



Council for
Intellectual Disability



Resources for Health Practitioners

**To support better appointments when working with
people with intellectual disability.**

These resources were collated as part of the Primary Care Enhancement Program, funded by the Australian Government Department of Health.

Copyright Council for Intellectual Disability, 2022. You may share this document, but not adapt it without permission.



TABLE OF CONTENTS

PART 1: Resources on Reasonable Adjustments and Communication	1
Tailorable resources for health appointments	1
Tips sheet	2
Links to key sources of accessible health information	5
<hr/>	
PART 2: Links to clinical resources	6
Guidelines	7
HealthPathways	7
Prescribing	7
Cardiometabolic health	7
What not to miss - By Professor Nick Lennox	8
Common unrecognised or poorly managed conditions	8
Other common areas of inadequate management	8
<hr/>	
PART 3: Resources on Care coordination	9
Medicare item numbers commonly used when working with people with intellectual disability	10
Resources on supported decision-making	12
Supporting young people with intellectual disability transitioning from paediatric to adult health services	17
Supporting adults with intellectual disability to consider and plan their future care needs	18
Coordinating opportunistic evaluations	19
Evaluations under sedation	19
Opportunistic Pathology requests	20
Explore adjustments too	20
<hr/>	
PART 4: Links to NDIS resources	21
NDIA / NDIS developed resources	22
Access information for GPs and Health Professionals	22
Acronyms and glossary	22
Disability vs health and other mainstream system responsibilities	22
Useful resources developed by other agencies	23
FAQ for GPs and Health Professionals (Summer Foundation)	23
What people get in an NDIS plan (Summer Foundation)	23
Guides for health practitioners on writing reports or providing evidence for NDIS	23
Excellent NDIS therapy reports – a guide for health professionals (VALID)	23
Summer Foundation Guide for writing for NDIS	23
Guide to accessing NDIS supports following hospital discharge	24
<hr/>	
PART 5: Other Resources	25

PART 1:

**Resources on
Reasonable Adjustments
& Communication**

TAILORABLE EASY READ APPOINTMENT LETTERS



Council for Intellectual Disability has developed a tailorable resource in Easy Read, which includes pictures.



www.cid.org.au/health/resources-health-professionals-app-letter

To use the sheet:

- Delete the parts you do not need.
- Insert relevant text where prompted.
- Optionally, you may also take a photo of the health professional and the person sending the letter and insert them into the document. Photos taken with a mobile phone are fine. Make sure the person being photographed is the only person in the frame.
- Here is a tailorable Easy Read sheet to describe how someone can reach your service:



www.cid.org.au/health/resources-health-professionals-find-us

- You can photograph your building, along with the reception desk and any specific points for directions.

These sheets were co-designed with people with intellectual disability, using funding from the Australian Government Department of Health.



Agency for Clinical Innovation has produced this template for an appointment letter.



https://www.aci.health.nsw.gov.au/__data/assets/word_doc/0009/275823/Appmt_letter_for_Parent_in_Easy_Read_2015_-_DP_TS_edit.docx

- The link above downloads a word file - look in your downloads.
- This sheet has easier text but no pictures.
- To use it, simply edit the text.

GOOD APPOINTMENTS, BETTER HEALTH

Tips to improve health outcomes for people with intellectual disability



COMMUNICATION

- ✓ Give information in a quiet place.
- ✓ Make sure to have the person's attention before talking.
- ✓ Talk to the person, even if they do not talk.
- ✓ Talk about one thing at a time.
- ✓ Speak clearly and slowly in plain, everyday language (avoid jargon).
- ✓ Don't just say it - show it. You can use:
 - Easy Read information during appointments and to take home, plus;
 - social stories;
 - videos;
 - demonstrate on yourself or a trusted person &
 - see the say-less-show-more method.
- ✓ Allow silent time to process information.
- ✓ Check that someone understands what you've said (see teach-back method).
- ✓ Check your understanding of what someone communicates.
- ✓ Give people time to make decisions. It may need a follow-up appointment.
- ✓ Ask the person if it's okay to talk to supporters and keep them included in the conversation when talking to others.
- ✓ Use Easy Read information during appointments and to take home.
- ✓ Write down information in plain words – give instructions in steps.
- ✓ Ask how they complete forms:
 - over the phone;
 - with support in your office &
 - with a supporter – send well ahead of time.



