina is also considering returning to part time employment.

8 Helpful links

- While the section on the NDIS and carers on the Carers Australia website is primarily designed to help carers understand the NDIS, it is also a useful resource for NDIA staff and partners to understand the carer's perspective.
- Carers Australia Carer Checklist. Carers are encouraged to fill out this checklist prior to engaging with the planning process. It also provides planners with some useful insights into the range and diversity of supports which carers provide and the ways in which caring can impact on their own lives and wellbeing. It may be useful to provide the checklist to carers and family members to help them prepare for a planning meeting.
- Carer Statement examples. These may help planners understand why in some cases it may be important for both the participant and the NDIA for carers to have an opportunity to tell their own story without having to do so in front of the participant.
    - Carer statement
    - Primary carer's statement
- How to speak NDIA guide on the Endeavour Foundation website. This can assist in understanding some of the communication problems which arise between NDIA professionals, participants and their carers.

Cerebral palsy Disability Snapshot

SGP KP Publishing

Exported on 2024-10-18 03:10:27

Table of Contents

This Disability Snapshot provides general information about cerebral palsy to assist you in communicating effectively and supporting the participant to develop their goals in a planning meeting. Each person is an individual and will have their own needs, preferences and experiences that will impact on the planning process. This information has been prepared for NDIA staff and partners and is not intended for external distribution.

1 What is cerebral palsy?

Cerebral palsy (CP) is a lifelong physical disability that begins in early childhood. It occurs in the developing brain in pregnancy or in early childhood. It effects movement, posture, muscle control and co-ordination of movement. Many people with CP may also have secondary disabilities.

CP may change and its impact may become more complicated over time but it is not a degenerative condition. CP is the most common physical disability in children. There are currently around 34,000 people living with CP in Australia and 1 in 500 Australian babies are diagnosed with the condition.

CP can affect gross and fine motor skills, as well as speech. This impacts on participation in everyday activities. Although CP is lifelong and non-progressive, factors such as puberty, ageing and weight gain may detrimentally impact a person's function.

Specialists such as paediatricians or neonatal specialists can diagnose CP. General practitioners (GPs) also frequently play a critical role in maintaining the daily functioning and wellbeing of someone with CP. The complexity of CP means interventions from a variety of specialists and allied health professionals are usually required to support participation in everyday activities.

2 Different types and measures for describing cerebral palsy

The different types of CP include spasticity, involuntary muscle movements (dyskinesis), writhing or repetitive movements (athetosis or dystonia) and involuntary coordination of movements (ataxia).

CP can affect people in different ways:

- quadriplegia where both upper and lower limbs are affected. Often the torso and head are also affected
- diplegia where the lower limbs are affected. The upper limbs may be only slightly affected
- hemiplegia where only one side of the body is affected.

The Gross Motor Function Classification System (GMFCS) is the most commonly used measurement tool for describing the severity of CP. This system has a 1-5 rating scale, with 1 being the least severe and 5 being the most severe. The GMFCS classifies the level of a person's function in terms of their ability to perform gross motor actions, including sitting, standing, walking and running.

3 Common characteristics and impacts of cerebral palsy

Although everyone with CP is different, there are some commonalities, including:

- Many people with CP have a second or third disability or associated impairments such as intellectual disability (50%), epilepsy (25%), hearing or vision impairment (10%), speech impairment (25%), behaviour disorder (25%), incontinence (25%), sleep disorder (20%) and saliva control problems (20%).
- Some people with CP have a mental health condition. Anxiety and depression are common. Reasons for this are not the underlying physical disorder but the associated psychological and social factors that may impact the individual.
- Many people with CP experience chronic pain (75%), particularly in adulthood.
- Most people experience a significant decline in physical functioning in adulthood. Exercise, stretching and therapy help people maintain their strength and function.
- People with CP can have muscle weakness.

These additional impairments can have a greater impact than the CP itself and will require higher levels of support to enable someone to engage in everyday life. For example, a person who does not have good hand function and a speech impairment, will likely need assistive technology to help them to communicate effectively.

4 Common misconceptions about cerebral palsy

- Most people with CP can walk with minimal support. In fact, some individuals mobilise with little or no support so their disability may go unnoticed by others.
    - The misconception is ‘everyone with CP uses a wheelchair or walking aid’.
- Intellectual disability only affects 50% of people with CP. Some people with mild CP have an intellectual disability and some
    - The misconception is ‘everyone with CP has an intellectual disability’.
- Approximately 10-30% of cases have a genetic component, with 1% being familial (multiple siblings have CP).
    - The misconception is ‘CP is not a genetic condition’.
- CP is not progressive or a life-limiting condition. In rare cases where a person has profound CP, associated risk factors may reduce their life expectancy.
    - The misconception is ‘everyone with CP has a limited life expectancy’.
- Most adults with CP can have regular sex. In some cases, physical limitations, societal attitudes and other social barriers may present challenges to sexual activity.
    - The misconception is ‘people with CP cannot be sexually active’.
- People with CP have the same reproductive systems as everyone else. Women with CP can expect to have typical pregnancies.
    - The misconception is ‘people with CP cannot have babies’.
- Non-verbal people with CP are most likely able to understand you. An inability to communicate verbally does not mean the person has an intellectual disability.
    - The misconception is ‘everyone who is non-verbal and has CP also has an intellectual disability and cannot understand me’.
- Some people with CP may appear unsteady if they have uncoordinated, shaky, walking patterns.
    - The misconception is ‘a person with CP appears to be drunk’.
- Everyone has the right to full citizenship and inclusion.
    - The misconception is ‘people with CP belong together and away from their community’.

5 Language and terminology

In all instances, use language which focuses on people's strengths and abilities instead of their CP.

Do say	Don't say and here's why
Person with cerebral palsy	Don't say: Spastic. Medically, spastic means tight and stiff muscles. It is ok to use in a technical medical context; however, it is offensive and derogatory when used to define, insult, tease or belittle someone.
Person with cerebral palsy	Don't say: Retarded. If discussing intellectual function use "intellectual disability". The term retarded is outdated, offensive and harmful. It is not socially acceptable, irrespective of context.
Wheelchair user	Don't say: Wheelchair bound. This term is offensive and outdated. It implies that people are permanently stuck in their wheelchairs. Wheelchair user is more appropriate because a wheelchair is used for mobility.
The person 'has' cerebral palsy, or is a person 'with' cerebral palsy.	Don't say: Suffers from CP. This phrase implies that the person is suffering and does not have a good life. This is often incorrect as many people with CP have great lives.
Has cerebral palsy	Don't say: Special needs. The term 'special' is now seen as derogatory, implying that the person is less than, or that people with CP are only amazing because of their CP and nothing else.
State their achievements only if they are out of the ordinary	Don't say: Inspirational. The term inspirational can be offensive when used in simple everyday circumstances like getting out of bed or going out with friends. Instead, say nothing and treat the person with CP the same as other people.

6 Enabling social and economic participation

It is important to explore how a person with CP can be supported to enable or maintain their participation in mainstream activities, education and employment, taking into consideration their interests and aspirations as an individual.

To enable and maintain work, ongoing supports or adjustments at work may be needed. This might require NDIS funding for specialist disability or employment related assessment services. Alternatively the person can access external employment retention and support initiatives such as Work Assist provided by the Disability Employment Services (DES) program.

NDIS funding for personal care, assistance with travel or assistive technology may also be required to support participation in the workforce.

If the person is preparing to enter the workforce, NDIS funded supports can assist people with CP to build life skills, capabilities and independence. Supports can be used to assist them identify what their interests are and what work might be suitable. The supports can assist with building specific work related skills, manage barriers to work or develop a career plan. Additionally, they can help prepare people with CP to connect with other government services such as DES.

7 Families and carers

Generally, the family of an individual with CP will play a vital role in their physical, social and emotional health for an extended period. A family's ability to provide these supports will vary based on their own physical and mental health, work responsibilities, parenting capacity, resilience and whether the parent has a disability themselves.

Family members of a person with CP are usually quite involved in providing direct support with personal care, daily living, assistive technology, implementing therapy, teaching and supporting communication, study and work, as well as attending medical and allied health appointments. This is often beyond the age you would generally expect a parent or family member to provide support.

Family members are often expected to advocate for their family member with CP, which is not always possible. Family members may feel disempowered, exhausted and lacking in confidence to challenge systemic barriers and mainstream services where supports are inadequate.

Supports including respite for family members can be critical to maintaining their own health and wellbeing and allowing them to continue providing informal supports.

Supporting and considering holistic family needs, as well as other informal supports is important when working with an individual with CP. This means the individual and those important to them can function at their best.

8 How can I tailor a meeting to suit a participant with cerebral palsy?

Every person with CP is unique and has different needs, wants, likes and dislikes. This means people with CP will have varied support requirements.

Before the meeting

- Ask if there are any accessibility requirements to consider.
- Check if the meeting place meets the participant's needs. (For example, if the participant is a wheelchair user the meeting place should have a ramp and/or elevator and spacious disabled toilet with a railing).
- Consider the time of day and duration of the meeting. It can take a number of hours for a person with CP to get up, dressed and ready to leave their home. Travel is also often more complex.
- People with CP may require breaks during meetings. Some people become fatigued easily and others with an intellectual disability may be overwhelmed with complex information. Consider the length of the meeting and ask what time of day suits them best.
- Ask the person if they require additional supports to understand information (such as pictographs or sign language). Check if the person has a hearing or vision impairment which may impact on how they need to receive information.
- Check to determine whether the participant will be bringing an advocate or support person with them.
- Provide as much information as possible about the purpose of the meeting ahead of time, as they may need to discuss and prepare their responses with their support person. People using a speech generating device to communicate may need to prepare messages and store them in their device before the meeting.
- Provide any written material in plain English or Easy Read well before the meeting if this is required.

Communication during the meeting

- It's important to remember each person is different in their communication and the support they might need. Approximately 25% of people with CP have challenges with verbal communication. They may have sensory issues that affect their vision or hearing, which may also affect their language and speech. They may have an intellectual disability with difficulty in planning how to say complex sentences. People with CP may have speech that is difficult to understand.
- When speaking, use appropriate volume and speed. Speak to the person directly and observe how those known to the person communicate with them. Listen to the person and clarify understanding.
- Check if the person has a personal communication system such as a communication book, board, iPhone, iPad or speech generating device. If they do, ensure you give them enough time to respond, ask questions and interact during the meeting.
- Don't assume people who have communication difficulties have intellectual disabilities. They may not use speech to communicate but may still be able to understand

everything you say. When communicating with someone with CP where speech may be affected, speak normally and use age appropriate language.

- If the person has an intellectual disability, use short sentences and provide pauses to give the person enough time to hear and process what you are saying. Avoid using jargon.
- If the person has speech which is difficult to understand, you may need to ask them to repeat what they are saying. Speaking can require great effort for people with CP, so repeat what you have understood so the person can concentrate on saying the part you did not understand. If the person has repeated themselves several times and you are still unable to understand them, try alternative ways to communicate such as using a gesture, communication board/device or pointing to an alphabet display.
- Speak as you usually would. Be aware it may take a while for someone to verbalise what they want to say. Do not correct them or jump ahead or make assumptions about what they are trying to say. Some people may use informal methods to communicate, including facial expression, gestures, body language and behaviour.
- Understand some people may need more meetings to discuss everything.

9 Peak body consulted

The following organisations assisted in the development of this resource:

- Cerebral Palsy Support Network (members and staff)
- Cerebral Palsy Education Centre
- Members of the AusACPDM
- Melbourne Disability Institute
- The Royal Children's Hospital (Victoria)
- Centre of Research Excellence - CP
- Murdoch Children’s Research Institute
- Victorian Paediatric Rehabilitation Service
- CP Australia
- CP Alliance/Alliance Research Institute NSW
- CPL QLD
- Ability Centre WA
- Novita/Scosa SA
- Australian Catholic University.

10 Helpful links

- Cerebral Palsy Support Network

Deafblind Disability Snapshot

SGP KP Publishing

Exported on 2024-10-18 03:10:47

Table of Contents

This Disability Snapshot provides general information about deafblindness to assist you in communicating effectively and supporting the participant to develop their goals in a planning meeting. Each person is an individual and will have their own needs, preferences and experiences that will impact on the planning process. This information has been prepared for NDIA staff and partners and is not intended for external distribution.

1 Peak body consulted

In developing this resource we consulted with the peak body representing people with this disability, Deafblind Australia.

2 What is deafblindness?

Deafblind is a term used when a person has a combination of both impaired vision and hearing. Dual sensory loss or dual sensory impairment are other terms used to describe deafblindness.

Deafblindness is described as a unique and isolating sensory disability having both hearing and vision loss or impairment. The disability can have a significant effect on communication, socialising, connecting with others, mobility and daily living (Deafblind Australia, 2004).

A person with deafblindness may strongly identify with the blind culture or the deaf culture (or in some cases, neither) as well as the culture of their family. An understanding of the complexity of each person's culture is important to respectfully establish communication, language and learning.

3 How many people are deafblind?

- Studies have reported 0.2% to 3.3% of the population may be deafblind.
- In Australia nearly 100,000 people are reported to be deafblind and two-thirds of these people are over the age of 65 years.
- One study reported 36% of individuals over the age of 85 years are deafblind.

4 Types of deafblindness

Congenital deafblindness is a term used when a person is born deafblind or when their combined hearing and vision impairment exists before any form of language or communication has developed.

Congenital deafblindness can occur due to:

- hereditary or genetic conditions
- infection contracted by the mother during pregnancy
- disease
- infection or injury that affects a child early in their development.

Acquired deafblindness is a term used when a person:

- is born deaf or hard of hearing and later in life experience a deterioration in their vision
- has deafness or hearing impairment at birth and has vision impairment later in life
- is born with a vision impairment or blindness and has hearing loss later in life
- has vision and hearing that deteriorates at a later stage in their life through accident, injury or disease
- experiences deafblindness through the ageing process.

5 What are the characteristics of deafblindness?

- A small number of people will have no sight and no hearing.
- Other people who are deafblind will have varying degrees of vision impairment and of hearing impairment.
- Experiences and understanding of their world will be different depending on whether a person was born deafblind or if they acquired vision and hearing loss through deterioration later in life.
- Becoming used to new environments and travelling independently and safely are challenges.
- Communication is a key challenge for all people with deafblindness.
- Balance issues may affect some people with deafblindness, particularly those with Usher Syndrome type 1. These balance issues can affect a person's mobility.

6 Psychosocial impact of deafblindness

The impact of deafblindness on a person's life will vary. The impact on a person who has a severe vision and hearing impairment can be significant.

Depression, anxiety, frustration, and boredom can occur from the isolation and other challenges experienced by people with deafblindness. A person with this diagnosis may experience low self-esteem and lack of confidence to move about independently and carry out daily tasks.

7 Communication

People with deafblindness are a very diverse group because of the varying degrees of their vision and hearing impairments. Some people who are deafblind may also have other disabilities. A wide range of communication methods might be used, including:

- speech, oral and aural communication (communication using verbal and non-verbal signals)
- various forms of sign language including tactile and deafblind fingerspelling alternative and augmentative communication (adding to communication often through devices like tactile feeling boards, use of signs and gestures)
- print and braille.

Do not assume all people who are deafblind communicate in the same way as they may use one primary form of communication or a combination of these. Some people who are deafblind (and people who are blind) use social haptics, a form of communication which involves touch signals on the body.

Because of the wide range of communication methods, it can be difficult for another person to know how to communicate with a person who is deafblind. Many organisations fail to recognise communication needs and preferences for people who are deafblind. This is especially the case when arranging the most appropriate interpreter. Different types of interpreters can be needed, for example tactile or Australian Sign Language (Auslan).

You need to be aware of, and have confidence to ask the person who is deafblind about their communication requirements. A person who is deafblind is often familiar and comfortable in explaining how they prefer to communicate.

8 Enabling social and economic participation

A person's support needs for social and economic participation will vary depending on their areas of strength and level of function. It is important to explore how a person with deafblindess can be supported to enable their participation in mainstream activities, education and employment, taking into consideration their interests and aspirations as an individual.

This may include using supports to assist a person through a vocational 'discovery' process to explore their strengths and interests in the context of work. For those who have acquired deafblindess later in life, re-exploring their strengths and interests will be important.

Individual supports can enable participants with deafblindness to build life skills capabilities and greater independence; including in the work place. Volunteering can be a first step in building confidence and connecting to the community and the idea of employment. Peer support from other people with deafblindness can also play a key role in improving social and economic participation.

To maintain work, ongoing support and customisation of work tasks to match the level of function should be considered, along with any needs related to personal care in the work place or assistance with travel. Supports should take into account the degenerative nature of some people's sensory abilities and mobility. This might require NDIS funding for specialist disability or employment related assessment services as well as access to employment retention and support initiatives such as Work Assist provided through the Disability Employment Services (DES) program. If regular, intensive ongoing support is required to assist a participant with deafblindness maintain meaningful participation in the workplace, supported employment supports could be considered.

Assistive technology or interpretation may also be required to support participation in work.

9 How can I tailor a meeting to suit a participant with deafblindness?

Consider the following for face to face communication:

- ask the person who is deafblind about their communication requirements and book the most appropriate interpreter/s. For information on deafblind interpreters refer to Communication access and supports below
- face the person and make eye contact
- identify yourself verbally and/or by signing. Say your name
- physically touch the person on the shoulder or elbow. The sense of touch is a core communication means for people who are deafblind. However each person has their own preference and sensitivity in terms of being touched. Ask each person their preference.

If the person has a preference for touch as a method of communication, you may find it beneficial to softly touch the back of your hand on the back of the person's hand or arm to ensure they are aware of you and are ready to communicate.

A lack of response by a person who is deafblind should not be considered as being rude, but rather as a sign of ineffective communication. This would also be the case if a person who is deafblind moves away from the speaker.

Observe the facial expressions of the person who is deafblind – an expression suggesting worry can indicate confusion or unhappiness with the type and effect of the communication.

Conversely, a person who is deafblind might interpret the other person's message and intentions by the person's body language. So, friendly and open body language will aid effective communication.

10 Communication access and supports

People who are deafblind can live independent lives and may travel with CommGuides. CommGuides are specialised support workers that understand the needs of deafblindness. They facilitate independent community participation through communication support and guiding support.

Deafblind interpreters are important to ensure people who are deafblind receive information and communicate effectively in more complex situations such as attending appointments and professional services.

A CommGuide can also be used for communication support during short informal interactions such as at the shops or at the gym. However, for any formal meetings or workshops an interpreter should be booked. In many instances two interpreters will be required depending on the length of the meeting and the potential need for tactile signing.

11 Written communication

Some people who are deafblind have not received appropriate support to access education and may require additional assistance with literacy and numeracy tasks. It is also important to note that for people who are deafblind and have Auslan as their first language, English is a second language.

Plain language should always be used. It should be simple, clear and straight to the point. Explain the context of the communication and keep it focused and relevant. Increase understanding by using examples. Avoid slang, acronyms and bureaucratic language.