SAFETY

- ✓ Organise pre-medication before a procedure if needed.
 - Confirm if it is taken at home or at the clinic to avoid waiting time.
- ✓ Allow people to have their chosen supports with them.
- ✓ Encourage people to bring distractions they find helpful e.g. iPad.
- ✓ Ask for consent and wait for affirmative response before touching someone.
- ✓ Tell and/or show someone what is going to happen before touching them.
- ✓ Talk about what you're doing as you're doing it.
- ✓ Actively check that someone is okay as you touch them or do a procedure.
- ✓ Stop as soon as someone asks or indicates distress.
- ✓ Check in about how someone feels after the procedure.



SCHEDULING

- ✓ Offer appointments that minimise waiting time.
- ✓ Offer to wait in a quieter space, away from others, or outside.
- ✓ Offer longer appointments to:
 - build comfort and trust &
 - allow time for communication.
- ✓ Offer multiple short appointments to:
 - build comfort and trust &
 - allow time for communication.
- ✓ Offer to send information about appointments to a support person too.



REFERRALS

- ✓ Check the service's eligibility before referring.
 - ✓ Check that any mobility needs can be met before referring.
 - ✓ Send the referral directly to the doctor.
 - ✓ Include information about adjustments that help the person.
 - Attach this list - tick the things you find helpful when working with them.
- A print-friendly version is available from www.cid.org.au/health/resources-health-professionals-good-appointments-referral
- ✓ Make the appointment for the person while they are still with you.

LINKS TO KEY SOURCES OF ACCESSIBLE HEALTH INFORMATION

Providing information in an accessible format is key to patients being actively involved in decision-making about their health. Here are some key sources of health-related information:

Council for Intellectual Disability

 <https://cid.org.au/resource-category/health>

Council for Intellectual Disability's My Health Matters folder is an accessible personal health record:

 <https://cid.org.au/resource/my-health-matters-folder>

Family Planning NSW has excellent sheets on preventative screening

 <https://www.fpnsw.org.au/justchecking>

ACI Network's Say-Less-Show-More resources

 <https://aci.health.nsw.gov.au/resources/intellectual-disability/hospitalisation/say-less-show-more>

Books Beyond Words (UK)

 <https://booksbeyondwords.co.uk>

Queensland Centre for Intellectual and Developmental Disability video about seeing the dentist

 <https://www.youtube.com/watch?v=JYBRraVwh7E>


PART 2:

Links to Clinical Resources

GUIDELINES

The **Therapeutic Guidelines** is an online guide providing clinicians with excellent guidance for the management of a range of challenging issues. It is by and for Australian practitioners.

The chapter on Developmental Disability is comprehensive. There is also a chapter on psychotropics which holds relevance for some people with intellectual disability:

 <https://tgldcdp.tg.org.au/guideLine?guidelinePage=Developmental+Disability&from-page=etgcomplete>

HEALTHPATHWAYS

HealthPathways is an online clinical and referral information portal for clinicians. Find your local HealthPathways via this page:

 <https://www.healthpathwayscommunity.org/Home/Access-to-HealthPathways>

PRESCRIBING

The Pharmacists Optimising Medication for People with Intellectual Disability and Autism group (POMPIDA) referral information for Home-Based Medicine review for those on a Positive Behaviour Support plan.

The STOMP website (UK) has resources, videos and guidance regarding safe prescribing and deprescribing for people:

 <https://www.england.nhs.uk/learning-disabilities/improving-health/stomp>

The National Prescribing Service's chart for monitoring adverse effects of antipsychotics is here:

 <https://resources.amh.net.au/public/antipsychotic-monitoring-tool.pdf>


CARDIOMETABOLIC HEALTH

3DN UNSW's "Postcards" targeting cardiometabolic health in people with intellectual disability are quick and easy to use:

 <https://www.3dn.unsw.edu.au/positive-cardiometabolic-health-ID>

DENTISTRY

Inclusion Australia's excellent resource for dentists is here:

 <https://inclusionmelbourne.org.au/wp-content/uploads/2019/05/Oral-health-and-disability-web-spreads.pdf>

WHAT NOT TO MISS - BY PROFESSOR NICK LENNOX

Below is a list of medical problems commonly missed or poorly managed in children, adolescents and adults with intellectual disability.

Not uncommonly, pain and obvious pathology such as infections are missed, ignored, or wrongly attributed to the person's intellectual disability and not investigated.

Any change in a person's function or behaviours warrants a thorough medical examination. Even a reduction in behaviours of concern (in the absence of new treatment) can be an indication of physical or psychiatric illness.

Clinicians need to pro-actively consider and examine for these conditions. Allied health professionals need to be assertive about checking if appropriate medical investigations have occurred (or are planned) when receiving referrals where a person with ID exhibits rapid or gradual changes in behaviour or function.

Common unrecognised or poorly managed conditions

- Psychiatric disorders e.g, depression, psychosis, anxiety disorders.
- Abuse & PTSD.
- Epilepsies; e.g. no management or emergency plan, inadequate medication review.
- Dental disease.
- GIT problems especially:
 - dysphagia;
 - reflux oesophagitis;
 - H. Pylori &
 - constipation.
- Hearing and vision impairment +/- unrecognised pathology.
- Obesity / malnutrition.
- Osteoporosis.
- Undescended testes/ hypogonadism.
- Vitamin D deficiency
- Sleep disorders.

Other common areas of inadequate management

- Incomplete immunisation schedules.
- Inadequate health screens – blood pressure, skin, breast, pap smear.
- Over-use and inadequate review of medications, especially anti-psychotics and anticonvulsants.
- Failure to investigate the cause of intellectual disability.
- Failure to provide information about:
 - menstrual management &
 - human relations and sexuality.
- Assessment of mobility.
- Assessment of continence.
- Planned end of life care.

PART 3:

Resources on Care coordination

MEDICARE ITEM NUMBERS COMMONLY USED WHEN WORKING WITH PEOPLE WITH INTELLECTUAL DISABILITY

Below is a list of Medicare item numbers and information regarding how frequently they can be used for each patient.


This information has been adapted with permission from a resource developed by The Village Medical Practice, Summer Hill, and Dr Aline Smith's presentation to the Central and Eastern Sydney Primary Health Network webinar.

You can watch the presentation here:

 <https://www.youtube.com/watch?v=CPRz9ptJROc>

Dr. Smith talks about MBS and getting adequately remunerated from 12:27 onwards.

A detailed table of item numbers relevant to NDIS paperwork is here:

 <https://www.cesphn.org.au/preview/ndis/2329-20181212-central-and-eastern-sydney-phn-gp-resource-mbs-billing-for-completion-of-ndis-arf-final-november-2018-commsv/file>

ITEM NAME	MBS NUMBERS	FREQUENCY
Health assessment	703 - 30 – 40 min 705 - 45 – 60 min - Long 707 - >60 min - Prolonged	1/yr
Care plans		
New Care plan	721 and 723	1/yr
Review of care plan	732	Every 3 months
Case conference	735 739 - >20 min - Longer	Every 3 months for Chronic disease Team care Arrangements
Mental health		
Mental health plan	2715 2717 - >40 min - Longer	1/yr
Mental health review	2712	2/yr: - 4 weeks after plan is made - 3 months after that
Mental health consultation	2713	Unlimited
Asthma		
Asthma	2552	1/yr
Home visits (every 4 weeks) Or via telehealth	24 36 >20 min – Longer	No limit
Medication review		
Home Medicine Review – GP item	900	1/yr or following significant change in person's condition
Home Medication Review –GP referral to Pharmacist	245	1/yr
Nurse item		
Bulk billing Nurse item	10990	Unlimited; add to each appointment

This information has been adapted with permission from a resource developed by The Village Medical Practice, Summer Hill.
Please check the Medicare website for accurate and up-to-date information.

RESOURCES ON SUPPORTED DECISION-MAKING

Supported decision making is a human right: all adults have the right to make their own decisions. A person's ability to make decisions varies according to the specific decision being made, as well as their own health and any other factors currently impacting them. The quality of support offered to a person can significantly assist them to make decisions. Providing information in an accessible way, providing choices and experiences and ensuring the person has support to make decisions plays a critical role in upholding their right to make decisions. For people who rely on others to interpret their will and preferences, support plays a critical role in upholding their right to be as involved in decisions as possible.

A person should be supported to make decisions regarding their life.

Below we have listed resources which can assist those who support people with intellectual disability to learn more about supported decision-making.

Substitute decision-making, where a person is given legal authority to make a decision on behalf of another person, is an option of last resort. Rules on who can be a substitute decision maker vary by state.

In some cases, a person may have a **guardian** to make health and lifestyle (but not financial) decisions. However, most people with intellectual disability do not have a guardian. Again, the laws surrounding this vary from state to state.

In all states and territories there is a mechanism that allows the treating practitioner to identify who can consent to treatment if the person is unable to. In many states this is called the Person Responsible; in Queensland it is known as Statutory Health Attorney. This person may or may not be a guardian.

State-based authorities provide relevant information on both medical and dental consent and guardianship on their websites. Some also provide information on supported decision making. Links to these sites are provided below, along with links to good supported decision making resources from other organisations.