12 Aids and equipment

There are a variety of aids and equipment which many people with deafblindness require to access communication, information and their environment. Common aids and equipment used by people with deafblindness include:

- Hearing aids and Cochlear implants
- Wireless microphones with Blue Tooth (Roger Pens)
- White mobility canes
- Seeing eye dogs
- Home/personal alert systems
- Magnifiers, such as Zoom text
- Jaws screen reader
- Closed circuit televisions
- Smart phone with accessibility apps (sometimes paired with braille display)
- Braille devices and displays (Braille watches)
- Smart watches with accessibility apps including haptics
- Vibration devices such as ‘Ditto’.

13 Technology

Technology is very important to people with deafblindness. Technology can assist with communication, social and community engagement, access to information and education, transport assistance (GPS), safety in the home and community and activities of daily living.

The following accessibility considerations may support a person to be able to access content on websites:

- adjustable font sizes
- contrasting colours
- accessibility for screen reading software
- plain language
- image descriptions – text format screen readers do not pick up images, so picture description is required.

14 Helpful links

- Deafblind Australia
- Deafblind Information website

Deafness and Hearing Impairment Snapshot

SGP KP Publishing

Exported on 2024-10-18 03:11:21

Table of Contents

This Disability Snapshot provides general information about deafness and hearing impairment to assist you in communicating effectively and supporting the participant in developing their goals in a planning meeting. Each person is an individual and will have their own needs, preferences and experiences that will impact on the planning process. This information has been prepared for NDIA staff and partners and is not intended for external distribution.

1 Peak body consulted

In developing this resource we consulted with Deaf Australia, Deafness Forum of Australia and Deafblind Australia, peak bodies for people with deafness, hearing impairment or deafblindness.

2 What is deafness and hearing impairment?

Deaf, deafness, hard of hearing, hearing loss, and hearing impairment are all terms used to describe the sensory disability that affects a person's ability to hear.

Levels of deafness vary from mild to profound and can occur at birth or at any age regardless of a person's gender or background. However, it can become more common as age increases.

The terms deafness and hearing impairment mean different things to different people and must be used sensitively. Deaf is the preferred term used by people who use Australian Sign Language (Auslan) as a primary or preferred communication method and who identify themselves as a member of the signing Deaf community. It is used to describe their unique cultural identity which is a result of their rich visual language and is used with pride. In this case the D in Deaf is capitalised.

Many in the Deaf community regard the terms 'hearing impairment' and 'hearing loss' as alienating and damaging because it implies deafness needs to be 'fixed'.

Because of the sensitivities around the different terms, it is particularly important that participants are encouraged to take the lead in describing themselves and their disability or cultural identity. Care needs to be taken to ensure that the terminology preferred by the participant is consistently used in all meetings and correspondence. See the language and terminology section of this Disability Snapshot for further detail.

People who are deafblind have specific needs beyond deafness and blindness. Their communication and mobility requirements will be highly specialised and often require one-on-one supports. See the separate Deafblind Snapshot for further detail.

How are deafness and hearing impairment diagnosed?

Australia has a system of universal, hearing screening for newborns in all hospitals. When deafness or hearing impairment is identified, a referral is made for the newborn to be assessed by a diagnostic audiologist.

In some states, hearing testing is done in primary schools. People can also be referred to an audiologist by their GP, health provider or family members.

Approximately 95% of children born with hearing loss are born to parents who can hear and speak. These parents may have no prior knowledge of deafness or hearing impairment. They may experience a range of emotions and not fully understand the implications of the diagnosis.

A number of children may have multiple disabilities, including deafness or hearing impairment. These children will need a range of supports to address their different needs.

People may acquire hearing loss through a wide range of causes such as illness, accident, exposure to loud damaging noise and the natural process of ageing. Often it is a family member that notices the hearing loss and encourages the person to seek professional advice.

Australian Hearing is the only provider in Australia who receives government funding to deliver hearing services (including the fitting of hearing devices) for children and young adults (under 26 years of age). Australian Hearing do not do diagnostic testing. Once a child has a confirmed hearing loss they are then referred to Australian Hearing.

3 Common characteristics

Lack of access to communication and information is the primary barrier to inclusion and wellbeing - communication and quality of life are very closely linked. Poor access to communication and lower levels of interaction are known to negatively *impact on* social, emotional, psychological and physical wellbeing.

People who experience deafness and hearing impairment need access to a range of strategies to access information and to communicate.

They may need to access several of the following supports and strategies:

- listening and spoken language therapies in conjunction with assistive hearing technologies
- Auslan, the sign language used by the Deaf community in Australia
- lip-reading (a specialised skill used by a small part of the population)
- devices that amplify or replace sound (e.g. hearing aids, cochlear implants) and therapy / rehabilitative supports
- hearing augmentation systems such as hearing loops, remote microphone systems, soundfield systems and captioning
- assistive visual devices and systems (for example flashing doorbells, telephones and smoke alarms and live captioning).

For more information see Appendix A: technology as an enabler as the end of this document.

The most helpful approach to the provision of supports is to provide a person and their family with as much information as possible to identify strategies that might work for them. It is not true that people who are deaf only require Auslan interpreters, or that a single item of assistive technology (AT) (for example a cochlear implant) is sufficient to resolve access to communication and information.

It is important that planners, Local Area Coordinators and Early Childhood partners support participants and their families to obtain independent recommendations for interventions and/or AT from organisations that are independent of service provision.

4 Common misconceptions about deafness and hearing impairment

- Hearing aids or cochlear implants can significantly reduce the disabling effects of hearing loss although hearing loss is irreversible. The ability to hear and the ability to understand sounds are two different things. People who wear hearing devices may still have difficulty hearing in a noisy environment, on the phone or comprehending spoken language and speech.
    - A misconception is that hearing aids or Cochlear implants ‘fix’ or restore hearing loss.
- For many Deaf people, being deaf is an essential part of their identity which leads to positive social, emotional and language developments. An assumption that intervention is needed to fix the deafness needs careful consideration of each person’s choice, communication needs and participation opportunities.
    - A misconception is that deafness needs to be ‘fixed’.
- Technology is usually most effective when combined with hours of learning to interpret the device’s sounds. This may be with the support of a speech pathologist or teacher, particularly during early childhood. Similar for all people with disability, intensive therapy needs to be balanced with other important elements of life such as recreation time, social interaction and general downtime.
    - A misconception is that hearing devices immediately allow a person to hear.
- Auslan (Australian Sign Language) is a visual and spatial language that has its own grammar rule. It has no written form. Auslan is recognised as a language. Auslan is different to English and does not translate directly. Sign language is not universal, Auslan is a unique language used within Australia.
    - A misconception is that Auslan is just a signed form of spoken English language.
- Lip-reading and listening skills are acquired through years of practice and training and these skills vary widely. It is difficult and complicated because there are many different speech sounds that look similar on the lips (for example ‘b’, ‘p’ and ‘m’). Lip-reading is a tiring exercise - it requires high levels of concentration irrespective of the age of the person.
-
    - A misconception is that all deaf people can lip-read.

5 Language and terminology

Terminology is a sensitive issue in the deafness and hearing impairment communities. NDIS participants must be given the opportunity to describe themselves and their disability. Take care to ensure the participant's preferred terminology is always used in any meetings and correspondence.

Preferred terms

- Deaf, for a person whose first language is Auslan.
- Person who is deaf and has other disability/s.

Description of terms

- Deaf (with capital 'D') is the preferred term used by people who use Auslan as a primary or preferred communication mode, and who identify themselves as a member of the signing deaf community. This group of people may also identify themselves as culturally Deaf. Auslan users have a unique language and experience, and like all cultural and linguistic groups, English is their second language. Auslan users are more likely to have been born deaf or have become deaf in early life. There are some who discover Auslan later in life and then use it as their primary language.
- deaf (with lower case 'd') is a general term used to describe people who have a physical condition of hearing loss of varying degree, no matter which communication mode they use (for example hearing devices, Auslan or lip reading).
- The term 'hearing impairment' refers to a full or partial decrease in the ability to hear. It is one of the commonly used terms to describe a person who has a hearing loss, irrespective of their level of hearing. This term must not be used as a blanket term for people who identify as 'capital D' Deaf. Some individuals may prefer to use hearing impairment to describe their identity but many Deaf and hard of hearing people find this term derogatory.
- 'Hard of hearing' is the internationally preferred term used to describe people with acquired hearing loss in a way that does not imply impairment.

6 Enabling social and economic participation

A person's support needs for social and economic participation will vary depending on their strengths and level of function. Identifying potential solutions for increasing access to communication and information is critical. This could include arranging assistive technology or Auslan.

To enable and maintain work, ongoing supports or adjustments at work may be needed. This might require NDIS funding for specialist disability or employment related assessment services. Alternatively the person may access external employment retention and support initiatives such as Work Assist provided by the Disability Employment Services (DES) program.

Peer support from people who identify themselves as a member of the signing community or with other people who are deaf can also assist to address challenges to social and economic participation.

7 How can I tailor a meeting to suit people who experience Deafness or hearing impairment?

- Offer a variety of options to contact you: email, fax, text message or letter. Some people will nominate a TTY phone contact via the National Relay Service (NRS) as their preference. Ensure you are familiar with the NRS before use.
    - Do not use a phone call as the first point of contact. It is important to communicate with people in the means which they find accessible and most comfortable.
- Always ask what communication access is needed for the meeting. This could be a hearing loop, live captions, a room with Auslan interpreters or a combination of supports.
    - Do not impose unwanted supports. Interpreter and captioners preferences must be respected. NDIS meetings often include a lot of information and may be quite overwhelming.
- Book communication support as soon as possible and confirm the details with the participant.
    - Do not ask interpreters and captioners to provide advocacy or other support. Their role is solely to interpret/caption all communication. There is a shortage of Auslan interpreters, captioners are in high demand, and not all meeting rooms have hearing loops.
- Make sure meetings are held in a quiet space that is well lit.
    - Do not presume that a busy office or café is a welcoming environment. A quiet, well-lit space is a place where conversations can take place free of background noise, strong background light and distractions.
- Ensure that you are clearly visible and facing the person.
    - Do not wave hands or hold other objects near your face while speaking. Some people can read lips for some words.
- Use normal clear speech at normal speed.
    - Do not exaggerate your speech. Try not to speak too quickly, don't mumble and don't yell. It's clarity that counts. Hearing devices (including ears) work best when they are receiving normal speech free of background noise. Some people can read lips for some words.
- Look at and speak directly to the person.
    - It is always good manners to look at the person you are speaking to.
- Use plain language that is clear. Rephrase as needed.
    - Do not keep saying the same thing over again or assume that a person with communication support needs has an intellectual disability because they have a limited vocabulary or language difficulties.
- Hearing devices might not pick up every word clearly. Remember that a person whose first language is not English (this may include users of Auslan) might not have a high English literacy level.
- Have paper and pen available.
    - Don't rely on one communication method only. All people in the meeting need to have the same understanding about key information, support requirements, outcomes and next steps.

- Ask for clarification and things to be reworded if you do not understand. Play it back to check that both parties have the same understanding.
    - Don't assume you know what the person is trying to say.

8 Helpful links

- Deaf Australia
- Deafness Forum of Australia
- Aussie Deaf Kids
- Better Hearing Australia
- CICADA (Cochlear implantee group)
- Parents of Deaf Children
- Hearing Topics A – Z
- The Meaning and Practice of Audism

Down syndrome Disability Snapshot

SGP KP Publishing

Exported on 2024-10-18 03:11:35

Table of Contents

This Disability Snapshot provides general information about Down syndrome to assist you in communicating effectively and supporting the participant in developing their goals in a planning meeting. Each person is an individual and will have their own needs, preferences and experiences that will impact on the planning process. This information has been prepared for NDIA staff and partners and is not intended for external distribution.

1 Peak body consulted

In developing this resource we consulted with Down Syndrome Australia.

2 What is Down syndrome?

Down syndrome is a genetic condition – it is not an illness or disease. Down syndrome is the most common genetic cause of intellectual disability. It occurs at conception as a result of an extra chromosome. In Australia, around one in 1,100 babies are born with Down syndrome.

People with Down syndrome have:

- Areas of strengths and other areas where they need more support, just like everyone else in the community.
- Some level of intellectual disability. The average IQ for a person with Down syndrome is 50, whereas two-thirds of the general population scores between 85 and 115.
- Some characteristic physical features, including a recognisable facial appearance and short stature.
- Significant delays in gross motor skills (whole-body movements like climbing and jumping jacks), fine motor skills (smaller muscle actions like picking things up between thumb and finger) and speech development. Plus ongoing difficulties and support needs in these areas.
- Increased risk of a range of health issues (which compound developmental delay and can impact functional ability), including congenital heart defects, respiratory, hearing and vision problems, childhood leukaemia, thyroid conditions, gastrointestinal issues, and earlier onset of ageing. Average life expectancy is currently around 60.
- Increased risk of younger onset dementia, with more than 50 per cent of people with Down syndrome having a diagnosis of Alzheimer's disease by the time they are 60. Dementia can be difficult to diagnose and needs to be addressed by a health professional. There are a range of strategies and supports that can be put in place if a person has dementia and Down syndrome.
- Increased likelihood of having other disabilities as well as Down syndrome. These can include physical disabilities, sensory disabilities, psychosocial disability or other conditions such as autism, ADHD and cerebral palsy. It is important to ensure that other disabilities and the need for support are not discounted due to the person having Down syndrome as their primary diagnosis. Sometimes, these other disabilities are the ones the person needs the most support with.

3 Common misconceptions about Down syndrome

- ‘People with Down syndrome all look the same’.
    - While people with Down syndrome usually have recognisable facial features, each person looks more like their family than like other people with Down syndrome.
- ‘People with Down syndrome can’t read, write or learn’.
    - Every person is different and will have different capabilities when it comes to reading, writing and other skills.
- ‘People with Down syndrome can’t communicate’.
    - Some people with Down syndrome speak well, others can be more difficult to understand and some may use little or no speech.
    - Many who have difficulty in speaking will understand what is said to them.
    - Some may need more time to communicate or use communication devices to help them have a conversation.
- ‘People with Down syndrome are childlike’.
    - Adults with Down syndrome are adults and should be respected and treated as such.
- ‘People with Down syndrome are always happy and loving’.
    - People with Down syndrome experience the same range of feelings and moods as anyone else.
- ‘People with Down syndrome can’t live an independent life’.
    - People with Down syndrome can live independently. Some own their own homes and don’t need much support, others need more support and the kinds of support will differ for each person.
- ‘People with Down syndrome are better off in segregated settings’.
    - In the past, many supports such as ‘special’ schools, sheltered workplaces and group homes were provided in separate places. Evidence suggests children with Down syndrome do better in inclusive education and adults with Down syndrome can work in regular workplaces and live in ordinary homes in the community. It’s just about providing the support each person needs in different places.

4 How is Down syndrome diagnosed?

Diagnosis is often made prenatally by sampling foetal cells to analyse the foetal chromosomes. After birth, Down syndrome is often identified based on the baby's appearance. The diagnosis is confirmed through a test called a chromosomal karyotype. Using a sample of blood, this test analyses the child's chromosomes. If there is an extra chromosome 21 in all or some cells, the diagnosis is Down syndrome.

5 Language and terminology

‘Person first’ language should be used to describe Down syndrome. This means, for example, saying ‘person with a disability’ or ‘man with Down syndrome’.

6 Enabling social and economic participation

A person's support needs for social and economic participation will vary depending on their areas of strength and level of function. It is important to explore how a person with Down syndrome can be supported to enable their participation in mainstream activities, education and employment, taking into consideration their interests and aspirations as an individual.

This might include:

- support to access mainstream sporting groups, dance groups or other activities
- supports to build capacity to participate in mainstream education settings
- social and community participation supports tailored to build 'soft skills' for employment
- travel training
- supports to facilitate participation in mainstream employment and
- supports to build capacity for independent living.

Barriers to social and economic participation

A Down Syndrome Australia survey found that people with Down syndrome experience significant barriers to social and economic participation.

Barriers to inclusion and participation include:

- discriminatory attitudes
- lack of understanding about Down syndrome and how to support inclusion
- bullying in schools and workplaces
- lack of accessible information (including in government services, the community, employment and schools)
- exclusionary educational systems, settings and practices
- difficulty accessing employment
- lack of support for transition between school and adult life
- difficulty accessing vocational education and skills training
- lack of suitable jobs (including accessibility issues and lack of flexibility)
- lack of workplace support including recruitment and ongoing support
- housing and lack of support to live independently from family
- inadequate support services to help build skills and capacity and make community connections
- getting to work or community activities.

Supporting social and economic participation

NDIS funding can support people with Down syndrome to build life skills, capabilities and independence. It can give them a greater understanding of what their interests are and what work might be suitable. It can also assist them build specific work related skills which could support them to engage with other government services such as Disability Employment Services (DES).

While some NDIS participants with Down syndrome may build their capacity and successfully participate in DES, many may need more intensive, regular, ongoing support in the workplace to help them meaningfully participate at work. This support is generally provided by Australian Disability Enterprises (ADEs).

In some instances work adjustments or NDIS funding for specialist disability assessment services can help create opportunities for jobs to be adapted to meet the capabilities and strengths of the individual.

Also consider the need for personal care support or assistance with travel in the work place.

7 Families and carers

Families provide different levels of support to a person with Down syndrome, but usually play an active role in providing a range of supports including assisting with daily living tasks, advocating for inclusion, and working to find employment. Families usually have a good understanding of the support the person needs to participate in the community and improve their independence.

While families are usually happy to provide some support, it can affect their own employment, ability to meet the needs of other family members, and their own needs and health, especially as they age.

It is not reasonable to expect a family to be the main source of support for an adult with Down syndrome. It is important to consider for children and adults whether the level of informal support being provided is sustainable and what impact it has on the family.

8 How can I tailor a meeting to suit a participant with Down syndrome?

Every person with Down syndrome is unique with individual personality, strengths and areas where they need support. It's important to remember that each person is different in their communication and the support they might need. Some key suggestions to support communication include:

- Get in touch before the meeting and ask what support they need to access and take part in the meeting.
- Provide any written material in Plain English or Easy English if required well before the meeting.
- Provide as much information about questions and things that will be discussed at the meeting ahead of time. This will give the person with Down syndrome an opportunity to discuss these questions with their support person and to have time to consider their responses.
- Always communicate and engage directly with the person with Down syndrome, not the person with them. Be patient and take their lead regarding whether the person with them helps them communicate.
- Speak respectfully in an age appropriate way. Don't treat an adult with Down syndrome as if they are a child.
- It can help to use visual information to help explain some concepts and messages. This could be pictures or objects, such as a clock or calendar. Easy English information can be used to help with discussion.
- Allow the person additional time to respond to questions where needed.
- Consider arranging a second planning meeting to ensure all elements are covered.

9 Helpful links

- Down Syndrome Australia

Fetal Alcohol Spectrum Disorder Disability Snapshot

SGP KP Publishing

Exported on 2024-10-18 03:11:52

Table of Contents

This Disability Snapshot provides general information about Fetal Alcohol Spectrum Disorder (FASD) to assist you in communicating effectively and supporting the participant in developing their goals. Each person is an individual and will have their own needs, preferences and experiences. This information has been prepared for NDIA staff and partners and is not intended for external distribution.

1 Peak body consulted

In developing this resource, we consulted with:

- Developmental Disability WA
- Dr Amanda Wilkins, a Developmental Paediatrician experienced in diagnosing FASD and who was involved in establishing FASD C.A.R.E Inc
- Dr Robyn Williams, a Nyoongar woman who completed her PhD on FASD in the south west region of Western Australia
- National Organisation for Fetal Alcohol Spectrum Disorder (NOFASD) Australia.

2 What is Fetal Alcohol Spectrum Disorder?

Fetal Alcohol Spectrum Disorder (FASD) is a term that describes the impacts on the brain and body of a person exposed to alcohol during pregnancy. It is a lifelong disability and people with FASD will experience challenges in their daily living. Each person with FASD is unique and will experience their own strengths and challenges.

To reach their potential they may need support with:

- motor skills
- physical health
- learning
- memory
- attention
- communication
- emotional regulation
- social skills.

Some children with FASD may have shorter than average height, low body weight and a small head size. They may also appear hyperactive and have poor coordination.

It is common for people with FASD to be able to express themselves but may have difficulty understanding, processing and retaining information.

3 How is Fetal Alcohol Spectrum Disorder diagnosed?

FASD is usually diagnosed by a multi-disciplinary team which may include paediatricians, psychologists, speech/language pathologists or occupational therapists. When assessing for FASD, a clinician will consider:

- the person's history and presenting concerns from an obstetric, developmental, medical, mental health, behavioural, and social point of view
- any diverse features such as unusually shaped or sized head or facial features and other major/minor features present at birth
- whether the child may have been exposed to alcohol during and after pregnancy
- any known medical conditions including genetic syndromes and other disorders
- the growth of the person.

Only 1 in 10 children with FASD will have identifiable facial features. Children with FASD will still have significant developmental impairments even if they do not have physically identifiable features.

An early diagnosis may lead to better outcomes for a child living with FASD. If a child receives early intervention and support, they may be less likely to develop other behaviours and issues in adulthood and the ongoing impact of the condition may be less severe.

4 Language and terminology

You should use strengths based language when talking about a person with FASD.

Instead of	Please Use
Suffering with…	Person/Individual living with…
Afflicted or affected by	Impacted by
FASD is caused by maternal alcohol use	FASD is caused when a developing baby is exposed to alcohol
Alcoholic/addict	Women who use alcohol or drugs

5 Enabling social and economic participation

Therapy and support services can be beneficial to enable social and economic participation for people with FASD. Supports will vary depending on the age and circumstances of the participant. Children under 7 years with FASD will be supported by the Early Childhood Early Intervention approach. Some young children may present with global developmental delay, before they have a formal diagnosis of FASD.

Common therapy supports include speech therapy and occupational therapy. People with FASD may also benefit with support from counsellors who are experienced in working with the disorder.

They may support people with FASD with:

- developing and improving communication, comprehension, and literacy skills
- learning social skills to develop and maintain friendships at school and in the community, and protect against isolation
- improving their memory and ability to process information
- capacity building in concepts such as planning, time, money and problem solving
- participation in programs to support self-regulation, emotional regulation and calming responses such as the “Zones of Regulation” program
- sensory processing skills
- daily living skills such as dressing, tying shoelaces, and writing
- education support and instruction for maths and other subjects
- developing social, educational and emotional maturity.

6 Families and carers

Families can provide different levels of support to a person with FASD. They assist with daily living tasks and encourage the participant to find a job. Family members may have a good understanding of the support the person needs to participate in the community and work towards independence.

While families are usually happy to provide support, it can impact their own employment, the needs of other family members, and their own needs and health – especially as they age. It is important to consider, for children and adults, whether the level of informal support being provided is sustainable and how it may impact the family.

Biological mothers of children with FASD may experience guilt or concern that they will be blamed for the disorder. It is important not to make assumptions about how or why an individual was exposed to alcohol during pregnancy. Many mothers of children with FASD do not have problematic patterns of alcohol use, may have been unaware of the early pregnancy and are not neglectful parents. They may feel frustration at the attitudes of health care providers toward them. This can affect their confidence in their ability to parent a child who already faces many challenges.

7 How can I tailor a meeting to suit a participant with Fetal Alcohol Spectrum Disorder?

Every person with FASD is unique and has their own individual personality, strengths and areas where they need support. It is important to remember that each person will have different needs.

You can tailor a meeting to suit the participant by:

- giving the person time to think about their answer and respond – some people will need more time than others
- asking questions to make sure the person understands you – don't assume the person's response means they have understood
- communicating in short, simple sentences and using Plain English
- keeping the number of people in a meeting to a minimum as the participant may be overwhelmed with too many people
- having shorter meetings, with follow ups if necessary, to get relevant information across
- reducing distractions such as visual distraction, background noise and artificial lighting if possible
- giving the person information about what will be discussed at the meeting ahead of time to give them an opportunity to consider responses and prepare with a support person
- communicating and engaging directly with the person with FASD, not just their family member, carer or another person who attends the meeting with them
- speaking respectfully in an age appropriate way
- visual information can be helpful to explain some concepts and messages, such as pictures or objects like a clock or calendar
- using Easy English written information to help with discussion
- writing the discussion points in simple dot point format and include any decisions made, this will be a helpful memory aid for a person with FASD.

8 What people with Fetal Alcohol Spectrum Disorder want you to remember

- Children with FASD may engage in behaviours that look like lying and can make poor decisions. This can mean young people with FASD are more likely to be involved in the justice system. The desire to please and difficulty remembering can have a significant impact in these situations.
- An individual with FASD may experience difficulties with impulse control, understanding consequences of actions and risks. This results from impairments in memory and poor connection between emotional and logical thought.
- Engaging in social interactions can be difficult for people with FASD, and if people behave differently to their expectations, they may respond by over-reacting or shutting down.
- Sometimes people with FASD may find it difficult to focus on, and give or maintain attention to a person or task.

9 Helpful links

- NOFASD Australia
- FASD Hub Australia
- DDWA - Supporting School-age Children with Fetal Alcohol Spectrum Disorder
- Marulu Strategy
- Practice Guide - Early Childhood Early Intervention
- Guide - Conversation style guide

Fragile X syndrome Disability Snapshot

SGP KP Publishing

Exported on 2024-10-18 03:12:05

Table of Contents

This Disability Snapshot provides general information about Fragile X syndrome to assist you in communicating effectively and supporting the participant in developing their goals. Each person is an individual and will have their own needs, preferences, experiences and capacity. This information has been prepared for NDIA staff and partners and is not intended for external distribution.

1 Peak body consulted

In developing this resource, we consulted with Fragile X Association of Australia.

2 What is Fragile X syndrome?

Fragile X syndrome is a genetic disorder and is the leading worldwide contributor to inherited developmental disability. It is caused by a mutation (change in DNA structure) on the X chromosome. The FMR1 gene is responsible for producing a protein important for brain development. When this gene lengthens through the mutation, it switches off production of the protein involved in brain development and other functions.

Fragile X syndrome occurs in around 1:3600 males and around 1:4000-6000 females. Fragile X syndrome is inherited from a female carrier of the FMR1 gene premutation. A premutation carrier does not have Fragile X syndrome, but may have mild expressions of some traits such as anxiety, social avoidance and difficulty with planning and organisation.

Men and women can be carriers of the premutation but only female carriers can pass on the syndrome to their children. Male carriers will pass on the premutation to their daughters who then become carriers. One in around 250 women are Fragile X premutation carriers, often unknowingly. As women have two X chromosomes, there is a 50% chance that women who are either premutation carriers or have Fragile X will pass on the syndrome to their children.

The impacts of Fragile X syndrome are lifelong. Key characteristics of Fragile X syndrome include developmental delay and anxiety (hyperarousal). There is a genetic link between Fragile X syndrome and autism spectrum disorder (ASD). Approximately 50% of males and 30% of females with Fragile X syndrome also have a diagnosis of ASD, and many other males will have autistic-type traits.

The impacts of Fragile X syndrome include a wide range of difficulties such as:

- daily living (anxiety, motor delays, difficulty sleeping, eating issues, toileting, etc.)
- learning challenges including short term memory, difficulty with abstract concepts and planning, expressive language deficits, inattention
- speech and language, including delayed speech or being fixated on something (perseveration)
- behavioural and emotional impacts such as anxiety, ASD, Attention Deficit Hyperactivity Disorder and aggression
- other social impacts
- medical impacts including low muscle tone, epilepsy and ear infections.

The effects of Fragile X syndrome will vary for each individual, ranging from mild to severe. While males commonly appear more severely affected by Fragile X syndrome, some females may also be severely affected. Intellectual disability occurs in 80% of males and about 30% of females with Fragile X Syndrome.

With appropriate care and supports, people who have Fragile X syndrome have a normal life expectancy. Support needs may change at times of transition and throughout life.

3 How is Fragile X syndrome diagnosed?

Fragile X syndrome is diagnosed by DNA testing, generally from a blood sample. A general practitioner, paediatrician, geneticist or any medical doctor can request the test. An individual should be tested for Fragile X if they have developmental delay, unexplained intellectual disability, or where there is a family history of Fragile X.

Some girls with Fragile X syndrome may be diagnosed much later than boys if there is no history of the condition in the family. Females are less likely to display symptoms because they can conceal the impacts of Fragile X syndrome.

4 Language and terminology

The expression ‘living with Fragile X syndrome’ is an acceptable way to describe someone who has been diagnosed with the condition. ‘Fragile X’ or FXS are acceptable abbreviations to use for Fragile X syndrome.

5 Enabling social and economic participation

There is no cure for Fragile X syndrome. Early intervention with a multidisciplinary approach and ongoing supports will maximise a person's capacity for daily living and social and economic participation.

People diagnosed with Fragile X syndrome experience communication, cognitive and behavioural impairments which present challenges in participating in school, employment and community settings.

Supports to enable the participant's social and economic participation may include:

- Occupational therapy such as sensory integration, developing structured routines, encouraging independence through capacity building, providing support in a workplace.
- Psychological therapies such as support with anxiety/hyperarousal.
- Support coordination to maintain consistency of therapeutic relationships, build capacity of the family unit and support carers.
- Support in the community including support workers to provide consistent, safe supports, and model appropriate social skills in a variety of situations.
- Assistive technology and appropriate equipment in the home, work or volunteer setting.
- Speech and language therapy.
- Education supports such as learning environments that are suitable for the Fragile X learning style and support executive function. Examples include using visual input (pictures, timetables); minimising distractions; using calming strategies; positively reinforcing good behaviour.

6 Families and carers

Families and carers play an important role in supporting the participant who has Fragile X throughout their life. They are usually involved in supporting the participant to gain access to the NDIS, planning and implementation of supports.

As Fragile X Syndrome is an inherited condition, it may impact other family members and the participant's home life. The family unit may need support through access to respite or support with the participant's daily living activities or community participation. The impact of raising a child or children with Fragile X syndrome can also affect a family unit. You should consider how funded supports for the participant can result in a break for families and carers.

As Fragile X syndrome is hereditary, the biological mother can experience feelings of guilt or other feelings associated with being a carrier of the condition.

Support coordination can be an effective support for the family/carer and individual with Fragile X syndrome.

7 How can I tailor a meeting to suit a participant with Fragile X syndrome?

Get in touch with the participant before the meeting to find out what support they might need. When meeting a participant with Fragile X syndrome, make sure to minimise any distractions and reduce any sensory stimuli in the environment. For example, bright or flickering light or background noise. Consider offering breaks during the planning discussion. Before the meeting, consider providing written material in plain English or Easy English, with questions and points to discuss.

During the discussion, allow time for people to reflect on questions and respond. Use open body language and a calm tone of voice. You can check understanding with questions such as “can you explain that back to me?”. Make sure you read back what has been written to ensure the participant is comfortable their goals have been accurately recorded.

Participants will often be accompanied and supported by family members for NDIS discussions, especially to provide support with communication. Where planning discussions involve mothers who are premutation carriers of Fragile X, be mindful of their feelings and possible level of anxiety. Additionally, a parent or family member may also have Fragile X syndrome and need support themselves. This might make it difficult for them to develop or implement the participant’s plan. Consider suggesting that the participant/family/carer involve an advocate, support coordinator, or support worker to support them in the meeting.

8 What people with Fragile X syndrome want you to remember

- Understanding the impacts of Fragile X on daily living are key to developing supports that allow an individual to live their best life.
- Fragile X syndrome is an inherited lifelong genetic condition, and families may have more than one child with Fragile X syndrome.
- Fragile X is diagnosed by DNA test, not behavioural testing or analysis of physical facial features.
- In around 30% of diagnoses there is no family history of Fragile X syndrome.
- Early intervention and ongoing therapies support capacity building.
- Fragile X presents differently in females and males.
- Females who have Fragile X syndrome may mask their cognitive-communicative disability through shyness or avoidant behaviour.
- Changes in behaviours usually have an additional cause, such as an undiagnosed medical condition, hormonal changes (for example, puberty, or ageing later in life), a change in environment (transitions can be difficult), adverse social interactions (for example, bullying in work or school). Further assessments by a professional will be required.

9 Helpful links

- Fragile X Association of Australia
- National Fragile X Foundation (USA)
- Fragile X Alliance

Global Developmental Delay Disability Snapshot

SGP KP Publishing

Exported on 2024-10-18 03:12:18

Table of Contents

This Disability Snapshot provides general information about global developmental delay to support you in communicating effectively and supporting the participant and their parent/carer in developing their goals. Each person is an individual and will have their own needs, preferences and experiences. This information has been prepared for NDIA staff and partners and is not intended for external distribution.

1 Peak body consulted

In developing this resource we consulted with Association for Children with Disability Tasmania. We would also like to acknowledge resources from Cerebral Palsy Alliance.

2 What is Global Developmental Delay?

Global developmental delay (GDD) describes a child who is taking longer to reach developmental milestones in two or more areas of functioning. GDD is diagnosed when a child experiences these delays in two or more areas of functioning which have continued for at least 6 months.

The developmental delays may impact the following areas:

- speech or language development
- gross motor skill development (or big movements), such as walking or sitting
- fine motor skill development (or little movements), such as drawing or holding a toy
- mobility and motor planning
- thinking, understanding and learning
- relating to other people, making friends and regulating their own emotions
- daily living tasks and activities, such as dressing and going to the toilet.

Early intervention programs can give many children with GDD a head start and a better chance to reach their full potential. Supports may improve functional outcomes relating to the child's daily activities, routines and social participation.

Children with GDD may go on to be diagnosed with another disability and need ongoing support.

3 How is GDD diagnosed?

GDD is diagnosed in children under five years of age and in many cases there are no known causes. GDD is diagnosed by a specialist – usually a paediatrician – after a developmental screening assessment by a general practitioner or maternal and child health nurse. A paediatrician will often complete a range of tests to assess for possible causes of the child's developmental delays. A child will be diagnosed with GDD when they are not able to undertake a formal assessment for intellectual disability.

A diagnosis of GDD highlights the need for regular assessments in order to determine the cause and extent of developmental delays. A child's diagnosis will usually change to intellectual disability, autism, or another condition as they get older. A person will not be diagnosed with GDD for the first time after age 5, – reports could say "initially diagnosed with GDD" as part of the person's history.

An assessment – either an adaptive functioning or an adaptive behaviour assessment – of the child's daily routines and participation in the community may also help to determine what types of support will benefit the child. This includes looking at how the child interacts with others at home, kindergarten, or in a community setting. It is important to assess how the child responds to intervention – whether the child is responding to the current supports, or if another intervention is more suitable.

4 Language and terminology

When talking about a child with GDD you should focus on the person, not the impairment. You should generally use inclusive person-first language. Use the phrases such as ‘a child living with GDD’.

As participants with GDD are children, most communication will be with parents or family members. Make sure to focus on the child’s strengths and abilities rather than what they can’t do. Understand that this is a difficult time for parents and make sure that your language reflects this.

5 Enabling social and economic participation

A child with GDD may benefit from early childhood intervention supports from the NDIS as well as mainstream health and early childhood education support. A multidisciplinary team – including physiotherapists, OTs, speech therapists, therapy assistants and medical personnel – is crucial for the assessment of and intervention with the whole child.

Mainstream supports may include:

- a general practitioner
- medical specialists such paediatricians or maternal and child health nurses
- early childhood educators and teachers who can help deliver an early learning program and support the child in pre-school and school.

You may consider recommending NDIS supports in the Core, Capacity Building, and Capital categories. These supports may vary depending on the child's age and circumstances. For example, support for daily living is largely funded through Capacity Building supports however if there is an evidenced need beyond what would be considered typical parental responsibility, Core supports for children may be considered.

Core supports:

Core supports may be considered in exceptional circumstances for respite or to support informal care from parents or carers. For example, where a child requires a level of support with daily activities significantly beyond the level usually required for children of the same age.

Capacity Building supports:

Capacity Building supports provide the participant with funding to access early childhood intervention (therapeutic supports). These supports will come from a multi-disciplinary team and aim to:

- develop self-care skills with tasks like picking things up, dressing or eating independently
- engage in suitable play activities
- support physical development, for example, walking and overcoming poor balance, muscle weakness, and motor planning
- develop speech and language skills
- auditory processing assessment and other sensory processing assessments
- monitor overall development, and assess and manage behavioural or emotional issues
- assess the child's vision and vision monitoring every 6 months to a year is important as the child develops.

Capital supports:

Capital supports include Assistive Technology to support the child with GDD with self-care and communication if necessary.

6 Families and carers

A diagnosis of GDD can be unsettling for family members and carers. They may still be coming to terms with the diagnosis and what changes need to be made as a result. They may be confused and anxious as GDD requires further assessment which may lead to a new diagnosis. Families and carers may experience different emotions at different times as the child's development progresses.

Families and carers play an important role in supporting a child living with GDD. They are usually involved in supporting the child to gain access to the NDIS, planning and implementation of supports for the individual.

Raising a child with GDD can have a significant impact on a family unit, particularly with other children. The family may need support to access respite, family counselling, and information and training on GDD. This can help parents and carers to understand the different therapies that may be included in their child's plan.

7 How can I tailor a meeting to suit a participant and with global developmental delay?

Family members will be the main contact and support for children with GDD and will accompany them at NDIS meetings.

- Allow enough notice for the family member to prepare for meetings (ideally four weeks) and be clear about what ‘prepared’ means.
- Listen non-judgmentally and collaborate with the family member to clarify the child’s needs, as well as their needs to support the child. Ask the person what they find important and don’t make assumptions. Use paraphrasing and clarifying questions to understand their wants and needs.
- Be honest and clear about what you can and cannot do.
- Discuss that information and recommendations from assessments will inform how the next NDIS plan is created to support the child.
- Provide information about your recommendations and why they are relevant, even if it seems obvious.

Parents and family members may not know what support is available. Talk to them about the types of supports that can be included in their plan and how they will be individualised for their child. Highlight what necessary supports and services family members have access to in order to support the child and the family unit as a whole.

8 What families of children with GDD want you to remember

- Family members/carers may be stressed or experiencing grief, especially if the diagnosis is recent. Be sure to acknowledge their experience and be sensitive to how they might be feeling.
- Families may be concerned that they might not get the right supports for their child, especially long term.
- Families may not know what supports are available, or which professionals they should access. They may be confused about which services will be provided through the NDIS or other mainstream services such as health or education.
- Families may be new to the system and not fully understand how the NDIS works. They may be trying to navigate this while learning to be new parents, or caring for other children in the family unit.