National standards on guardianship are outlined in this Easy Read sheet from the Australian Guardianship and Administration Council:


 <https://www.agac.org.au/assets/images/easy-eng-nat-stds-public-grdship.pdf>

National resources on Supported Decision Making

- Video explaining supported decision making as a human right:

 <https://www.youtube.com/watch?v=al3aJfs6-X4&t=237s>

- Training for disability support workers:

 <https://www.nds.org.au/events-and-training/all-events-and-training/supported-decision-making-e-learning-module-3039>

- La Trobe University has a Supported Decision Making Framework for support workers and family members, available here:

 www.supportfordecisionmakingresource.com.au

- A rights-based guide for individuals, families and the disability sector, developed in Western Australia, is here:

 <https://waindividualisedservices.org.au/resources/supported-decision-making>

- ADACAS Advocacy has a series of resources which raise some good questions for person supporting someone to make decisions:

 <https://support-my-decision.org.au/supporting-decisions>

State-or territory-based sites on substitute decision making

NSW

Agency and tribunal:

- NSW Trustee and Guardian

 www.tag.nsw.gov.au

- NSW Civil and Administrative Tribunal

 <https://www.ncat.nsw.gov.au>

Resources:

- Specific information for health professionals: (includes FAQs)

 <https://www.tag.nsw.gov.au/guardianship/information-medical-and-healthcare-practitioners>

QUEENSLAND

Agency and tribunal:

- Office of the Public Guardian:

 www.publicguardian.qld.gov.au

- Queensland Civil and Administrative Tribunal:

 <https://www.qcat.qld.gov.au>

Resources:

- Health decisions pages:

 <https://www.publicguardian.qld.gov.au/health-decisions>

- Restrictive practices decision making guidance:

 <https://www.publicguardian.qld.gov.au/restrictive-practices/policy>

ACT

Agency and tribunal:

- Public Trustee and Guardian:

 www.publictrustee.act.gov.au/guardianship

- ACT Civil and Administrative Tribunal:

 <https://www.acat.act.gov.au>

TASMANIA

Agency and tribunal:

- Public Trustee and Guardian:

 <https://www.publicguardian.tas.gov.au>

- Tasmanian Civil and Administrative Tribunal:

 <https://www.tascat.tas.gov.au/guardianship>

VICTORIA

Agency and tribunal:

- Office of the Public Advocate:

 www.publicadvocate.vic.gov.au

- Victorian Civil and Administrative Tribunal:

 <https://www.vcat.vic.gov.au>

Resources:

- A video guide for health professionals is here:

 <https://www.publicadvocate.vic.gov.au/the-public-advocate/in-the-news/our-news/360-launch-of-healthcare-conversations-video>

SOUTH AUSTRALIA

Agency and tribunal:

- Office of the Public Advocate:

 www.opa.sa.gov.au/what_we_do/guardianship

- SA Civil and Administrative Tribunal:

 <https://www.sacat.sa.gov.au>

Resources:

- SA OPA's series of fact-sheets includes information on decision-making capacity, consent for health treatment and restrictive practices, amongst others. This includes several Easy Read sheets and an explanation of informal arrangements. They can be accessed here:

 http://www.opa.sa.gov.au/resources/fact_sheets

WESTERN AUSTRALIA

Agency and tribunal:

- Office of the Public Advocate:

 <https://www.publicadvocate.wa.gov.au>

- State Administrative Tribunal:

 <https://www.sat.justice.wa.gov.au>

Resources:

- Guide on making treatment decisions:

 https://www.publicadvocate.wa.gov.au/M/making_treatment_decisions.aspx-?uid=4727-3795-2343-5639

NORTHERN TERRITORY

Agency and tribunal:

- Office of the Public Guardian:

 www.publicguardian.nt.gov.au

- Northern Territory Civil and Administrative Tribunal:

 <https://ntcat.nt.gov.au>

SUPPORTING YOUNG PEOPLE WITH INTELLECTUAL DISABILITY TRANSITIONING FROM PAEDIATRIC TO ADULT HEALTH SERVICES

General Practitioners have a key role to play in coordinating a young person's transition to adult services.

- There is excellent information in the Therapeutic Guidelines on this topic.
- Consider offering an annual health assessment during adolescence to ensure high quality care and develop a relationship as the person moves towards leaving paediatric services.
- A Chronic disease management plan may be needed to ensure a young person can access relevant services.
 - When referring a person to new services, print off the tips checklist, tick those you find most helpful when working with the young person, and send that with the referral.
- The young person may need to access new or additional resources under the NDIS. Information on how health practitioners can support NDIS applications is here.
- Consider the young person's privacy and autonomy. Here is a sheet of links to information about supported decision-making. Families may find this information helpful. A young person with intellectual disability may find it empowering as they transition to adult services.
- Share information with families about transitioning services, from the age of 14.