9 Helpful links

- Cerebral Palsy Australia - Global Developmental Delay
- Raising Children - Developmental Delay
- Mencap UK - Global Developmental Delay
- Early Childhood Early Intervention intranet page

Huntington’s Disease Disability Snapshot

SGP KP Publishing

Exported on 2024-10-18 03:12:32

Table of Contents

This Disability Snapshot provides general information about Huntington's disease to help you to communicate effectively and support the participant in a planning meeting. Each person living with Huntington's disease is an individual with their own needs, preferences and experiences. This information has been prepared for NDIA staff and partners and is not intended for external distribution.

1 Peak body consulted

In developing this resource, we consulted the Consortium of Australian Huntington's Associations.

2 What is Huntington's Disease?

Huntington's disease (HD) is a rare, hereditary, chronic, neuro-degenerative neuromuscular disease with no cure. However, there are treatments and strategies to minimise the impact of the disease. Signs and symptoms often begin to appear when people are in their 30s and 40s.

- SIGNS are changes as noted by others.
- SYMPTOMS are changes noticed by the HD affected person.

Common early signs and symptoms include:

- loss of fine motor coordination
- muscle stiffness
- involuntary body movements (often pronounced) known as chorea
- cognitive or behavioural changes (for example, memory loss, mood swings, trouble with concentration, difficulty in making decisions, and behaving impulsively).

Not all people with HD will have the same changes, even those from the same family.

Huntington's disease will progressively affect how the person functions each day, and will change their everyday needs. Eventually, HD will significantly impact a person's ability to make rational decisions, walk safely, speak clearly and swallow normal food safely.

Most people with HD have a life expectancy of 10 – 20 years after measurable changes begin, but they have usually had signs and symptoms for much longer.

3 How is Huntington's disease (HD) diagnosed?

Huntington's disease is often diagnosed when a person with a family history experiences mild changes in their functioning. Their GP will usually organise a general physical and neurological exam, and should refer them to a Huntington's disease specialist clinic if one is accessible. They will likely recommend an MRI scan of the brain.

A genetic test will confirm the diagnosis, usually following genetic counselling for the family in a genetics clinic.

It is important to understand that while most people with HD are aware of a family history of the disease, this is not true for everyone. The family history issue needs a sensitive, tactful approach.

4 Communicating and supporting people with HD

People with HD may struggle with communication because they become less aware of other people. They may also experience psychological symptoms such as anxiety, depression and personality changes.

To successfully communicate with people with HD, it's crucial to understand that they may not be aware of their own physical and cognitive changes.

The progress of the disease varies between individuals with HD, and over time for the same person, so a flexible, individualised care plan will work best. The changes tend to be gradual. However, if a sudden change in ability is noticed, professional help may be needed to treat any reversible conditions such as infection, or to understand and manage what may be triggering behavioural responses.

The participant's plan may need to be reassessed often, and there may be frequent changes in how they manage to do things.

5 Language and terminology

You should use language which reflects the person first, for example "person living with Huntington's disease". Some of the language used when talking about Huntington's disease is explained below.

- **Chorea***:* involuntary, dance-like movements – the person may be unaware they have chorea even when it's obvious to others
- **Hereditary***:* passed on from one family generation to the next
- **Dominant***:* one mutated copy of a gene is enough to cause disease
- **Neurodegenerative***:* a condition of the nervous system that will continue to get worse over time.

6 Enabling social and economic participation

You're best able to support a participant with HD when you know what challenges and barriers to social and economic participation they're likely to face.

For example, a participant with HD could experience challenges in their personal relationships because of the impacts of the disease. They will gradually lose their physical independence and often experience psychological and/or behavioural symptoms which can place a strain on their relationships.

Counselling or other types of psychological support may help them and their carers better cope with their changing life circumstances. Arranging appropriate social activities, especially outings, can make a big difference to their quality of life.

Although the cognitive impacts of HD may be subtle, they can affect the participant's ability to communicate their needs clearly during a planning meeting. Keep this in mind when talking to the participant and/or their carer.

It's important to include support coordination for the participant to implement their plan. For example, because of the impact of HD the participant may find it difficult to communicate with their service providers. Having a support coordinator to help them will make sure they keep getting the supports they need. If the participant experiences a behavioural crisis , the support co-ordinator may be able to adjust the supports the participants needs instead of needing a change to the participants plan.

7 How can I tailor a meeting to suit a participant with Huntington's disease?

It's important to remember that Huntington's disease is a degenerative disease and the participant's needs are likely to change over time. Make sure to check with the participant and their carer for any adjustments they might need for the meeting beforehand. It's important to check with both a family member or carer as well as the participant to gain a full understanding of their symptoms, diagnosis or problems.

While sensitivity is needed when discussing future support needs, it's important to be realistic about the participant's growing and potentially unpredictable need for support as their Huntington's disease progresses.

You should consider supports that will:

- enable the participant to make the most of their independence, and keep them safe for as long as possible
- help maintain the participant's social and economic participation
- help maintain their relationships.

You should also ensure;

- there is funding in the plan for specialist training in providing support to participants with HD as many service providers often have no background or experience with HD.

Funding in the plan may include things like assistive technology or psychological support. It's important to listen to the participant as well as their carers to make sure you get all the information you need to make your decisions.

8 What people with Huntington's disease want you to keep in mind

In building a successful relationship with a person with HD, it's very important to convey a strong sense of respect, and be direct and simple in your choice of words. Always request feedback to check they have got the message you wish to convey, without hurrying the person as they may take much longer than expected to formulate their response.

Huntington's disease affects everyone differently, even within the same family. Keep this in mind when supporting multiple participants from the same family.

9 Helpful links

- Huntington's Australia
- NSW Huntington Outreach Service

Intellectual Disability Snapshot

SGP KP Publishing

Exported on 2024-10-18 03:12:44

Table of Contents

This Disability Snapshot provides general information about intellectual disability to assist you in communicating effectively and supporting the participant to develop their goals in a planning meeting. Each person is an individual and will have their own needs, preferences and experiences that will impact on the planning process. This information has been prepared for NDIA staff and partners and is not intended for external distribution.

1 Peak body consulted

In developing this resource we consulted with Inclusion Australia.

2 What is intellectual disability?

Intellectual disability usually begins before the age of 18 and affects people their whole life. Intellectual disability does not define who a person is, and each individual person has their own personality, interests, skills and needs[i].

A person with intellectual disability experiences significant limitations[ii] in their intellectual functioning. This includes:

- reasoning
- planning
- problem solving
- understanding complex ideas.

Intellectual disability also affects adaptive behaviours such as:

- academic skills - for example, language, reading, writing and arithmetic
- social skills - for example, interpersonal skills, communication, self-esteem, gullibility, and social problem solving
- practical skills - for example, personal care, use of money, safety, health care, domestic tasks, and travel.

3 How is intellectual disability diagnosed?

Intellectual disability is diagnosed by a psychologist accredited in conducting standardised assessments of intelligence and adaptive behaviour.

4 How many people have intellectual disability?

People with intellectual disability are one of the largest primary disability groups in the NDIS.

- 11% of NDIS participants at 30 December 2019 had an intellectual disability[iii].
- Approximately 45% of people with intellectual disability will have another significant disability, for example, autism, physical, psychosocial or sensory disability[iv].

5 What causes intellectual disability?

Intellectual disability can occur before, at, or after birth. There are a range of causes of intellectual disability, including:

- Prenatal – for example, chromosomal disorders, gene disorders, syndromes, metabolic conditions, brain malformation or injury, parental substance abuse, maternal malnutrition, or violence
- Perinatal – for example, labour or birth injury
- Postnatal – for example, malnutrition, child abuse and neglect, chronic illness, and degenerative disorders[v].

6 Common characteristics and impacts of intellectual disability

Communication

Challenges with communication are common for many people with intellectual disability. This can make it difficult for a person to navigate service systems.

Some people with intellectual disability have good conversation skills whereas others have limited or non-verbal communication skills.

People with intellectual disability have the right to be supported to make or contribute to making their own decisions (supported decision making). Even when an individual has a legal guardian or appointed nominee (substitute decision making), it is the responsibility of the guardian or nominee to support them increase their capacity to make decisions.

For both supporting and appointed decision makers, the rights, dignity, interests, choices and wellbeing of the person with intellectual disability are paramount.

People with intellectual disability can be vulnerable to suggestion and may agree to what is asked or said because they think it is expected of them. They may agree with authority figures because they want to please people.

It is essential to check with the participant during meetings to ensure they understand the discussion and are able to communicate their wishes, opinions or decisions. A simple check of understanding can be made by asking an individual; “can you explain that back to me in your own words?”

Behaviour

Some people with intellectual disability may have “behaviours of concern” or “challenging behaviour” which may include self-harming behaviour, verbal or physical aggression, or property damage. This behaviour is often a form of communication due to an inability to convey messages through typical forms of communication.

People with intellectual disability who experience difficulty with their behaviour need strategies and support to develop appropriate behaviours. This then allows them to feel comfortable and included in typical community activities.

Physical health and mental health

The physical health and mental health of people with intellectual disability can impact on their functional capacity.

Some individuals with intellectual disability enjoy good health and mental health which allows them to participate fully in work and community activities. Other individuals with intellectual disability have significant health limitations that can restrict personal, social and economic activities, and may require special medical attention.

Complex support needs

Some people with intellectual disability also have complex support needs. This may mean they require supports for daily activities from a range of mainstream and community service systems including:

- health and mental health
- criminal justice
- alcohol and drug
- housing
- education and employment.

7 Enabling social and economic participation

Full inclusion

Historically people with intellectual disability have been grouped together in separate settings for living, education, work, and day activities. People with intellectual disability do not need to be grouped together to meet their individual needs for education, work, living or community participation.

For people with intellectual disability, full inclusion means being involved and accepted as equal participating members in the Australian community.

The NDIS provides people with intellectual disability with the reasonable and necessary supports to pursue their areas of interest and fully participate in roles and activities in the community.

Some people with intellectual disability require frequent or intensive support to promote development, maximise independence and well-being.

Expectations

People with intellectual disability are frequently and unfairly at risk of low expectations about their capacity to learn and do tasks.

For example, if we think a person cannot learn to use public transport, we may choose not to teach a person how to use public transport. Without travel training, a person will not get the opportunity to learn how to travel.

This low expectation can be a self-fulfilling prophecy. It can lead to an individual becoming dependent on others to do daily tasks despite having the capacity to learn and take on these tasks independently.

Research and lived experience indicates we can assume people with intellectual disability can learn, work and participate in community activities.

Skill development and support

Research and lived experience have shown people with intellectual disability may find it difficult to generalise or transfer skills from one setting to another. This makes it essential for skill development to happen in the place a person with intellectual disability is to perform that skill.

For example, the most effective open employment strategy is to train a person with intellectual disability in a regular workplace in the open workforce[vi].

A person with intellectual disability may benefit from NDIS supports like taking part in a vocational ‘discovery’ process. This allows the person to explore their strengths and interests in the context of work. Volunteering can also be a first step in building confidence and connecting to the community and the idea of employment.

Once in work, many NDIS participants with intellectual disability may need regular, ongoing support in the workplace to help them undertake daily work tasks, as well as develop and maintain skills in the workplace. This level of support to work has traditionally been provided in an Australian Disability Enterprise (ADE).

Assistive technology may also be required to support participation in work.

8 How can I tailor a meeting to suit a participant with intellectual disability?

Every effort must be made to enable people with intellectual disability to lead discussions and actively participate in meetings.

Consider what will support a successful planning meeting. Do not assume what a person may need.

It may be helpful to:

- provide written information in easy to read English before the meeting
- provide the questions and points to discuss before the meeting
- if the person has a communication aid, ensure it is available for the meeting
- ask the participant what support they may need to participate in the meeting
- use pictures or objects, such as a clock or calendar when explaining abstract concepts such as time
- always talk directly to the person wherever possible, not to a support person
- speak respectfully in an age-appropriate way. Allow the person whatever time they need to respond
- hold meetings in a quiet setting free of distractions and take breaks if required to maximise attention
- consider having a second meeting to ensure everything is discussed
- consider having a family member to participate in the meeting as families often play an active role in the lives of people with intellectual disability. This will require consent from the person, unless a family member is a legal guardian, appointed nominee or child representative
- consider having an advocate who is not a family member to participate in the meeting.

9 Helpful links

- Inclusion Australia

[i] American Association on Intellectual and Development Disability (2010). Intellectual Disability: Definition, Classification, and Systems of Supports. AAIDD: Washington. American Psychiatric Association (2013). Diagnostic and Statistical Manual of Mental Disorders (DSM-5). Arlington, VA: American Psychiatric Publishing

[ii] Significant limitations are defined as approximately two standard deviations below the mean for a standardised assessment of intellectual functioning and adaptive behaviour

[iii] NDIS COAG Disability Reform Council Quarterly Report, 31 December 2019, page 103.

[iv] Australian Institute of Health and Welfare 2018. Disability support services: Services provided under the National Disability Agreement 2016–17. Canberra: AIHW

[v] American Association on Intellectual and Development Disability (2010). Intellectual Disability: Definition, Classification, and Systems of Supports. AAIDD: Washington.

[vi] (a) Department of Social Services. National Disability Employment Framework – Issues Paper 2014. Migliore, 2010. (b) International Encyclopedia of Rehabilitation. Centre for International Rehabilitation Research Information and Exchange (CIRRIE).

Motor neurone disease Disability Snapshot

SGP KP Publishing

Exported on 2024-10-18 03:12:55

Table of Contents

This Disability Snapshot provides general information about motor neurone disease to assist you in communicating effectively and supporting the participant in developing their goals in a planning meeting. Each person is an individual and will have their own needs, preferences and experiences that will impact on the planning process. This information has been prepared for NDIA staff and partners and is not intended for external distribution.

1 Peak body consulted

In developing this resource we consulted with the peak body, Motor Neurone Disease Australia.

2 What is motor neurone disease?

Motor neurone disease (MND) is the name given to a group of diseases in which the muscles that enable us to move, speak, breathe and swallow fail to work normally. These muscles and the nerves that supply them are known, collectively, as the motor system - the system that is concerned with action and movement (as opposed to sensation).

The system fails because the nerve cells that control movement (the motor neurones) degenerate and die. This loss of motor neurones causes an increasing loss of function over time. The patterns of weakness in MND vary from person to person and currently there is no effective treatment or cure.

There are two different types of motor neurones, and both may be affected:

- Upper motor neurones in the brain - damage to these neurones causes spastic or stiff paralysis of the muscles that they serve.
- Lower motor neurones in the spinal cord - damage to them causes flaccid or floppy paralysis.

Without nerve impulses (messages from the brain and spinal cord) the muscles have nothing to activate them and they gradually waste away.

The average life expectancy for a person with MND is two to three years from diagnosis or three to five years from the onset of early symptoms. However, about five to ten per cent of people with MND will have a slowly progressive form of the disease and may live with the disease for up to ten years or more.

3 Common characteristics and impacts of motor neurone disease

The pattern of symptoms of MND varies from person to person. Usually the condition begins by affecting only one part of the body then gradually spreads. In some people the symptoms are widespread from the start. Often only upper or lower motor neurones are affected in the early stages, but both are usually involved as the condition progresses.

Early symptoms are usually mild. They may include problems with walking or holding objects in the hand, slurred speech or difficulty swallowing. Some people find that emotional responses such as laughing or crying are more easily triggered.

Cramps are common as is muscle twitching (fasciculation), which is a sign of damage to lower motor neurones (those in the spinal cord). Damage to upper motor neurones (those in the brain) results in stiffness of the muscles (spasticity) and slowed movements. Sometimes the muscles will spasm or jerk spontaneously.

Overtime, the loss of mobility and independence means that many people with MND will need help with personal care, including washing, dressing and going to the toilet. While most people maintain their ability to control their bowel and bladder, their reduced capacity to move about can mean it is harder to get to the toilet. This can be very distressing. Constipation can also occur because they are moving less and have made diet changes to adapt to their swallowing difficulties.

In the past, it was thought that MND only affected the neurones controlling the muscles that enable us to move, speak, breathe and swallow. It is now known that up to 50 percent of people with MND can experience changes in cognition, language, behaviour and personality. Most people experience relatively mild changes. However, a small proportion (5 -15 percent) will show more significant changes and will receive a diagnosis of motor neurone disease with frontotemporal dementia (MND/FTD). Often the symptoms of dementia come before the motor symptoms, sometimes by a number of years.

MND does not affect memory or the senses (sight, hearing, taste, smell and touch).

4 What are the different types of motor neurone disease?

There are four main forms of MND:

- Amyotrophic lateral sclerosis (ALS) is the most common form, characterised by muscle weakness and stiffness, over-active reflexes and rapidly changing emotions. Upper and lower motor neurones are both affected and the limbs cease to work properly.
- Progressive muscular atrophy (PMA) is characterised by muscle wasting and weakness, loss of weight and muscle twitching. Only the lower motor neurones are affected.
- Progressive bulbar palsy (PBP) mixed bulbar palsy and pseudo-bulbar palsy all involve the muscles of speech and swallowing. The nerves that control these muscles are in the lower part of the brain (the bulb), hence the term bulbar palsy (palsy means paralysis).
- Primary lateral sclerosis (PLS) is very rare with upper motor neurone damage causing stiffness and paralysis of the limbs. PLS may begin in the arms (flail arm type) or the legs (flail leg type).

5 How is motor neurone disease diagnosed?

It can be difficult to diagnose MND as there are several other conditions resembling it. Doctors may need to keep the person under review for weeks, months or years to formally diagnose. The person will probably be referred to a neurologist - a doctor who specialises in conditions affecting the brain and nervous system.

The doctor may order various tests, including some to eliminate other conditions. These include nerve conduction studies (NCS) and electromyography (EMG) which look at how nerves are functioning by stimulating a nerve electrically and recording the muscle activity that results. The EMG will involve putting a fine needle into muscles which can be uncomfortable.

Currently there is no cure for MND, although worldwide research is showing encouraging progress.

6 Enabling social and economic participation

A person's support needs for social and economic participation will change as the disease progresses. Maintaining maximum independence in work, personal relationships and in the community will be an important focus.

- To maintain work, ongoing customisation of work tasks to match the level of function will be important, along with consideration of personal care in the work place or assistance with travel. This might require NDIS funding for specialist disability assessment services as well as access to external employment retention and support initiatives such as the Work Assist program provided by Disability Employment Services.

Common barriers to social and economic participation include:

- **Lived challenges***:* mobility, communication, decision making, social connection, respiration, emotional lability, swallowing and secretion control, workplace and housing modifications, transport, obtaining appropriate assistive technology (AT).
- **Concerns and sensitivities***:* the future, maintaining relationships, living arrangements such as being able to remain in their own home, embarrassment, activities of daily living, personal care, family and carers, finances, death.

7 How can I tailor a meeting to suit a participant with motor neurone disease?

It is common for people in the early stages of MND to present with reasonable functional capacity and a person therefore may decline formal personal supports. While a person may be currently able to continue with their current duties at work, it will be important to discuss and plan for functional changes. Participants and employers should be encouraged to work together as early as possible to discuss customisation of work tasks. This conversation would include planning for the supports that may be introduced to maximise their independence and longevity at work.

It is important to be aware that support needs will change over time and sometimes rapidly. Sensitivity is needed when discussing the wishes of the person with MND and their family. Planning for formal support needs may have to be encouraged initially to enable a smoother transition when there is a need for more intensive supports.

As MND causes progressive deterioration and loss of function it is more appropriate to ask the person about their priorities and what actions to take to address these in their plan. This is preferable to using the term, goal setting.

Planning meetings should provide the person with MND and their family with the opportunity to think about, discuss and set some immediate and longer term priorities.

These may include:

- maintaining employment and independence in the community
- deciding how they would like to be supported
- health and lifestyle decisions
- maintaining relationships
- carer needs
- equipment and assistive technology including rental or purchase, maintenance and replacement (to maintain independence, social inclusion, safety and communication)
- assistance with planning and managing changing supports.

Supports for a person with MND are often complex and cross many sectors including health, disability, community and housing. Individuals often have an ongoing need for assistance with planning and using their informal, mainstream and funded supports. Given the rapidly degenerative nature of MND and complexity of supports required, it is highly recommended that support coordination is included in the plan.

8 Accessibility or support

The participant may prefer the planning meeting takes place in their home due to mobility issues, assistive technology in use, toileting concerns, transport issues and fatigue. Accessibility or support requirements for the meeting should be discussed with the participant prior to the meeting taking place.

Ensure the participant is aware they can have one or more support people present at the meeting. Ask about communication and AT needs when making arrangements for the meeting. Remember the needs of people living with MND can be complex and will vary from person to person.

9 Helpful links

- MND Australia
- MNDcare

Multiple sclerosis Disability Snapshot

SGP KP Publishing

Exported on 2024-10-18 03:13:06

Table of Contents

This Disability Snapshot provides general information about multiple sclerosis to assist you in communicating effectively and supporting the participant to develop their goals in a planning meeting. Each person is an individual and will have their own needs, preferences and experiences that will impact on the planning process. This information has been prepared for NDIA staff and partners and is not intended for external distribution.

1 Peak body consulted

In developing this resource we consulted with Multiple Sclerosis Australia.

2 What is multiple sclerosis?

Multiple sclerosis (MS) is the most common degenerative neurological condition diagnosed in young adults. It is an incurable and chronic, long-term condition. MS affects the central nervous system. It affects the brain, spinal cord and/or optic nerve and interferes with the normal conduction of nerve impulses around the body. It is characterised by scarring of the fatty insulating myelin sheath which protects the nerve fibres. This happens when the body's own immune system attacks the myelin sheath, causing inflammation.

These attacks happen early in the disease process and cause a gradual loss of function due to nerve damage. The attacks result in brain atrophy, creating both cognitive issues and functional impairments.

Depending on where in the body these attacks and the resulting damage occur, a diverse range of symptoms, both sensory (sensation) and/or motor (movement) may develop.

3 Important things to note

- The condition course is unpredictable and differs from person to person.
- For some people, it is a disease that fluctuates in severity with periods of unpredictable relapse and remission. For others, it is a progressive decline over time. For all, it is life changing.
- Symptoms interact and cannot be assessed in isolation.
- Symptoms interact with other co-occurring conditions causing a compounding effect.
- Symptoms can be unpredictable and may vary on any given day.
- Invisible symptoms can be debilitating and result in a range of functional impairments.

4 Common symptoms

MS symptoms can be any combination of the five major functional impairments, including:

- **motor control** – lack of muscle control or coordination of movements (ataxia), muscular spasms and tremors, muscle weakness, impaired style or manner of walking (gait), coordination problems, speech and communication difficulties (such as dysarthria and dysphonia), abnormal tone, hyper-tonicity, swallowing difficulties (dysphagia), breathing difficulties, heart problems, imbalance and impaired upper and lower limb function
- **fatigue** – debilitating fatigue often in combination with heat sensitivity. Fatigue may impact other active symptoms, for example, the ability to walk distances, concentrate or complete daily tasks and work
- **other neurological symptoms** – including dizziness (vertigo), pins and needles, nerve pain (neuralgia), ongoing pain, discomfort, and visual disturbances including impaired vision (diplopia) and depth perception, involuntary eye movement (nystagmus) or partial or complete sight loss
- **bladder and bowel dysfunction** – including incontinence, failure to store or empty, urgency, waking up more than usual to urinate at night (nocturia), faecal impaction and constipation, diarrhoea and sexual problems
- **neuropsychological symptoms** – including ‘brain fog’, impaired memory and concentration, changes in processing speed and ability, impaired executive function (for example reasoning and problem solving), personality changes, emotional changes, anxiety, depression, suicidal thoughts, cognitive impairment, and difficulties sleeping.

5 How is multiple sclerosis diagnosed?

To help identify MS symptoms earlier, more awareness of MS is needed. Some people may delay seeking treatment for their symptoms and some GPs and health professionals can miss early symptoms.

Patients usually experience a first neurological episode caused by inflammation of the nerve tissue. This can be significant, especially if it is inflammation of the optic nerve in the eye (optic neuritis) and there is impaired vision.

Generally, a patient might present to a GP, hospital or specialist with unexplained symptoms. For example, visual disturbances or loss of physical function in their hands, arms or legs.

MS is usually diagnosed by a specialist MS neurologist following at least one episode of neurological symptoms and MRI scan results showing new and old lesions in the brain and spinal cord.

For an accurate diagnosis and effective management, best practice suggests a diagnosis and ongoing support should be provided by a team of health professionals specialising in MS.

6 Types of multiple sclerosis

- **Relapsing-Remitting MS (RRMS):** characterised by unpredictable attacks followed by partial or total recovery (also called exacerbations, relapses, or flares). This is the most common form of MS. 70 to 75% of people with MS begin with a relapsing-remitting course. Treatments aim to reduce attacks to improve long-term outcomes.
- **Secondary-Progressive MS (SPMS)***:* a relapsing-remitting course which later becomes steadily progressive. Some attacks and partial recoveries may continue to occur. Of the 70-75% who start with relapsing-remitting disease, more than 50% will develop SPMS within 10 years; 90% within 25 years.
- **Primary-Progressive MS (PPMS)***:* a progressive course from onset. Symptoms generally do not remit. 15% of people with MS are diagnosed with PPMS, although the diagnosis usually needs to be made later on, when the person has been living for a period of time with progressive disability and no acute attacks.

7 Common experiences and impacts of multiple sclerosis

People living with MS are more likely to be under-employed or unemployed and experience financial hardship as a result. Some patients might try to hide their symptoms, have persistent denial of diagnosis or don't disclose their diagnosis, perhaps for fear of losing their job.

There are also a number of indirect and direct costs (out of pocket expenses) associated with MS.

Due to the condition's complexity, people living with MS may struggle to navigate the health and disability sectors.

Some invisible symptoms such as cognitive and visual disturbances, muscle weakness, spasms or decreased motor control can impact day to day activities and the ability to:

- engage in long conversations or follow long sentences
- concentrate for lengthy periods
- understand abstract concepts
- complete forms
- use a computer.

Slurred, slow or impaired speech can be misinterpreted as the person being intoxicated or of lower intelligence. Psychosocial impacts may include reduced self-esteem, social isolation and/or interpersonal and relationship difficulties.

Furthermore, carers of people with MS can experience significant carer burden and this has the potential to lead to relationship difficulties and breakdown.

8 Enabling social and economic participation

It is important to explore how a person with MS can be supported to continue their participation in current activities, education and employment, taking into consideration their interests, level of function and fatigue.

It may be appropriate for some participants with MS to explore ways to maintain their current career/profession with supports in place. Peer support from other people with MS can also help support social and economic participation.

Employment supports that might be considered through the NDIS include, personal care in the workplace, assistance with travel, assistive technology and funding for specialist disability or employment related assessment services. Employment retention and support initiatives can be accessed through Work Assist, the Disability Employment Services (DES) program.

9 How can I tailor a meeting to suit a participant with multiple sclerosis?

These are some accessibility or support requirements to consider:

- face to face meetings are recommended. Phone conversations are often hard to manage
- check individual preference for best time of day due to possible brain fog or fatigue.
- check accessibility requirements. Advise participant of location and availability of accessible parking
- check if there is a need to break up a face-to-face meeting into two parts or provide a break
- schedule a reminder for appointments
- encourage a person with MS to bring a support person along to provide reminders, assist with reading and provide general support
- check comfort levels and ensure adjustable air conditioning is available during a meeting
- ensure the person knows the location of the nearest restrooms/toilets. Allow for breaks
- consider that coordination of supports is often required. MS Australia members have found that plans are often not activated or progressed and can become too complex to manage when coordination of supports is not included in a person's plan
- treat someone with the progressive form of MS with urgency, as achieving optimal functioning in the progressive stage is important to maintain quality of life
- ensure the person knows to notify the NDIA of any changes in circumstances and how to do so. Consider building flexibility into their plan.

10 What people with multiple sclerosis want you to remember

- MS can be challenging, complex and frustrating. Listen with sensitivity.
- Be flexible and prepared to ‘think outside the box’.
- Quite often a person living with MS ‘presents well’ and it is only after more in-depth questioning that their needs become apparent.
- While some symptoms are relatively easy to discuss, others can cause discomfort or embarrassment. For example, cognitive symptoms, bladder and bowel dysfunction, sexual dysfunction and even depression.
- People living with MS may have symptoms that fluctuate greatly from one day to another. It’s important to ask about hidden (invisible) symptoms and how the person functions on a ‘bad’ day.
- Good questions to ask are “what makes your symptoms worse?” and “what makes them better?”
- Ask about other co-occurring conditions/disabilities and how these and various medications compound the person’s ability to perform daily tasks.
- Fluctuations in mood and mental health are common and greatly impact on functioning and quality of life. Someone living with mood changes and mental illness may find goal setting and evaluation difficult.
- For many people living with MS, impaired cognition can be a major issue and they may not be fully aware of the full effects of their condition. A person with MS may have prepared a checklist ahead of the planning meeting to help prompt their memory. It is important that you adhere to any agreed follow up, for example, by phone or email. Lack of timely communication is very stressful for people with MS and their carers.
- Consider each person’s support and social network, stability, vocational and family history, and circumstances. Be mindful of carer burden, relationship breakdown, social isolation, children with special needs, child protection and family violence issues.

11 Answers to common questions

- Does everyone's MS follow the same path?

No. Because of the epidemiology of MS, each person's disease course and the resulting functional impairments are unique to them.

- Is there a particular age group susceptible to MS?

No, MS can be diagnosed at any age – even in children. The majority of people diagnosed are in their early 30's.

- Is there a cure for MS?

No, there is no cure for MS. There are treatments, but only for relapsing-remitting MS. Treatments aim to reduce inflammation and relapses in order to slow disease progression and resulting disability. Each person responds differently to treatment.

12 Helpful links

- Multiple Sclerosis Australia

Snapshot for Muscular Dystrophy

SGP KP Publishing

Exported on 2024-10-18 03:14:28

Table of Contents

This Disability Snapshot provides general information about muscular dystrophy and neuromuscular disorders to assist you in communicating effectively and supporting the participant. Each person living with muscular dystrophy is an individual and will have their own needs, preferences and experiences. This information has been prepared for NDIA staff and partners and is not intended for external distribution.

1 Peak body consulted

In developing this resource, we consulted with Muscular Dystrophy Australia.

2 What is muscular dystrophy?

Muscular dystrophy is a type of neuromuscular disorder classified by the breakdown of muscle fibres leading to progressive and irreversible degeneration of muscles. Symptoms of types of the disorder appear at birth or in young babies, but in other cases the symptoms may only start to show in childhood or even in adulthood. Some types of muscular dystrophy can lead to significant impairment and impact on life expectancy, while other types can be much milder.

Around one in every 625 individuals will be affected with a muscular dystrophy during their lifetime. There are over 60 separate and distinct types of neuromuscular disorders, each with their own unique symptoms, treatments and prognosis. There is no cure for any type of muscular dystrophy.

Neuromuscular disorders are classified into four groups:

- muscular dystrophies
- spinal muscular atrophies
- motor neurone disease
- peripheral (affecting feet and hands) neuropathies.

This snapshot focuses mainly on muscular dystrophy.

3 Common characteristics

The common characteristic in all neuromuscular disorders is progressive and irreversible muscle deterioration which has a significant effect on people's lives. There are varying differences in symptoms between the disorders. Among the muscular dystrophy community, there are people with different degrees of independence, mobility and carer needs.

One of the most important things to remember is that the condition is progressive, which means that a person's needs may change over time. Plans may need to be reassessed often and there may be frequent changes in functional capacity.

Some people with high support needs may need support with:

- breathing via ventilators or cough machines
- personal care such as getting out of bed using a hoist or support for showering and toileting.

More information about common muscular dystrophies can be found in the table below.

Common muscular dystrophies	Age of onset	Symptoms	Progression
Duchenne	2-6 years	General muscle weakness and wasting, affecting pelvis, upper arms and upper legs first	Slowly, yet eventually involves all voluntary muscles including lungs. A wheelchair is required by about age 8 to 11 years
Becker	2-16 years	Almost identical to Duchenne yet less severe	Affects pelvis, upper arms and upper legs. Becker progresses more slowly than Duchenne.
Facioscapulohumeral	Teens to early adulthood. There is also an infantile-onset form	Muscles of the face, shoulder blades and upper arms are among the most affected but other muscles are usually affected	Slowly with periods of rapid deterioration, disease may span many decades
Limb-girdle	Late childhood to middle age	Weakness and wasting, affecting muscles around shoulders and hips first	There are more than 20 different subtypes – some progress to loss of walking ability within a few years and cause serious disability, while others progress very slowly over many years and cause minimal disability.

Life expectancy for people with muscular dystrophy can vary, particularly if they experience other non-related conditions.

4 How is muscular dystrophy diagnosed?

Diagnosis usually starts with a visit to a general practitioner (GP). A parent might notice their child falling over more than his or her friends, or an adult finds they can no longer walk very far without tiring. The GP may carry out initial tests but these conditions are often difficult to diagnose and the individual will usually be referred to a specialist – typically a neurologist. The specialist will use different tools and tests to reach a clinical diagnosis that best explains the symptoms and test results.

Tests may include:

- muscle biopsy
- genetic testing
- electromyography
- blood tests.

5 Language and terminology

You should use language which reflects the person first such as ‘person with a neuromuscular disorder’, or ‘person living with muscular dystrophy’.

Some of the language used to talk about the common characteristics of neuromuscular disorders is further explained below:

- **Neuropathies:** damage, disease, or dysfunction of one or more nerves especially of the peripheral nervous system. This is typically marked by burning or shooting pain, numbness, tingling, or muscle weakness or atrophy (often degenerative).
- **Muscle wasting:** weakening, shrinking, and loss of muscle.
- **Myotonic disorders or ‘Myotonia’*:*** the inability to relax muscles following contraction. Myotonic dystrophy can also affect many other tissues and organs in the body.

6 Enabling social and economic participation

When assessing Assistive Technology (AT) or Capacity Building (CB) support needs, the same priority needs to be given to work and outside work activities. Not everyone living with muscular dystrophy is able to work, and everyone has a right to the best quality of life. When you are considering AT needs for work purposes, you should always explore mainstream services such as the Employee Assistance Fund (EAF).

Depending on the type of muscular dystrophy and its stage, patients might benefit from different types of AT, including:

- adapted devices for using a computer, phone, or appliances, including head pointers, a switch adapted mouse, sip-and-puff switches, and mouth sticks.
- software for alternate access such as voice recognition and auto-type software
- eye gaze systems such as an eye-tracking device of specialised computer input device
- environmental control software such as smart switches and bulbs, and automated thermostats.

CB supports for people living with muscular dystrophies, depending on the type and stage, could include:

- disability related respiratory supports
- speech therapy
- occupational therapy
- support coordination.

7 Families and carers

Families provide different levels of support to a person with muscular dystrophy, and usually play an active role in a range of supports including:

- assisting with daily living tasks
- advocating for inclusion
- supporting the participant to find employment.

Families usually have a good understanding of the support the person needs to participate in the community and work towards independence. Some family members may find it confronting to consider the impact of further deterioration of their loved one's condition over time and may need support to think about future support needs.

While families are usually happy to provide support, it can affect their own employment, ability to meet the needs of other family members, and their own needs and health. This will increase especially as they age. It is unreasonable to expect a family to be the main source of support for an adult living with muscular dystrophy. It is important to consider, for children and adults, whether the level of informal support being provided is sustainable and what supports might be included in the plan that result in a break for carers.

Funded support including respite, support to access the community and personal care in the home can offer relief from family and carer stress.

8 How can I tailor a meeting to suit a participant with muscular dystrophy?

It's important to think about how people living with muscular dystrophy can be supported to be included in education, employment, and community and mainstream activities alongside their peers.

Some people, particularly those with later onset conditions, may have been living with symptoms for years while struggling to receive a diagnosis. The relative rarity of some forms of muscular dystrophy means it can be hard to find a specialist who can confidently diagnose the condition and predict its likely progression. For these individuals, thinking about what supports they might require in the future may be more difficult.

Specific issues to be considered:

- helping the individual consider not just their current capacity in the 'here and now', but also likely progression of their condition over the length of the plan
- consideration of transport modifications and technology to maintain schooling, employment, interests, and activities of everyday life
- whether physiotherapy is appropriate, either at home under the guidance of a physio or at an external venue
- adaptions needed to the home environment to access wheelchairs, hoists, or walking supports
- consideration of suitability of formal and informal carer supports
- consideration that the person's condition will change over time, meaning that plans may need to be reassessed regularly and the participant may need an unscheduled review.

9 What people with muscular dystrophy want you to remember

- Each case is different and will have different requirements.
- Make yourself familiar with each condition by referring to this snapshot and other resources, but also consider each individual's needs.
- Muscular dystrophies are **progressive** disorders, which means the participant's functional impairment will require regular reassessment.

10 Helpful links

- Muscular Dystrophy Australia (MDA)
- MDA Peripheral Disorders
- MDA Spinal Muscular Atrophy
- MDA Duchenne Muscular Dystrophy
- MDA Becker Muscular Dystrophy

Physical Disability Snapshot

SGP KP Publishing

Exported on 2024-10-18 03:13:20

Table of Contents

This Disability Snapshot provides general information about physical disability to assist you in communicating effectively and supporting the participant in developing their goals. Each person is an individual and will have their own needs, preferences and experiences. This information has been prepared for NDIA staff and partners and is not intended for external distribution.

1 Peak body consulted

In developing this resource, we consulted with Physical Disability Australia.

2 What is Physical Disability?

A physical disability refers to an impairment that affects a person's range of body movements when compared to someone without physical disability. It is important to note many different diagnoses fall under this broad category, and there may be other conditions that can limit a person's physical capacity.

Generally, physical disability does not affect a person's mind or ability to sense their environment. It is important to not make assumptions about a person's cognitive capacity or how their condition may progress as they get older.

This broad category includes the following disabilities in the NDIS Business System:

- cerebral palsy
- spinal cord injury
- multiple sclerosis
- stroke
- other neurological
- other physical.

People with physical disability experience fewer opportunities for social, economic and cultural participation. They experience more difficulty moving around and interacting with their physical environment compared to people without physical disability. Many people with physical disability use mobility aids (such as wheelchairs, scooters, walking frames, etc.), prosthetic limbs, home and vehicle modifications, and other assistive technology devices.

This information provides a general overview and you should always talk to the participant about their individual experience. Refer to Helpful links for further information on some of the specific physical disabilities identified above.