The Agency for Clinical Innovation has developed resources for families with a young person with intellectual disability to help them prepare to transition to adult health services. It is available here:

 <https://aci.health.nsw.gov.au/resources/transition-care/intellectual-disability/health-care-transition-for-young-people-with-intellectual-disability>

While it was developed in NSW, much of the information is relevant throughout Australia.

Other state-specific sites are:

- NSW – Trapeze (Sydney Children's Hospital Network): <http://www.trapeze.org.au>
- Tasmania: <https://www.primaryhealthtas.com.au/resources/moving-on-up-framework-and-resources>
- Victoria: <https://www.rch.org.au/transition>
- Western Australia: https://pch.health.wa.gov.au/~/_media/Files/Hospitals/PCH/General-documents/Patients-and-Families/Health-facts/Transition/Transition---Info-for-parents-of-a-young-person-with-an-intellectual-or-developmental-disability.pdf

SUPPORTING ADULTS WITH INTELLECTUAL DISABILITY TO CONSIDER AND PLAN THEIR FUTURE CARE NEEDS

Encourage people with intellectual disability and their supporters engage in conversations about future care options and preferences early on. This is especially important for those living with older parents, who may otherwise face a crisis-driven transition triggered by either their own, or a parents' health declines. Involving the person in conversations when they are still healthy is likely to mean they are more able to engage in decisions, as well allowing more time to explore different options.

Many people have a preference to 'age in place' and it should be supported where possible.

Health practitioners can play an important role in:

- raising the topic and encouraging families to talk and to explore options;
- sharing resources on:
 - supported decision-making (see above),
 - the NDIS,
 - the myagedcare website: www.myagedcare.gov.au/support-people-living-with-disability and
 - links to local services from HealthPathways.
- asking separately about each person's needs for support – both practical and emotional and making referrals as needed.

There is excellent information in the Therapeutic Guidelines on this topic. Practitioners supporting patients in these age groups are encouraged to read them.

COORDINATING OPPORTUNISTIC EVALUATIONS

Evaluations under sedation

Some people with intellectual disability require sedation to tolerate health checks, blood tests, or dental work.

When a person requires sedation (for any reason, planned or otherwise), it is beneficial to arrange all necessary tests at once.

- Specialists or dentists can helpfully alert the GP when someone requires sedation.
- A GP can liaise with hospital staff to ensure all needed tests can be done at once.

Consider if any of the following are needed:

- Dental check-up and cleaning, radiographs if due or indicated.
- Breast examination; cervical screening if necessary.
- Testes check; prostate screen if needed.
- Immunizations - check if due for any of the following:
 - dTpa
 - Hep A
 - Hep B
 - Influenza
 - Pneumococcus
 - Meningococcal
 - MMR
 - HPV cervical cancer
 - COVID-19
- ENT - Look inside their ears; remove ear wax if needed.
- Have an ophthalmologist assess their eyes.
- Feel their abdomen; arrange plain X-ray if constipation is indicated; bowel screening if indicated for age; endoscopy if indicated.
- H. Pylori test.
- Listen to their lungs.
- Other investigations e.g., MRIs if indicated.
- Blood screening including FBC, CMP, thyroid function, other screening indicated based on their health conditions, risk factors, or medications - pay particular attention to the commonly missed conditions and consider if they need evaluation; genetic testing if indicated and with consent (run a cell line if possible for future tests). If showing signs of functional decline or behavioural change, also assess standard tests for cognitive decline vitamin B12.

Opportunistic Pathology requests

Some general practitioners give the person and their supporters a pathology request form with basic bloods panel and any tests the person needs regularly on it. In the event they attend emergency, or see a specialist who orders bloods, they are able to easily request those tests at the same time. Ensure the request asks for a copy of the results to go to their GP.

Explore adjustments too

While some people do require sedation for the sake of such assessments, others are able to cope with health checks if adjustments are made.

It is helpful to:

- Check with local services (e.g. Breast Screen, skin checks, local dentist) to see if they are able to offer assessments broken into multiple visits to allow a person to cope.
- Share information with the new service about adjustments that can help a person to cope when sending a referral. You can print the tips sheet at the start of this book and tick those you find helpful when working with the person. Send that along with the referral.
- Provide information in an accessible format to help the person prepare for a test or health check. [Click here for links to sources of accessible health-related information.](#)

PART 4:

Links to NDIS resources

NDIS RESOURCES FOR HEALTH PROFESSIONALS


NDIA / NDIS DEVELOPED RESOURCES

NDIA resources for GPs and other health professionals

 <https://www.ndis.gov.au/applying-access-ndis/how-apply/information-gps-and-health-professionals/practical-resources-gps-and-other-health-professionals>

Access information for GPs and Health Professionals

Comprehensive resources to assist GPs and health professionals with applications to access the NDIS. Includes information, practical resources and answers to commonly asked questions e.g. providing evidence, medical definitions etc.