3 How is Physical Disability diagnosed?

Physical disability can be diagnosed in many different ways depending on the individual and their circumstances. This may be through physical assessment or further testing. Some physical disabilities are congenital, meaning a person is born with the disability. A congenital physical disability may be obvious when a child is born, or it may develop as the person grows older and be diagnosed later in life.

Other physical disabilities can be caused by injuries or diseases that lead to a significant physical impairment. This results in either a loss of function to part of the body, or a change in the person's capacity to use their body.

4 Language and terminology

Person-first language should be used. You should take care not to identify a person with physical disability by their impairment. The person with disability has the right to determine what terminology they prefer and how they identify.

Regardless of their speech or verbal capacity, it is important to approach any discussion with a person with physical disability as you would with a person without a physical impairment.

5 Enabling social and economic participation

Some people with a physical disability will use mobility aids to enable access to community participation, study, employment and volunteering opportunities. People with different impairments may also benefit from a wide range of assistive technology that supports access the community and to assist daily living activities. These may include communication aides, portable ramps, and devices to assist with turning taps and holding utensils.

Learning from the participant's lived experience is the best way to understand the type and level of supports a person with physical disability needs. Each individual will have preferred strategies to overcome the barriers that limit their social and economic participation.

Capacity building supports may assist a person with physical disability to participate in social and economic life in their community. For example, physical and occupational therapies can support people with physical disability to maintain or improve mobility, making it easier to engage in an ordinary life.

While capacity building supports are an important part of supporting people with employment goals, the NDIS is also responsible for funding frequent and ongoing supports that assist a person with disability to take part in work. This support includes day-to-day, on the job assistance designed to assist the participant to meaningfully participate in work. Economic participation has a number of benefits for participants including income, confidence, social interaction and networks, and a sense of independence.

6 Families and carers

People with physical disability live in many different settings and can be receiving support from family members, as well as other informal and formal supports. Sometimes a participant may have limited living options, may not have chosen their current living situation and they may not be happy with these arrangements. It is important not to make assumptions about the informal support they may (or may not) be receiving.

For example, some people with physical disability may have ‘living independently’ as one of their goals. They may want to live outside of the family home and gain more self-independence.. Alternatively, they may want to move out of accommodation run by a service provider and have more choice and control over who they live with, the supports they receive and where they receive them.

Think about whether additional support in the home, support to access the community or short term accommodation, including respite, could offer the participant some independence from family members.

7 How can I tailor a meeting to suit a participant with Physical Disability?

When organising a meeting with a participant, ask them directly, using their preferred communication method, what they need in terms of access and support to attend meetings. It may be useful to ask open ended questions to understand the participant's needs, such as:

- 'How would you like to meet with us?'

Travel can be difficult for some people with physical disability so telephone or video-conference calls may be their preferred option.

- 'Do you have any physical access requirements for our meeting?'

Some people with physical disability have specific access requirements such as mobility aids and you will need to make sure your location is accessible, spacious, level and free of trip hazards.

- 'Will you be bringing anyone with you?'

This may include family members, support workers, communication facilitators and/or advocates.

- 'How do you want to receive information from us?'

Paper can be hard for some people with physical disability to manage so it's a good idea to discuss alternative formats that are available.

8 What people with Physical Disability want you to remember

People with physical disability need you to understand they:

- do not (generally) have a cognitive impairment and they can understand the discussion
- can express their goals and identify barriers to achieving them
- have a good understanding of their disability and level of functional impairment, and what it means in terms of their capacity to lead an ordinary life
- can express what supports they need and why they consider them reasonable and necessary.

9 Helpful links

- Physical Disability Australia
- Western Sydney University - Key facts on physical disability
- BetterHealth - Physical disabilities
- Disability Snapshot – Cerebral Palsy
- Disability Snapshot – Multiple Sclerosis

Polio-Related Disability Snapshot

SGP KP Publishing

Exported on 2024-10-18 03:13:32

Table of Contents

This Disability Snapshot is about polio-related disability and will assist you in supporting the participant and communicating effectively. This information is a general guide only – each person is an individual and will have their own needs, preferences and experiences. This information has been prepared for NDIA staff and partners and is not intended for external distribution.

1 Peak body consulted

In developing this resource, we consulted with Polio Australia.

2 What is polio-related disability?

Poliomyelitis (polio) is a highly infectious disease caused by a virus. It affects the nervous system and can cause complete paralysis. Polio-related disability affects those who have survived polio, knowingly or unknowingly. Many polio survivors have lived with neuromuscular disability since their polio infection, which usually occurs in early childhood. Other polio survivors develop disability later in life, which is known as Late Effects of Polio (LEoP). Some polio survivors will go on to have a specific diagnosis of Post-Polio Syndrome (PPS) from a specialist doctor.

LEoP is the general term describing the varied and progressive condition experienced by those with a history of polio. The symptoms of the condition develop between one to five decades after infection, and usually include:

- new or increasing muscle weakness affecting quality of life or safety
- fatigue of muscles of the limbs or trunk, and/or central (exhaustive) fatigue
- pain in muscles and/or joints of the limbs or trunk
- difficulty sleeping
- other symptoms, including breathing problems, speech and swallowing issues, and poor thermoregulation.

The majority of polio survivors that access the NDIS are likely to come from migrant or refugee populations where polio is not eradicated in their home country. Many polio survivors in Australia are already over the age of 65 and may not be eligible for the NDIS.

Polio survivors mostly display physical disabilities which vary widely from person to person. Many polio survivors need long-term limb bracing and use assistive technology to increase their function.

3 How are Polio, LEoP and PPS diagnosed?

Polio is a virus that can only be diagnosed at the time of infection. Some people don't know they have had polio, and it can be diagnosed later in life based on the person's history and the likelihood of a previous infection.

LEoP is an informal diagnosis that accounts for a person's current symptoms and abilities in context of their polio history. Examples include:

- back pain from scoliosis or limping
- difficulty maintaining a strong voice during conversations
- being exhausted from performing household tasks like doing laundry.

A General Practitioner can diagnose these symptoms and develop a plan to support the polio survivor. Often, LEoP is only recognised after many other possible illnesses and conditions have been ruled out. Getting a diagnosis can be an exhausting and traumatic process.

PPS is a specific diagnosis based on five criteria, made by a specialist doctor:

1. prior paralytic poliomyelitis with evidence of motor neuron loss
2. a period of partial or complete functional recovery after acute paralytic poliomyelitis
3. slowly progressive and persistent new muscle weakness or decreased endurance, with or without generalised fatigue, muscle atrophy, or muscle and joint pain
4. symptoms that persist for at least a year, and
5. exclusion of other neuromuscular, medical, and skeletal abnormalities as causes of symptoms.

Not all polio survivors who develop LEoP go on to be diagnosed with PPS, but those who are diagnosed with PPS have most certainly been experiencing LEoP.

4 Language and terminology

People who survived polio are commonly called polio survivors or survivors. Some survivors refer to themselves as “polios”, however this term is used by the polio community and its use by others is not encouraged.

When talking about function and activity, you should prioritise managing LEoP, rather than attempting to find solutions. Ask questions like “how could you make things easier to manage?” or “if you changed a few things, do you think you might be able to …?”.

Using this type of language, the polio survivor can focus on what they can achieve and avoid unrealistic goals that may not be achieved with their condition.

5 Enabling social and economic participation

Support to enable social and economic participation for polio survivors varies. This can depend on the person's degree of physical difficulty and any compounding cultural or language barriers. Required supports may include:

- access to culturally-relevant services and supports
- collaboration with local cultural services regarding accessibility issues
- referral to allied health professionals (especially those trained in post-polio management)
- assistance and/or capacity building in using public transport, or transport funding in certain situations where public transport is not suitable because of fatigue or low mobility
- vehicle modifications to increase access, both as a driver and a passenger
- workplace assessment and appropriate modifications.

Being able to participate in social and community engagement are also important for polio survivors to increase daily functioning and to promote good mental health.

You should respect the polio survivor's own ideas about how to achieve their goals, but keep in mind that many polio survivors might not know how the best way to work within their level of function and limit fatigue and muscle weakness. Many polio survivors may be overdoing activity, leading to a further loss in function over time.

For polio survivors from a migrant background, it can be difficult to access employment because of marginalisation due to physical disability, language barriers, and cultural differences. They may try to hide their disability out of fear of jeopardising their residency in Australia. They may also work in manual labour jobs, which are more likely to make their LEoP conditions worse.

6 Families and carers

Informal support from family members can range from full time carers to assistance with specific tasks. With the polio survivor's permission, it may be appropriate to give the carer or family member information about the Late Effects of Polio, support services available and direct contacts who are able to offer guidance. This may be useful to understand the reasons for the polio survivor's functional limitations.

Links to resources, contacts and further information can be found in the Helpful Links section.

7 How can I tailor a meeting to suit a participant with PPS and LEoP?

When organising a meeting you should consider fatigue and mobility issues. You should contact the participant when booking the meeting to make sure the time suits their routine and any fatigue they make experience at different times of the day. Some polio survivors may appreciate the option of a phone or online meeting.

For face-to-face meetings, make sure:

- the meeting room is close to the building's entrance
- accessible parking is available, and
- the room is at a moderate temperature as polio survivors can experience cold intolerance.

Before the meeting, take some time to develop an understanding about LEoP and PPS. Don't make assumptions, take time and actively listen to understand the history of the person – both physical and psychological.

It is common for polio survivors to give an impression of more independence than they actually experience. Use open-ended questions to encourage more detailed answers. For example, ask: "How do you manage your shopping?", rather than "Are you able to shop without help?".

8 What people with polio-related disability want you to remember

- A polio survivor's disability is physical – there is usually no intellectual or cognitive component (except where fatigue impacts on memory and concentration).
- Their condition often progresses due to neurological breakdown.
- Health professionals can often give generic advice on exercise and activity, and recommendations must be customised to the individual.
- Survivors have often overcome stigma and trauma, and may conceal their disability.
- Polio survivors are resilient and determined due to overcoming stigma and limitations. Keeping their independence is often an important goal.
- Their mental health can deteriorate if LEoP/PPS symptoms return, unpleasant childhood memories from infection surface, their independence reduces, or they feel socially isolated.
- Polio and LEoP/PPS affects each person differently – talk to the person directly about their own experience, functional capacity and goals.

9 Helpful links

- Polio Australia
- Fact sheets and guides for polio survivors
- Fact sheets and guides for professionals
- Find a local professional who is familiar with LEoP/PPS
- State and territory based Polio organisations

Prader-Willi syndrome Snapshot

SGP KP Publishing

Exported on 2024-10-18 03:13:47

Table of Contents

This is a snapshot and is not designed to be a comprehensive guide. It provides general information about Prader-Willi syndrome (PWS) for NDIA staff and Partners. It is not to be distributed externally.

Each person with PWS is an individual but there is a commonality of impairment. Beyond that, each has their own additional needs, preferences and experiences that will impact on the planning process.

In developing this resource, we consulted with Prader-Willi Syndrome Australia.

1 What is Prader-Willi syndrome?

Prader-Willi syndrome (PWS) is a rare neuro-behavioural genetic disorder. It is a very complex, multistage disorder that permanently affects multiple systems in the body. PWS presents at birth and continues, with significant intensity, throughout life. It occurs equally in males and females.

People with PWS have a flaw in the part of the brain called the hypothalamus. This part of the brain is an important supervisory centre and hormone regulator. The hypothalamus when fully functioning, registers feelings of hunger and satiety (fullness). For individuals with PWS this does not occur and individuals with PWS never feel full. There is a constant pre-occupation with food accompanied by an overwhelming physiological drive to eat.

Currently there is no cure for PWS, although advances are being made through treatment with Growth Hormone. Most people with PWS require specialist support and a supervised diet for life. Generally, PWS is not inherited (except in 5% of cases) and can occur in any family. A suspected diagnosis of PWS is usually made by a physician based on clinical symptoms and a genetic test confirms a diagnosis of PWS. It is estimated that the incidence of PWS varies from 1:15,000 to 1:25,000 births.

2 Common characteristics and impacts of Prader-Willi syndrome

PWS significantly impacts the behaviour, mental, emotional and physical status of the people who have it. People with PWS have cognitive, social, emotional, behavioural and learning impairments, which limit their ability to manage daily living tasks, to work or participate in the community.

In Australia, life expectancy for people with PWS is much lower than the rest of the population, with life expectancy less than 38 years of age. Morbid obesity results from overeating and can lead to a range of health complications and even death.

Compulsive eating and obsession with food usually begins in childhood. Consistent food security management is essential to maintain a healthy weight. Without supervision for the entirety of their life, individuals may die prematurely due to complications of obesity and other related co-morbidities. People with PWS are also at higher risk of diabetes, sleep apnoea, choking, and stomach rupture. The reduced vomiting reflex means that the ingestion of uncooked, spoilt or toxic substances can cause serious gastric complications.

There are however, environmental modifications and management strategies that can help reduce or manage some of the symptoms caused by PWS and improve a persons' quality of life.

Food control relates to the management of access to food and beverages for a person with PWS. This may extend to locking kitchens and food storage areas. These are considered to be restrictive practices and need careful consideration taking into account the capacity of the person with PWS to make specific decisions about their eating.

Properly managed food security practices can significantly reduce the risk of harm due to overeating and can improve the quality of life and the life expectancy of a person with PWS.

For a person with PWS, access to money means access to food. It is important to make sure that there is sufficient support and supervision around money and budgeting. Someone with PWS doesn't see taking other people's money as 'stealing' but as an act of survival.

Although everyone with PWS is different, there are many characteristics that exist, to a greater or lesser degree, including:

Common Impairment	Functional Impact
Chronic feeling of hunger due to hyperphagia - lack of satiety.	• Constant food seeking behaviour. • Unusual metabolism and BMI: low-calorie diet required. • Obesity and related comorbidity.
Morbid obesity and related comorbidity caused by excessive food seeking behaviour.	• Lifelong calorie restriction and exercise required.

Common Impairment	Functional Impact
	• Difficulty to live an ordinary life due to mobility and energy limitations. • Increased ill health over time, including diabetes, sleep apnoea and incontinence.
Genetic malfunction of central nervous system, endocrine gland and hypothalamus.	• Unable to monitor their own health and wellbeing accurately. • High pain threshold; body temperature abnormalities - altered temperature sensitivity. • Overestimate their own ability or state of health.
Global development delay: • Learning/intellectual disabilities (borderline to moderate). **Note:** For the person with PWS, IQ is not an accurate guide for the actual function and comprehension level of the person. The person with PWS will have 'pockets' of more limited capability, with a significant adverse impact on day to day functioning.	• Do not perform as well in daily life as expected from their IQ. • Risk to welfare due to impulsivity, very poor decision making and a limited ability to perceive consequences. • Low receptive and expressive language skills. • Problems with abstract thinking and concepts. • Difficulty understanding that what happens in one situation may not happen in another. • Low short-term memory and auditory processing skills makes it harder to learn at school or work. • Rigid reliance on routines, lack of motivation, poor judgement, friction with others, lack of concentration, reduced ability to learn, limited ability to take responsibility or behave responsibly. • Home environment may be very unsafe due to hoarding, food stealing, poor environmental hygiene levels.
Deficits in executive brain function; not good at planning and organising and poor concept of time.	• Challenges with sequential processing, initiating or effectively completing tasks from start to finish and switching from one activity to another. • Poor at assessing reality and recognising consequences. • Interpersonal friction may be caused due to excessive risk taking, egocentric behaviour, lack of empathy and decision-making skills.
Poor emotional and social development.	• Tendency to alienate others.

Common Impairment	Functional Impact
	• Difficulty maintaining friendships or resolving conflicts and expressing feelings appropriately, particularly when anxious. • Inappropriate behaviour in public due to failure to understand appropriate social conduct.
Chronic behaviour disturbance; centrally driven maladaptive behaviours, characterised by constant high anxiety and extreme stress sensitivity.	• Challenging behaviours tend to escalate with age. • Complex behavioural problems, for example, argumentative, aggressive and destructive actions, over-active, temper tantrums, obsessive-compulsive behaviour, stubbornness, rigidity, stealing, and lying (especially related to food), lying in a plausible way and exaggerating (confabulation), manipulation of responsible adults.
Higher risk of developing mental health problems in adolescence and early adulthood, including depression, bipolar disorder and psychosis.	Psychosocial impairments including; • lack of motivation • poor self-care • low volition (deciding and committing to a course of action) • lack of judgement • irritability.
Atypical physical features (especially if no growth hormone treatment): • Short stature • Small hands and feet.	• Often unable to participate with peers in energetic activities. • Self-esteem and self-image often affected. • Often impacts how others react to them (adults treated as children; older children treated as younger children).
Very low muscle tone (Hypotonia).	• Speech difficulties (Dyspraxia); require alternative communication techniques. • Delayed developmental milestones. • Prone to tripping and falls. • Reduced ability and desire to engage in exercise. • Reduced vomit reflex. • Complications due to severe constipation. • Gait and mobility difficulties.
Delayed or incomplete puberty (Hypogonadism).	• Social difficulties; hormone replacement program required.
Sleep disturbance.	• High risk of obstructive sleep apnoea and daytime sleepiness.

Common Impairment	Functional Impact
	• Affects day to day performance and ability to participate. • Requires consistent monitoring and management (for example, using CPAP machine).
Skin picking - open sores and bruises can lead to life-threatening infection.	• Easily becomes a habit due to the disabling effects of high anxiety and sensory stimulation. • Scratching and picking at the skin, sometimes triggered by insect bites or other skin lesions which leads to skin infections and scarring.
Communication difficulties	• Articulation difficulties - Fluency issues or stuttering. • Significant language delay/disorder. • Most people with PWS have receptive or expressive language difficulties or both. • Impaired pragmatic language skills. • The veracity of their language is often further diminished due to fictitious disorder/confabulation and perseveration.

Every person with Prader-Willi syndrome needs specialist support and treatment. The complexities of PWS require interventions from a variety of providers to maintain daily functioning and wellbeing including behavioural support, medical specialists and allied health professionals throughout the person's life.

3 Myths and misunderstandings

Myth	Fact
People with PWS tell lies.	Yes, but no; it is officially called 'confabulation'. To the outside world, this seems like lying. But it is a direct result of their disability. People with PWS can form a belief and can't be shaken from it, even in the face of evidence to the contrary. Arguments will only result. Authority figures should always corroborate information before making important decisions, rather than relying on the word of the person with PWS.
Some people with PWS can speak well, therefore, they are competent in all aspects of their lives.	All people with PWS have planning and organisational deficits that mean they cannot safely or reliably put good ideas into completed actions (for example, they may not necessarily be able to maintain their own hygiene, or that of their environment, without support). The inability to control impulses or understand potential consequences often endangers their own welfare.
People with PWS are generally physically capable, therefore they don't need 24/7 support.	The cognitive impairments experienced by someone with PWS mean that they are usually unable to enact the requirements of daily life without supports. They need even greater support for community and economic participation due to a lack of volition and self-management capabilities and the risk of impulsive behaviours. They need prompting at minimum and much more proactive and detailed support where their capability declines. It is recognised internationally that people with PWS require a high level of support due to the broad variety of disabling characteristics in one person.
Once the capacity of a person with PWS has been built, the supports can be reduced.	This has not been demonstrated. People with PWS find it extremely difficult to extrapolate from one situation to another. They have ongoing, genetic impairments in executive function, satiety and regulating anxiety and emotions. The risk of early death from overeating does not ever reduce and supports must always be in place to manage food (and money) security.

4 Common barriers to social and economic participation

People with PWS have the same aspirations as everyone else; to be in a loving relationship, to have friends, to participate in community life and work and to feel included as full citizens. However, like many people with disability, people with PWS encounter multiple barriers to social, economic and civic participation. These barriers include discriminatory attitudes, perceptions and misconceptions as well as environmental and social barriers.

- Community attitudes
    - Lack of community awareness and understanding about the complexities of PWS resulting in stigma and exclusion.
- Difficulty accessing services in the mainstream community
    - Limited community resources and venues to support people with PWS to be included in the community such as sporting clubs and public spaces.
    - Reluctance on the part of organisations and facility staff to seek training and explore ways to support people with PWS who want to access mainstream activities and facilities.
    - Inadequate access to mental health services where there has been a tendency to attribute difficult behaviour to the intellectual disability, rather than an emerging mental illness.
- Education
    - Reluctance on the part of schools to fund professional development, PWS training and explore ways to support people with PWS so they can access and participate in the full school curriculum.
- Difficulty accessing and maintaining employment.
- Housing
    - Lack of housing options that provide safe and supported accommodation that meets the specific needs of the person with PWS including substantive support, food security and adequate staffing capabilities.
- Transport
    - Lack of flexible transport arrangements and supports to allow management of unsupervised access to food and challenging behaviours.
    - While people with PWS are able to physically use public transport, it may not be an option all the time, for reasons of safety for the person with PWS and those around them.

5 What is the role of the family in providing support?

Families provide different levels of support to the person with PWS depending on the individual family circumstances. Usually they play an active role in the areas of management of food security, dietary and exercise management, supporting daily living tasks, medical care, money management and advocating on their behalf. This is often beyond the age that you would generally expect a parent or family member to provide support.

Parents of children with PWS consistently report higher levels of stress than families of other complex disabilities and have higher incidence of family relationship problems. This is often due to the 24/7 vigilance required to manage the hyperphagia and other behavioural problems such as aggression.

Even if the person with PWS transitions to supported accommodation the family often chooses to remain involved to advocate for their family member. Where possible, families may choose to also have a role in attending medical and allied health appointments. But due to the extensive list of medical and allied health appointments, parents and family members may find this difficult to manage.

Consideration should be given to a holistic approach when reviewing informal supports to maintain sustainability and to safeguard against disintegration of the family unit.

6 How can I tailor a meeting to suit a person with PWS?

It is important to be aware of the characteristics of PWS before you meet someone with PWS. There is a high risk of underestimating the difficulties experienced by someone with PWS and this can lead to inadequate support and a decline in the participant's health, safety and wellbeing.

People with disability are presumed to have capacity to make decisions that affect their lives. Every effort must be made to enable the leadership and participation of the person with PWS in meetings. It is a good idea to make sure that an appropriate support person is included in the meeting to confirm facts and provide additional information. People with PWS are prone to confabulation and you should attempt to corroborate information with family/carers. It is also important to give family/carers an opportunity to talk about their role in providing informal supports and whether the NDIS can help them to take a break.

Consider what will support a successful planning meeting. Prior to any meetings it may be helpful to consider the following:

Before the meeting:

- Provide any written material in Easy English or other languages on request prior to the meeting.
- Provide as much information about the purpose of the meeting in advance so the person with PWS and their support person can prepare their answers thus reducing the stress level at the actual meeting.
- Allow more time for the meeting, as the person may want to revisit some of the discussion to understand and assimilate the information and alleviate their anxiety.
- People with PWS frequently have a minimal sense of time. So, realistic planning for a day, week, month, year or the future will be difficult for them to conceive of or act upon, despite the words they say to you.
- If a change of accommodation is planned, see the Prader-Willi Syndrome Australia Residential guide.
- The person may have some mobility difficulties (for example, low muscle tone or obesity), tire easily and need ready access to a toilet.

Communication during the meeting:

- Be aware that the person with PWS may be able to speak to you clearly, with good expressive language. However, they have a relatively poor level of comprehension and typically:
- May lie and exaggerate about themselves and their circumstances (confabulation), putting themselves at risk
- Will unreliably report on their state of health
- Have poor short-term memory and auditory processing difficulties and find it hard to take in lots of information, especially in conversation

- Can think through things slowly, ask questions and understand small amounts of information at a time.
- Speak in short sentences; allow enough time for the person to think and respond. Avoid jargon, slang or acronyms.
- Look for body cues that the participant is not telling the truth such as avoiding eye contact more than previously.
- Address the questions to the person with PWS rather than the support person. The person with PWS may elect to request assistance from their support person.
- Speak respectfully to the person with PWS in an age appropriate fashion.
- Rephrase or repeat the question if you or the support person suspect they haven't understood the question.
- Be patient, as the person with PWS will need time to process the response.
- People with PWS tend to be literal thinkers. Do not make any comments that may be interpreted literally, or promises that you cannot keep.
- People with PWS often give answers that attempt to please others. Use a variety of questioning techniques to try to get the participant's own views.
- Information supplied by the person with PWS which will be used to make decisions may need to be corroborated by another party. Ensure you apply reasonable and necessary decision making to determine any appropriate funded supports to be included in the participants plan.

7 Helpful links for further information

Prader-Willi Syndrome Association of Australia

Guide for NDIA Technical Advisory Branch (for staff members who are providing advice during planning or reviewing a plan for a person with PWS)

Clinicians and Allied Health Professionals advice

Best Practice Guidelines for Residential Care

Prader-Willi Syndrome: A Primer for Psychiatrists

Prader-Willi Syndrome Association UK

Prader-Willi Syndrome Association (USA)

International Prader-Willi Syndrome Organisation

8 Representative bodies consulted when developing this Snapshot

In developing this resource, the NDIA consulted with the Disability Advocacy Network Australia who worked with Prader-Willi Syndrome Australia to develop this snapshot.

Psychosocial Disability Snapshot

SGP KP Publishing

Exported on 2024-10-18 03:14:01

Table of Contents

This Disability Snapshot provides general information about psychosocial disability to assist you in communicating effectively and supporting participants to develop their goals. Each person is an individual with their own needs, preferences and experiences. This information has been prepared for NDIA staff and partners and is not intended for external distribution.

1 Peak body consulted

In developing this resource we consulted with Community Mental Health Australia (CMHA) and Mental Health Coordinating Council of NSW (MHCC).

2 What is psychosocial disability?

Psychosocial disability refers to the social and economic consequences related to mental health conditions. It is used to describe the challenges, or limitations, a person experiences in life that are related to mental health conditions. This may include challenges or limitations in their capacity to:

- have a good social network including friends and a family of their own
- participate fully in life
- experience full physical health
- manage the practical, social and emotional aspects of their lives
- engage in education, training, cultural activities and economic participation
- achieve their goals and aspirations.

The impact of psychosocial disability can vary over time because of the difficulties people experience with mental health conditions and many other factors in the individual's life. Not everyone living with mental health conditions will experience a significant psychosocial disability and individuals will experience psychosocial disability differently.

In Australia, people with a psychosocial disability make up a significant proportion of Australia's most disadvantaged population. People with a mental illness (21.7%) are the second largest group receiving the Disability Support Pension.

People with psychosocial disability may also have lived and living experience related to trauma, suicidal ideation, and substance use. The complexity of this means you should adopt a whole of person approach.

3 How is psychosocial disability identified?

A person may be diagnosed with a mental health condition, but psychosocial disability is not a diagnosis. Psychosocial disability is **identified** by the impacts of, or impairment resulting from, the person's mental health conditions.

A health professional such as a GP, psychiatrist or allied health professional may identify psychosocial disability through assessment or testing.

Impairment resulting from psychosocial disability can be episodic or fluctuating. To understand the functional impact and psychosocial disability for an individual, it can be helpful for an allied health professional (for example occupational therapist, psychologist, speech therapist, social worker) to provide an overall assessment of the person's functioning.

It is important that the assessment considers the impacts in relation to:

- mobility
- communication
- social interaction
- learning
- self-care
- decision-making.

Psychosocial disabilities often include cognitive difficulties which may affect function in the areas of:

- memory
- communication
- organising and planning skills
- social interactions
- visual interpretation.

The symptoms of a mental health condition may be of an episodic nature and vary in intensity and need for support. How this impacts on psychosocial disability may mean that there will be times when a person may experience significant limitations; while at other times they may be able to go about their daily life without experiencing the same challenges.

4 Language and terminology

When talking with or about a person with a psychosocial disability, use ‘person first’ language. For example, saying ‘person living with a psychosocial disability’ rather than ‘disabled person’. People with mental health conditions usually prefer not to be defined by them. Using strength-based language, rather than focusing on a person’s limitations, maximises a person’s sense of self, and independence.

The term ‘recovery’ is used widely throughout the mental health service system and can have different meanings for different professionals/disciplines and people accessing the services. The NDIA defines recovery as achieving an optimal state of personal, social and emotional wellbeing, as defined by each individual, whilst living with or recovering from a mental health condition.

Recovery is an individual and unique process. It is defined by the person and driven by their needs and preferences.

Recovery involves:

- having hope
- being motivated
- feeling optimistic about the future
- having the skills and strategies to manage the challenges the participant may experience
- ensuring that services are delivered using a trauma-informed recovery-oriented practice approach.

It is important to use language that reflects the recovery-based approach. You can find more information on recovery-orientated language in the Helpful Links section and in the Practice Guide – Psychosocial Disability.

5 Enabling social and economic participation

Some of the consequences of psychosocial disability may include:

- poverty
- discrimination
- unemployment
- poor educational outcomes
- poor housing.

The relationship between these consequences and the underlying mental health condition can be interconnected and two-way. For example, loss of connection with family, friends and community can worsen a participant's mental health. It is important to focus on building and maintaining social connection and relationships.

The earlier a person connects with services and supports, the better. The episodic nature of a mental health condition may vary on a day-to-day basis or over the person's life span, and their plan needs to be flexible enough to respond effectively.

A self-directed, strengths-based, trauma-informed, recovery-oriented approach to a person's mental health and well-being is highly effective. This may mean working with the person to help them identify some safe activities to start such as building their social networks or getting back into work. Capacity building supports are important to this approach as well as core and assistive technology supports. Adopting a **strengths-based approach** in supporting the participant to identify their goals, objectives and aspirations is vital to build rapport and develop independence. In using a strengths-based recovery approach, you will focus on the participant's talents, positive attributes and potential and identify how that will help them to achieve their goals.

Capacity building supports:

- A **Recovery Coach** support can provide assistance in building capacity and resilience in people with psychosocial disability and support them to live a more fulfilling life. Recovery coaches work with participants, families, carers, and other services to get the best outcomes from NDIS supports.
- A **support coordinator** can be effective in maintaining continuity of supports and allows for supports to be increased quickly and/or accessed at short notice as needed. Support coordinators can also ensure appropriate support is available around transitions from hospital to community, and that an ongoing relationship is there to facilitate engagement in social, economic and community life.
- An **occupational therapist** with specialist knowledge in mental health can assess functional capacity and provide support in maintaining a job, volunteer role, study, and/or social networks.
- An**exercise physiologist** can provide an accessible and achievable exercise program to support a person's mental health and build community networks.

Core supports:

- A functional home environment can improve mental health. **Support workers** can assist with daily living activities in the home like meal preparation and cleaning.
- **Support workers** can also assist with and encourage participation in an exercise plan given by an exercise physiologist and promote self-care with regards to personal care and physical health.
- Access to **community groups** can help facilitate social inclusion and build relationships.

Assistive Technology (AT):

- **AT** can provide both functional and emotional support for example by assisting individuals to learn new information and build organisation, concentration and planning skills.

6 Families and carers

Family, friends, carers and kinship groups play an important role in a person's recovery. Mental health carers can include a parent caring for a child, an adult caring for a partner, friend, parent, or sibling, or a child caring for a parent. Due to the episodic nature of mental health conditions, people living with psychosocial disability may require regular on-call care. Family members often provide care for many years, often either in their own home or the home of the person living with psychosocial disability.

Other informal supporters are often unexpectedly called upon to play a role in mental health care. They may have found themselves in this carer role because they see it as part of their relationship with the person with psychosocial disability. Nevertheless, they may not think of themselves as a 'carer'.

It is important to consider whether the level of care provided by family members, carers or informal supports is sustainable. It may be reasonable and necessary to include core supports and respite to prevent carer burnout. To support carers and family members in this role, provide them with relevant resources and information.

Refer to the **Helpful Links** section for more information.

7 How can I tailor a meeting to suit a participant with psychosocial disability?

Many people who live with psychosocial disability may have experienced trauma in their life and can become distressed if they do not feel safe. To facilitate a sense of safety make sure you:

- Allow enough notice for the person to prepare for meetings (ideally four weeks) and be clear about what 'prepared' means.
- Consider the environment and ask the person what helps them feel safe in a room. Let them know the choices they have, such as having the meeting in a familiar place, having a support person with them, and whether the gender of the support person and the NDIA representative is important. A support person may need to be invited to attend as they can be particularly important to help convey a person's needs.
- Provide easy access to exits and offer breaks or follow-up meetings.
- Be honest and clear about what you can and can't do. Set boundaries and expectations early and allow the person to set their own boundaries if possible.
- Maintain confidentiality and be clear about what information will be kept and what it will be used for.
- Provide information about your recommendations and why they are relevant, even if it seems obvious.
- Ensure the participant understands what choice and control means in the conversation. People may feel very disempowered by those they see as 'authority figures' and may feel intimidated. Encourage the person to take part in the process, allow them space and time to speak up. An example question could be: "Is this the ideal outcome today from your point of view? How do you think we could achieve this?"
- Listen non-judgmentally and collaborate with the person to clarify their need. Ask the person what they find important and don't make assumptions. Use paraphrasing and clarifying questions to understand their wants and needs.
- Use the Reimagine Workbook (see the Helpful Links section) which has a tool to use in collaboration with the participant.

8 What people with psychosocial disability want you to remember

- People living with psychosocial disability have first-hand knowledge of what they experience.
- Involving a support person in a planning meeting can help the participant feel safer and more confident to ask for what they need and don't want.
- The road to recovery varies from person to person.
- People with psychosocial disability often experience stigma and discrimination which can be highly distressing.
- Psychosocial disability is not a visible disability, but the impact on a person's life is very real.
- Take the concerns of the person living with psychosocial disability seriously.
- Social inclusion and community connection are significant to recovery.

9 Helpful links

- Reimagine
- Reimagine my life Workbook
- Mental Health Carers Australia
- Recovery Oriented Language Guide
- Unravelling Psychosocial Disability Booklet
- Practice Guide – Psychosocial Disability
- Guide - Conversation style guide

Schizophrenia Disability Snapshot

SGP KP Publishing

Exported on 2024-10-18 03:14:12

Table of Contents

This Disability Snapshot provides general information about schizophrenia. It will assist you in communicating effectively and supporting the participant in developing their goals in a planning meeting. Each person is an individual and will have their own needs, preferences and experiences that will impact on the planning process. This information has been prepared for NDIA staff and partners and is not intended for external distribution.

1 Peak body consulted

In developing this resource we consulted with Mental Health Australia.

2 What is schizophrenia?

Schizophrenia is an established medical disorder that is common worldwide. Up to 1 in 100 people will experience schizophrenia.

3 Schizophrenia is characterised by symptoms that are grouped as positive, negative and cognitive:

- **positive symptoms** are intense episodes of psychosis, in which a person may experience auditory and/or sensory hallucinations and delusional beliefs, including paranoia. Psychosis can make it difficult for a person to distinguish between what is real and what isn't real
- **negative symptoms** are often characterised by reduced expression and/or reduced motivation and/or a reduced capacity to function in everyday life
- **cognitive symptoms** generally relate to attention, memory, verbal skills and may include longer periods of slowed or confused thinking.

Antipsychotic medicines are the main form of treatment for schizophrenia.

It is important to note that people experiencing schizophrenia do not have a split or multiple personalities and they are not inherently more prone to violence. In fact they are more likely to become a victim of violence.

4 How is schizophrenia diagnosed?

Schizophrenia may take time to diagnose. A person will only receive a confirmed diagnosis of schizophrenia after experiencing one month of psychotic symptoms and six months of reduced functioning.

A GP or other medical professional might make the initial assessment, and would then refer the person to a specialist, usually a psychiatrist for diagnosis. The specialist might then make a working diagnosis of schizophrenia, so that treatment can begin without delay.

There is no known biological marker for schizophrenia. Schizophrenia is primarily a clinical diagnosis, it is diagnosed by identifying signs and symptoms and monitoring how the symptoms develop over time.

5 Language and terminology

People living with mental illness don't like to be defined by their diagnosis, to be stigmatised or have assumptions made about them. Therefore phrases such as 'schizophrenia sufferer' or 'he's a psychotic' are inappropriate.

Instead say:

- she lives with schizophrenia
- she has had an experience of schizophrenia
- he has had an experience of psychosis
- person living with schizophrenia
- the person has schizophrenia.

6 Enabling social and economic participation

Support to participate in the community and in work can help prevent social isolation and promote recovery and wellness for people living with schizophrenia. It is important to explore how a person with schizophrenia can be supported to participate in activities, education and employment, taking into consideration their interests and aspirations as an individual.

NDIS supports can assist participants build life skills, capabilities and greater independence. This may include being supported through a vocational 'discovery' process to explore their strengths and interests in the context of work, particularly for young people transitioning from school into employment.

Early access to pre-vocational training and employment opportunities can improve long-term outcomes in both employment and education. Peer support from other people living with schizophrenia can also play a key role in improving participation in work and the community.

Volunteering can also be a first step in building confidence and exploring the person's interests and strengths.

7 How can I tailor a meeting to suit a participant with schizophrenia?

People experiencing schizophrenia are above all, individuals the same as you and me. No two people with schizophrenia are alike, they will experience schizophrenia in different ways and their needs will vary as much as anyone else. They enjoy family, friends, have a sense of humour, sporting interests and like to participate in all aspects of the community.

Many people living with schizophrenia are indistinguishable from people without the condition and they may not require any special considerations or treatment.

However, a person experiencing schizophrenia may be affected by slowed or confused thinking, or reduced expression, motivation and functioning. They may also experience distressing side-effects of their medication. This may mean the person might require more time than usual to understand what is being said and to compose or express their thoughts.

When meeting with a person with schizophrenia, provide a quiet, respectful and calm environment. Allow the person the time they need. Avoid the temptation to finish their sentences or rush them. Do not assume you know what they need or want.

A person experiencing active psychotic symptoms, delusional beliefs and/or sensory hallucinations may find it very difficult to concentrate and to trust the situation they are in. They may feel irritated, agitated or frightened. Remain calm, show respect and compassion and focus on how they feel, rather than the details of their delusions or hallucinations.

8 Helpful links

- Spotlight on Schizophrenia — SANE Australia website.

Spinal Cord Injury Disability Snapshot

SGP KP Publishing

Exported on 2024-10-18 03:14:43

Table of Contents

This Disability Snapshot provides general information about Spinal Cord Injury to assist you in communicating effectively and supporting the participant in developing their goals. Each person is an individual and will have their own needs, preferences and experiences. This information has been prepared for NDIA staff and partners and is not intended for external distribution.