 <https://www.ndis.gov.au/applying-access-ndis/how-apply/information-gps-and-health-professionals>

Acronyms and glossary


Glossary of NDIS terms, and a list of commonly used acronyms.

 <https://www.ndis.gov.au/about-us/glossary>

 <https://www.ndis.gov.au/about-us/glossary/acronyms>

Disability vs health and other mainstream system responsibilities


Information about what is considered the health system responsibility vs disability system responsibility. Covers other mainstream services as well e.g., housing, education, justice etc.

 <https://www.ndis.gov.au/understanding/supports-funded-ndis/disability-related-health-supports>

USEFUL RESOURCES DEVELOPED BY OTHER AGENCIES

FAQ for GPs and Health Professionals (Summer Foundation)

Comprehensive FAQ, written specifically for health services. Provides answers to common questions asked by health professionals working with the NDIS, covering topics including access, plan implementation, health vs. disability, and others.


 <https://www.summerfoundation.org.au/wp-content/uploads/2020/02/Frequently-Asked-Questions-For-health-services-working-with-people-with-disability.pdf>

What people get in an NDIS plan (Summer Foundation)

Short, easy to understand guide explaining what types of disability supports might be included in an NDIS plan.

 <https://www.summerfoundation.org.au/wp-content/uploads/2018/04/What-can-I-get-in-an-NDIS-plan.pdf>

Royal Australian College of General Practitioners information for GPs

 <https://www.racgp.org.au/FSDEDEV/media/documents/Running%20a%20practice/Practice%20resources/NDIS-information-for-general-practitioners.pdf>

GUIDES FOR HEALTH PRACTITIONERS ON WRITING REPORTS OR PROVIDING EVIDENCE FOR NDIS

Summer Foundation Guide for writing for NDIS

Comprehensive yet easy to understand guide to the NDIS access criteria and how to write evidence which addresses the criteria. If someone has had trouble accessing the scheme, evaluate the evidence provided against this guide.

 <https://www.summerfoundation.org.au/wp-content/uploads/2018/04/getting-the-language-right-web.pdf>

STRIDE Providing Evidence of Psychosocial Disability chart

This resource focuses on psychosocial disability, not intellectual disability. However, it is short and gives practical guidance and examples of the types of information, observations and language that can help provide evidence for the NDIS.

 https://stride.com.au/wp-content/uploads/2020/06/06-Providing-Evidence-of-Psychological-Disability-Matrix-_S.pdf

Excellent NDIS therapy reports – a guide for health professionals (VALID)

An easy-to-understand guide on how to provide evidence for participants (i.e. people in the scheme). Useful for all scenarios where a participant might need evidence e.g. scheduled review, unscheduled reviews, change of circumstances etc.

 <https://www.valid.org.au/sites/default/files/10-steps-to-excellent-National-Disability-Insurance-Scheme-NDIS-therapy-reports-v1.pdf>

Guide to accessing NDIS supports following hospital discharge

Guides to discharging people from hospital into appropriate NDIS supports. Particularly useful for when something has changed for the participant e.g. newly acquired disability, deterioration of condition, loss of supports etc.

 <https://www.summerfoundation.org.au/wp-content/uploads/2020/02/Internal-and-External-Escalation-Guideline-17-MARCH-2020.pdf>

 <https://www.summerfoundation.org.au/wp-content/uploads/2019/12/CDA-guide-17.4.20.pdf>

PART 5:

**Other
resources**

ORGANISATIONS FOCUSED ON DISABILITY AND CULTURALLY AND LINGUISTICALLY DIVERSE (CALD) COMMUNITIES

National

First People's Disability Network:

 <https://fpdn.org.au>

National Ethnic Disability Alliance:

 <http://www.neda.org.au>

NSW

Multicultural Disability Advocacy Association:

 <http://mdaa.org.au>

Ethnic Community Services Co-operative:

 <https://ecsc.org.au/about>

Indigenous Disability Advocacy Service:

 <https://www.facebook.com/IDAS.ORG.AU>

Disability and Diversity Alliance:

 <http://www.ddalliance.org.au>

QLD

Aboriginal and Torres Strait Islander Disability Network of Queensland:

 <https://atsidnq.com.au>

VIC

Action on Disability within Ethnic Communities:

 <https://adec.org.au>

Disability and Diversity:

 <https://www.mrcnorthwest.org.au/services/disability-services>

WA

Kin Advocacy:

 <https://kinadvocacy.org.au>

CONSIDERATIONS SURROUNDING TELEHEALTH FOR PEOPLE WITH INTELLECTUAL DISABILITY

Pros and cons of telehealth when working with people with intellectual disability

Telehealth consultations have become commonplace in Australia. However, the proportion of people with intellectual disability in Australia who access the internet is presently unknown, as is the number who engage with telehealth consultations. What is clear is that many people with intellectual disability do not access the internet. Council for Intellectual Disability recommends that accessing services using technology should be offered as one option, but not the only option.