1 Peak body consulted

In developing this resource we consulted with Spinal Cord Injuries Australia.

2 What is Spinal Cord Injury?

Spinal Cord Injury (SCI) occurs as a result of trauma or catastrophic injury such as a fall or car accident, or from a medical condition such as a stroke or other spine conditions. The impacts of an injury will depend on where it occurs on the spine. Generally, the higher the injury level on the spine, the greater the functional impairment.

The types of SCI are:

- **Quadriplegia or Tetraplegia** which is motor or sensory impairment of all four limbs caused by SCI above the first thoracic vertebrae in the cervical spine.
- **Paraplegia** which is impairment in motor or sensory function of lower extremities caused by SCI below the seventh cervical vertebrae in the thoracic, lumbar or sacral spine.

Each injury is either **complete**, with no movement or sensation below the level of injury, or **incomplete** which means there is some sensation and/or movement below the injury level.

As a result of SCI, an individual may experience the following:

- bowel or bladder dysfunction
- skin issues such as pressure areas or skin breakdown because of mobility
- difficulty regulating body temperature and increased likelihood of hypothermia (dangerously low)
- sexual dysfunction
- autonomic dysreflexia (overactivity of the autonomic nervous system), commonly caused by bladder, bowel or skin irritation, which can lead to seizures, stroke or death if not managed immediately and correctly.

3 How is Spinal Cord Injury diagnosed?

SCI is an acquired disability diagnosed by a neurosurgeon or spinal physician using the American Spinal Injury Association classification for motor and sensory impairment level. Spinal cord injuries lead to paralysis, which means that people will often spend many months in hospital in a specialist spinal injury unit for intervention and rehabilitation. Physiotherapists and occupational therapists may provide treatment and rehabilitation.

4 Language and terminology

When talking with a person with a spinal cord injury, you should focus on the person, not the impairment. Inclusive person first language should generally be used, but some people have their own preferences. Avoid negative language such as ‘wheelchair-bound’. A wheelchair is a mobility aid supporting independence; ‘wheelchair user’ is an appropriate term.

5 Enabling social and economic participation

As SCI is an acquired disability, it is likely a person's routine and activities before their injury will have been severely disrupted. They may need time to come to terms with their disability and support to re-engage in social and economic participation. Some people with SCI may be able to continue with their role with some workplace adjustments. However if they cannot continue working in their pre-injury role, many others may need to develop or relearn skills, look for a different career or participate in vocational training to re-enter the workforce. You should consider these factors when discussing employment goals, and include employment related supports in the participant's plan.

Social and community participation is important to build confidence and connect with people as the person with SCI adjusts to their new reality of impairment. The impact of the injury will vary for each person, so supports will need to be highly individualised.

Supports to enable the participant's social and economic participation may include assistive technology (AT) such as:

- manual and power wheelchairs and other mobility aids to help get around
- equipment to maintain good health and facilitate independence, such as electric beds, pressure relieving mattresses and wheelchair cushions, and shower commode chairs
- environmental control units that allow for controlling the home, including lights, doors and electrical appliances
- speech recognition software for home, education and vocational needs.

People with SCI may use consumables associated with incontinence. These items, and the daily regimes to manage bowel and bladder function, are important for ongoing social and economic participation.

6 Families and carers

SCI is a significant injury and it has a long-term impact on the individual and their family members. SCI will cause many individuals and their families to experience sudden and significant changes following the injury. It is important for the individual and their family to take some time to learn about the injury and adjust to the disability and changes in the individual's life.

The role that family plays after an injury is different for everyone. This will depend on their age and how they balance formal and informal supports for assistance with daily living, personal care, and social and economic participation. It may take some time for the individual and their family members or carers to find supports and strategies to manage SCI.

Family members and carers may feel overwhelmed as they support the person with SCI, as well as balance other commitments such as work and the needs of other family members. It is important to offer support to the family during this time and offer strategies to balance informal and formal supports and give carers a break. This can be through funded supports to offer the participant independence from their family and provide respite to family members.

7 How can I tailor a meeting to suit a participant with Spinal Cord Injury?

When meeting with a person with SCI, always communicate directly with the individual, even if family members join them. Make sure the meeting is held in a place with accessible facilities and that you give the person plenty of time to make themselves comfortable.

A person with SCI is likely to engage with the NDIS soon after their injury. They may still be undergoing rehabilitation and adapting to life with their disability. They may not know what supports they need and how their condition will progress over time. You should be mindful of this when meeting them for the first time and deciding what supports to include in their first plan. Consider following up with them before finalising their plan to see how they are adjusting and if anything has changed, and whether any additional supports might be needed.

8 What people with Spinal Cord Injury want you to remember

- SCI is an acquired disability which will require time to adjust to
- supports in a plan should empower the individual and focus on finding different ways to engage in social and economic participation
- no two injuries are the same and each person should receive individualised support
- each person's individuality and right of choice should be respected.

9 Helpful links

- Spinal Cord Injuries Australia
- ParaQuad
- NSW Agency for Clinical Innovation - Spinal Cord Injury Resources
- Spinal Cord Injury Levels and Classification

Thalidomide Survivors Snapshot

SGP KP Publishing

Exported on 2024-10-18 03:14:52

Table of Contents

This is a snapshot and is not designed to be a comprehensive guide. It provides general information about Thalidomide Survivors for NDIA staff and partners and is not intended for external distribution. Each Thalidomide Survivor has been impacted individually and will have their own needs, preferences and experiences that will need to be taken into consideration across the planning process.

In developing this resource, we consulted with Thalidomide Group Australia.

1 About Thalidomide

Thalidomide was the active ingredient most commonly associated with the medication ‘Distaval’ and was marketed to pregnant women in the late 1950s and early 1960s, to ease symptoms of morning sickness.

Though pregnant mothers had no way of knowing the effects of Thalidomide, taking just one tablet during the first trimester could cause malformation of limbs, facial features and, significant internal injuries to babies. Today, those adults living with Thalidomide disabilities are aged in their mid to-late 50s. They identify as Thalidomide Survivors.

2 The impact of Thalidomide

The main deformities caused by Thalidomide included:

- Quadruple absence/deformities/shortness of both upper and lower limbs
- Absence or hypoplasia - underdevelopment or incomplete development of arms preferentially affecting the radius and the thumb
- Thumbs with three joints or no fingers at all
- Defects of the femur and of the tibia
- Defects of the muscles of the eye and of the face
- Absence of the auricles - visible part of an ear, with deafness
- Malformations of the heart, the bowel, the uterus, the digestive tract and the gallbladder; or
- Defects of the spine.

Thalidomide continues to impact each individual differently – in accordance with the level of impairment that occurred in the womb. The individual type of thalidomide malformation depended on the quantity and length of time the Thalidomide was taken by the pregnant mother. While there are common characteristics associated with the deformities, each adult is unique in themselves.

The following impacts are likely still present and may be heightened by the early ageing process, medically acknowledged to be occurring in Thalidomide Survivors around the world:

- Congenital malformation and functional impairment
- Thalidomide induced injuries and impairment
- Premature ageing
- Chronic health conditions
- Psychosocial impact

Myth	Fact
All Thalidomide babies were born with deformities to their arms or legs.	Babies affected by Thalidomide could have significant injuries to internal organs, without showing an external effects.
All Thalidomide babies survived.	While it is undeterminable how many babies were affected by Thalidomide, it is estimated that 40% of all thalidomide babies died in the womb or within their first year of life.
All Thalidomide survivors have an intellectual impairment as well as significant physical disability.	Thalidomide is NOT linked to intellectual impairment or disability.

Myth	Fact
Thalidomide is known to be the biggest medical disaster the world has ever seen. It will never be forgotten.	Many doctors today have no idea what Thalidomide is, how it affected the unborn foetus, and how to now treat a survivor.

3 Common barriers to social and economic participation

Australia currently has around 150 *recognised* Thalidomide survivors. It is likely those numbers *may* increase, should further investigations occur. The relative few numbers have not warranted (until now) specialist Australian medical research – so there has been reliance on international studies.

Research from the UK indicates that most people born affected by Thalidomide have gone on to have happy lives with families and/or a career. However, the wear and tear on their bodies as they get older has become increasingly noticeable. The Thalidomide Trust (UK) has recently researched issues of health and wellbeing with all of their members and, the results show that two-thirds rate their physical health as the same or worse than the lowest 2% of the general population.

The key health problems noted are:

- pain that can be severe and / or continuous (90% of beneficiaries noted this)
- reduced flexibility and mobility that make it difficult to undertake everyday tasks;
- significant neurological impairment and pain;
- tingling and numbness and,
- poor reduced emotional resilience which in some people may lead to anxiety, depression and suicide ideology.

The cost of specially tailored clothes, prosthetic limbs, wheelchairs and hearing aids/implants has been noted as difficult to cover financially - particularly as many people find they are no longer able to work due to their disability.

4 Common language and terminology

Don't say	Instead say	Here's why
Thalidomide victim	**Thalidomide survivor**	Those with the resulting disabilities have actively resolved to 'live' despite the significant impairments.
"You're a Thalidomide baby!"	**You're a Thalidomide survivor.**	Today, those adults living with Thalidomide disabilities are aged in their mid-to-late 50s.

5 Engaging with families and carers

The families of Thalidomide Survivors, particularly survivors' parents, spouses and children, live with the effects of what Thalidomide did to the person they love. Parents of Thalidomide Survivors experienced trauma, guilt, and life changing carer responsibilities. The spouses and children of survivors have missed life opportunities and continue to make considerable personal commitments as they provide care and support to their loved one.

Carers may need support and relief and, in particular, may need to take a break from time-to-time to sustain their own wellbeing, their relationships with other family members and friends and their capacity to continue caring.

Taking time off can reduce carers’ stress and give them an opportunity to recharge their batteries. It can also assist their capacity to continue to provide quality care. It may also assist participants.

6 What specific supports might a Thalidomide Survivor need?

Each Thalidomide Survivor is different and the reasonable and necessary funding in their plan will reflect their functional impairment and the support they need to achieve their goals.

A range of supports might be considered in determining how best to support Thalidomide Survivors into the future, including:

- Assistive technology
- Home help - assistance with everyday needs, household cleaning and/or yard maintenance.
- Social interactions
- Home modifications
- Vehicle modifications
- Physiotherapists and/or Occupational Therapists
- Clothing alterations specific to the disability needs
- Transport; or
- Supports that result in a break for carers.

7 How can I tailor a meeting with a Thalidomide survivor?

Most Australian Thalidomide Survivors have remained active members in their local communities and many have not sought disability support services or government payments. Ensure you talk through what mainstream community and government services and programs might be available – 'you don't know what you don't know!'

Many Thalidomide Survivors will require a table for writing and a drink at a meeting.

Some Thalidomide Survivors are no longer able to take physical notes during a meeting. Ensure notes are made available at the conclusion of meetings.

Consider also general preparation, prior to the meeting, during the meeting and at the conclusion of the meeting.

8 Helpful links for further information

Thalidomide Group Australia

The Thalidomide Trust (UK)

Younger Onset Dementia Snapshot

SGP KP Publishing

Exported on 2024-10-18 03:15:03

Table of Contents

This is a snapshot and is not designed to be a comprehensive guide. It provides general information about younger onset dementia for NDIA staff and partners and is not intended for external distribution. Each person with dementia is an individual and will have their own needs, preferences and experiences that will impact on the planning process and considerations for social and economic participation.

1 Peak body consulted when developing this Snapshot

In developing this resource we consulted with Dementia Australia.

2 What is Younger Onset Dementia?

Dementia is a term used to describe a collection of symptoms that are caused by conditions affecting the brain. It is not one specific condition.

Dementia can affect memory, thinking, behaviour, movement and the ability to perform everyday tasks, which in turn impact on a person's social or working life.

Younger Onset Dementia (YOD) refers to any form of dementia that occurs in a person under the age of 65. Currently there are approximately 27,247[1] people with YOD in Australia. While dementia is less common in people under 65, it has been diagnosed in people in their 50's, 40's and 30's. There are also rare occurrences of childhood dementia.

Alzheimer's disease is the most common type of YOD, however Frontotemporal dementia, Alcohol-Related dementia and Vascular dementia are also commonly identified causes.

There is also a link between Down syndrome and dementia. Studies show that by the age of 40, almost 100% of people with Down syndrome who die have the changes in the brain associated with Alzheimer's disease.

Dementia is a degenerative neurological condition for which there is currently no cure.

3 How is Younger Onset Dementia diagnosed?

Diagnosing dementia in a younger person can be difficult. When symptoms first appear, GP's and families may assume that they are caused by other factors like depression, stress, marriage breakdown or other physiological conditions and as such, it may take a number of years before relevant tests are carried out. In some cases it can take many years to get a diagnosis of YOD.

Diagnostic Process

Initial signs and symptoms are generally first reported to a GP who will begin to screen for relevant medical causes. This initial testing may include a medical/family history, physical examination, blood tests and neuropsychological or cognitive testing.

The diagnosis of dementia is undertaken by a process of elimination. As other medical causes, e.g. depression, stroke/brain injury, urinary tract infection, etc. are ruled out, a person is likely to be referred to a relevant medical specialist for more comprehensive assessment and testing. This may include brain imaging/scans, extensive neuropsychological or psychiatric assessment and laboratory testing.

Once this testing is complete, the specialist, usually a neurologist, geriatrician or neuropsychiatrist, will make a formal diagnosis.

4 Addressing challenges to social and economic participation

People living with dementia may experience difficulties in a range of areas which could have a significant impact on their social and economic participation. For example:

- **Remembering, particularly recent events** – a person may not remember to take their medication or attend an important appointment. They may forget who a person is, including a family member or support person. Assistive technology/memory aides might support participants to manage their daily routines for example, reminders about appointments, tasks to be completed.
- **Making decisions** – sometimes even decisions that appear fairly straightforward, such as what to wear or what to eat may become difficult. Developing routines that minimise everyday decisions at home and work can relieve stress for people living with dementia.
- **Expressing their thoughts** – a person may lose the ability to communicate their thoughts and needs to others.
- **Understanding what others are saying** – some people may find it difficult to process and understand what is being said by others. They may not respond at all, or provide a response that doesn't fit the question, e.g. answering 'yes' to 'what would you like to do today?'.
- **Finding their way around** – a person may become easily disorientated, even in familiar environments, and find it difficult to navigate to their intended destination e.g. returning home after going out for a short walk.
- **Performing more complex tasks** – tasks that have multiple steps, such as using a microwave, can become difficult for people. Similarly, responding to instructions with multiple steps, such as 'get ready for a shower', can also be difficult for people to process. Visual and audio prompts can be effective in managing complex tasks.
- **Behavioural changes** – a person may experience mood and behaviour changes which can include, but are not limited to, apathy, aggression, agitation, depression, disinhibition and hallucinations. Frontotemporal dementia is more common in younger people, and will often present as changes in ability to regulate emotions, difficulty responding appropriately in social settings, exhibiting disinhibited behaviour, and impaired judgement.
- **Managing finances** – a person may have reduced insight into the appropriateness of their purchases, e.g. buying another loaf of bread before using the one they purchased yesterday, or have difficulty understanding or performing financial calculations. Or indeed, understanding the value of money.

Considerations in Education and Employment

People diagnosed with younger onset dementia are often employed at the time of diagnosis. They may have financial responsibilities such as supporting a family or paying a mortgage. Deciding whether or not to continue their employment and whether to tell their employer about their diagnosis is very complex. There are no rules that will work for everyone. Factors that may affect a person's decision include:

- safety and duty of care
- the extent to which the symptoms affect their ability to do the job

- the pace at which the symptoms are progressing
- the support that is required (or likely to be offered) by their employer

Employers and work colleagues will require information, education and support to allow for adaptions in the workplace. This can be delivered through a participant's plan to maximise successful social and economic participation.

Job customisation is also an important part of supporting a person to harness their skills while recognising certain tasks would induce stress or errors. Job customisation is an evidenced based methodology to ensure that participant's abilities are matched to the jobs they are asked to perform.

Many people that decide to leave work still feel fit and capable to participate in community activities and may wish to consider volunteering roles. Some people may also wish to become a dementia advocate, to help raise awareness about dementia and share their story with others.

5 Engaging with families and carers

It is also important to remember that caring for a person living with dementia can be physically and emotionally tiring and stressful. Families and carers can easily become isolated, particularly if they are unable to leave the person they are caring for. Supports for the person living with dementia that provide a ‘break’ for carers, such as respite or regular social support can assist carers and family members to manage their own health and wellbeing and help them to sustain their informal supports over a longer period of time.

6 Common language and terminology

People with dementia may refer to their condition in different ways. Some terms about dementia may be upsetting or offensive to people with dementia and their families. It is important to check with the participant how they prefer to describe their condition. In addition you can confidently use the following terms;

Dementia, a form or type of dementia, symptoms of dementia, a person/people with dementia, a person/people living with dementia, a person/people with a diagnosis of dementia, a person with Younger Onset Dementia.

The term Younger Onset Dementia is seen as preferable to other terminology, including ‘early onset dementia’ as it specifically refers to any form of dementia where symptoms appear in people under the age of 65.

7 How can I tailor a meeting to suit a participant living with younger onset dementia?

- It is important to remember that everyone's experience with dementia is very different, even if they share the same underlying cause, e.g. Alzheimer's disease.
- Function can fluctuate on a regular basis. Even if a person presents well at their planning meeting, it may not be representative of their normal day to day function.
- People with dementia vary greatly in their level of insight. Some will be aware of their condition, and will be able to identify their deficits and challenges. Others, and this is more common, will have very little insight even at a very early stage. For these people, they will present a false picture of how they are going. It is important to know that this is not deliberate or contrived, but rather, they truly believe that nothing or little is wrong.
- Include the person with dementia in discussions and ensure they feel seen and heard.
- A person with dementia may not know what their needs and goals are, or be able to express them accurately.
- Informal supports, such as family and friends, play a critical role in supporting a person living with dementia. Primary carers and other family members often have a wealth of information regarding the person's needs and goals and should be included in the planning process wherever possible.
- Confirm meeting details with the person's primary carer or support person and confirm that they can attend the meeting with the participant as required.
- Travelling to appointments can be extremely stressful for a person living with dementia. Home environments for more complex meetings can be beneficial.

8 Helpful links for further information

About Dementia

https://www.dementia.org.au/about-dementia/what-is-dementia

Types of Dementia

https://www.dementia.org.au/information/about-dementia/types-of-dementia

Dementia and Down Syndrome

https://www.dementia.org.au/about-dementia/types-of-dementia/down-syndrome-and-alzheimers-disease

Diagnosing Dementia

https://www.dementia.org.au/information/diagnosing-dementia

Dementia Friendly Language

https://www.dementia.org.au/resources/dementia-language-guidelines

YOD and the NDIS

https://www.dementia.org.au/resources/younger-onset-dementia-and-the-ndis

Employment and Dementia

https://www.dementia.org.au/about-dementia/i-have-dementia/employment-and-dementia

Dementia Advocates Program

https://www.dementia.org.au/about-us/dementia-advocates-program

[1] Dementia Australia (2018) Dementia Prevalence Data 2018-2058, commissioned research undertaken by NATSEM, University of Canberra