Below we summarise some of the advantages and challenges of using telehealth with people with intellectual disability. However, it is important to note that more research is needed in this area, as most studies are limited and most research samples are small. The information here has been drawn from a recent review of the evidence, along with tips given to us by people with intellectual disability and health professionals.

Advantages:

Telehealth consultations can offer ways to access medical and allied health services that may otherwise not be possible due to location or accessibility.

It removes waiting room time, which some people with intellectual disability find challenging. It also limits the risk of contagion.

Telehealth may provide increased opportunities to access therapeutic interventions:

- Emerging evidence suggests interventions like Cognitive Behavioural Therapy and life skills training can be successfully delivered digitally for some people with intellectual disability, although a hybrid model may be better.
- Some people with intellectual disability can learn the basic functions of devices and apps, particularly when apps are designed to be accessible and if support is available

Technology also offers new ways of communication amongst patients, health professionals, families, and supporters. Apps can also offer health monitoring, reminders, and alerts. This is an area of rapid change. However, many apps have not been developed with accessibility for people with intellectual disability in mind, focusing more on supporters. Health professionals need to consider and discuss privacy issues and ensure appropriate consent for sharing information has been given.

Challenges:

Telehealth is not appropriate for every type of consultation. It may be more difficult to observe someone, and physical examinations are not possible, increasing the potential for health concerns to be missed.

Some people with intellectual disability may find it difficult to feel comfortable with a health professional online, especially if they have not seen them in-person before.

A range of barriers may impact people with intellectual disability more than others, including:

- Interventions may take longer if delivered online
- Cost of devices, as well as ongoing costs like internet charges
- Difficult experiences in learning to use technology may contribute to aversion
- Physical barriers, such as screen and button size if using a phone
- Sensory barriers
- People with intellectual disability may have an increased susceptibility to misinformation, scams, or online abuse and bullying
- A person may not have ready access to the internet within a private space if they live with others.

Tips if offering telehealth appointments for people with intellectual disability:

Choose a more accessible telehealth app, with options to control settings:

- The more less-heavy it is, the more accessible it will be
- If more than two people are involved in the consultation, plan how you will manage this. In some apps, the order of people's images swaps each time a new person speaks or turns their camera on or off. This can be unsettling for people with intellectual disability. It may take them a while to figure out who is speaking. To overcome this:
 - Use an app and settings where all people remain on the screen in the same position
 - Some apps allow you to "pin" your own screen for all, giving you greater control

Tips for setting up the appointment:

- Check ahead of time if the person (and their supporters as appropriate) feels comfortable with using telehealth. Offer a choice of other options where possible.
- Allow more time in the booking
- For those with higher support needs, ensure a supporter can be with them
- Explain ahead of time what they need to do, and when. For example, if you will send the link just before the appointment, tell them this.

- Provide an opportunity to trial the technology ahead of time, or share a video on using it.
- Explain ahead of time how it will be billed
- Ensure you conduct the call from a room that preserves the person's privacy and confidentiality
- Pay attention to your own background and lighting, where feasible. There is presently no research specific to people with intellectual disability to support a recommendation regarding a specific background. However, consider the following:
 - Clutter can be distracting. A plain wall behind you is better.
 - Using a virtual background may result in some parts of your body being clipped, especially if the contrast between the real life colours and virtual colours is low. Gradient backgrounds reduce this problem.
 - Some people who are concerned about their privacy may also feel unsettled using virtual backgrounds that block them seeing what or who is in the room with you. There is a power imbalance if a health professional can see into the person's home but they can't see anything of your office.
 - Good lighting is important to make sure people can see you clearly. Remove lights behind you, which can darken your face, and ensure your face is well lit. A lamp may be a useful addition to ensure you are well lit.

During the consultation

- Ensure everyone the call is introduced
- Keep cameras on (rapport and trust, and to limit screen changes)
- Say your name before you speak in a multi-person call.
- Address confidentiality and consent to involve others early on:
 - Ask the person if they feel comfortable with the people who with them, or should someone move to another room
 - Ask the person for permission to speak with family members who are present
- A person with higher support needs might leave the room during the consultation. Make support people aware that they should not try to force the person to stay. With appropriate consent established, be flexible and speak with their support person if appropriate. Respectfully offer the person another chance to engage if they come back in.
- Pay extra attention to checking communication in both directions. See our tips on communication in our tips sheets called Good Appointments, Better Health, available here: www.cid.org.au/health/resources-health-professionals-good-appointments-referral

BACKGROUND TO THESE RESOURCES

Australians with intellectual disability face a number of health inequalities. The impact of this has been highlighted in recent research.

Compared to people without intellectual disability, those with intellectual disability:

- Die an average of 26 years earlier ¹
- Have over twice the rate of avoidable deaths ¹
- Are 4 times more likely to experience a potentially preventable hospitalization ²
- Have much higher rates of polypharmacy, including for psychotropic drugs ^{3, 4, 5, 6}
- Access preventative healthcare less often ⁷
- Have higher rates of physical and mental health conditions ^{8, 9, 10}

In 2019, a Roundtable identified the key elements of a National Roadmap for Improving the Health of People with Intellectual Disability. These included better support for health professionals to provide improved care for people with intellectual disability. A short-term priority under the Roadmap was a Primary Care Enhancement Program (PCEP) focusing on the needs of people with intellectual disability.

As part of the PCEP, the Council for Intellectual Disability led the development of a suite of national resources with input from people with intellectual disability and their families, four lead PHNs, clinical and academic experts, disability service providers, and the Department of Health.

The resources developed are in two parts:

- Accessible resources for people with intellectual disability. These are available at <https://cid.org.au/resource-category/health>
- Collation, and where needed, creation, of resources for health professionals. These are contained in this booklet.

References for this section:

1. Trollor, J., Srasuebku, P., Xu, H., & Howlett, S. (2017). Cause of death and potentially avoidable deaths in Australian adults with intellectual disability using retrospective linked data. *BMJ open*, 7(2), e013489.
2. Weise, J. C., Srasuebku, P., & Trollor, J. N. (2021). Potentially preventable hospitalisations of people with intellectual disability in New South Wales. *Medical Journal of Australia*
3. O'Dwyer, M., Peklar, J., McCallion, P., McCarron, M., & Henman, M. C. (2016). Factors associated with polypharmacy and excessive polypharmacy in older people with intellectual disability differ from the general population: a cross-sectional observational nationwide study. *BMJ open*, 6(4), e010505.
4. Schoufour, J. D., Oppewal, A., van der Maarl, H. J., Hermans, H., Evenhuis, H. M., Hilgenkamp, T. I., & Festen, D. A. (2018). Multimorbidity and polypharmacy are independently associated with mortality in older people with intellectual disabilities: a 5-year follow-up from the HA-ID study. *American journal on intellectual and developmental disabilities*, 123(1), 72-82.
5. Haider, S. I., Ansari, Z., Vaughan, L., Matters, H., & Emerson, E. (2014). Prevalence and factors associated with polypharmacy in Victorian adults with intellectual disability. *Research in Developmental Disabilities*, 35(11), 3071-3080.
6. Chitty, K. M., Evans, E., Torr, J. J., Iacono, T., Brodaty, H., Sachdev, P., & Trollor, J. N. (2016). Central nervous system medication use in older adults with intellectual disability: results from the successful ageing in intellectual disability study. *Australian & New Zealand Journal of Psychiatry*, 50(4), 352-362.
7. Weise, J., Pollack, A., Britt, H., & Trollor, J. N. (2016). Primary health care for people with an intellectual disability: an exploration of demographic characteristics and reasons for encounters from the BEACH programme. *Journal of Intellectual Disability Research*, 60(11), 1119-1127.
8. Buckley, N., Glasson, E. J., Chen, W., Epstein, A., Leonard, H., Skoss, R., ... & Downs, J. (2020). Prevalence estimates of mental health problems in children and adolescents with intellectual disability: A systematic review and meta-analysis. *Australian & New Zealand Journal of Psychiatry*, 54(10), 970-984.
9. Reppermund, Simone, Theresa Heintze, Preeyaporn Srasuebku, Rebecca Reeve, Kimberlie Dean, Melinda Smith, Eric Emerson et al. "Health and wellbeing of people with intellectual disability in New South Wales, Australia: a data linkage cohort." *BMJ open* 9, no. 9 (2019): e031624.
10. Wilson, N. J., Lin, Z., Villarosa, A., & George, A. (2019). Oral health status and reported oral health problems in people with intellectual disability: A literature review. *Journal of Intellectual & Developmental Disability*, 44(3), 292-304.

This document was published in 2022.

Copyright Council for Intellectual disability. You may share these resources, but may not adapt them without permission.