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Intellectual Disability Across the Lifespan

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NSLHD Specialist Intellectual Disability Health Service

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Acknowledgement of Country

I would like to acknowledge and pay my respects to the Traditional custodians of the Northern Sydney Local Health District, the Guringai and Dharug peoples.

Their spirit can be found across the land and we honour the memory of their ancestors and Elders past and present.

As we endeavour to serve the health needs within the community, we recognise the importance of the land and waterways, as an integral part of people's health and wellbeing.

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intellectual disability: a retrospective cohort study from New South Wales, Australia. BMJ Open, 16(2), e110184. https://doi.org/10.1136/bmjopen-2025-110184 [bmjopen.bmj.com]

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Northern Sydney Intellectual Disability Health Service (NSIDHS)

- A specialised multidisciplinary ID health service for people living in NS, MNC and NNSW LHDs
- Consultative service
- Children and adults with ID diagnosis
- Current complex and unmet health need
- Referrals from treating medical officer
- Community and inpatient consultations
- Comprehensive health assessment, joint consultation, case discussion, psychosocial support, reasonable adjustment advice, general advice and capacity building/education

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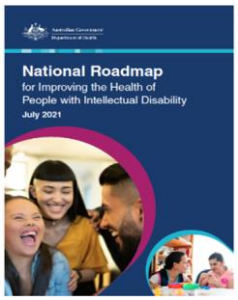
National Initiatives



The Roadmap aims to:

- Develop better models of care
- Support health professionals to deliver quality care for people with intellectual disability
- Improve health monitoring

Concurrent funding for action priorities, including the **National Centre of Excellence in Intellectual Disability Health**

Lead by UNSW Sydney

- Launched late 2023

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Common reasons for referral

- Unmet/changing physical health needs
- Transition care – adolescent moving to adult health services
- Psychosocial needs
- Decision making
- Carer/family support
- Behaviors of Concern
- Cognitive/ functional decline

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Health Status and Intellectual Disability

Complex interrelationships between disability and medical, social and psychological factors

5.4 medical conditions
Higher ED use
Longer hospital stays

2-3 x more likely to have a Mental Health condition

Extremely poor health status with mismatch between health needs and accessible service

Health Inequality and people with Intellectual Disability- Research Summary Prof J Troller and Dr J Small.
https://www.3dn.unsw.edu.au/
Survey of Disability, Ageing and Carers, 2015

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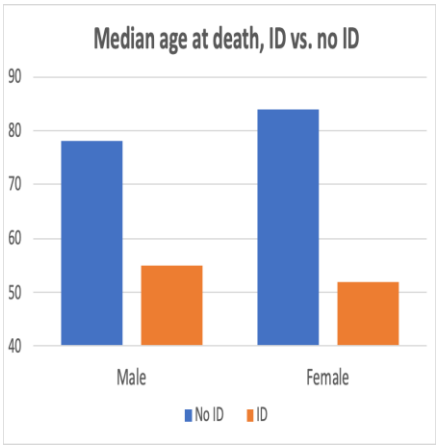

38% of deaths in the ID cohort (vs. 17% in the comparison cohort) were potentially avoidable

Trollor et al., *BMJ Open*, 2017; 7:e013489

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First 2000 days- what next?

- Identified developmental delays / Global developmental delay
- Referred for early intervention
- Now the child is aged 4 or 5 and needs to start school next year and is still globally delayed

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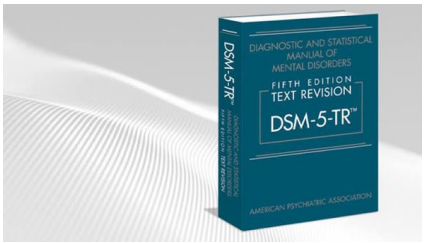

Global Developmental Delay

vs

Intellectual Disability / Intellectual Developmental Disorder

- Diagnostic and Statistical Manual of Mental Disorders- 5th Edition, Text Revision (DSM-5-TR)
  - Global Developmental Delay
    - Children under 5 Years old
    - Delays in two or more developmental domains, INCLUDING cognitive
  - Intellectual Development Disorder
    - Mild
    - Moderate
    - Severe

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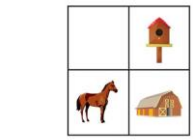
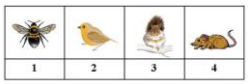
Cognitive Assessments (IQ tests)

- Weschler Preschool and Primary Scales of Intelligence – 4th Edition (WPPSI-IV)
  - Age 2 years 6 months- 7 years 7 months
  - Normed for AUS/NZ
- Weschler Scales of Intelligence – 5th Edition (WISC-V)
  - Age 6- 16 years
  - Normed for AUS/NZ
- Weschler Adult Intelligence Scale (WAIS)
  - Age 16+





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Functional Assessment

- Required as part of assessment for Intellectual Disability
  - Informal or formal clinical assessment of everyday functioning
    - Occupational therapists, psychologists, physiotherapist, medical specialists
  - WHODAS-2.0
  - PEDI-CAT
  - Adaptive Behavioural Assessment Scales –third edition- (ABAS-3)
  - Vineland Adaptive Behaviour Scales (Vineland-3)
- Functional Capacity Assessment
  - Primarily Occupational therapists
  - Covers mobility, communication, social interaction, self-care, self-management, learning

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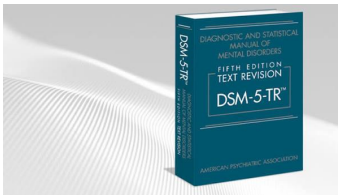
Intellectual Disability/Intellectual Developmental Disorder



*Neurodevelopmental disorder characterized by impairments in intellectual **AND** adaptive functioning (ADL's such as communication and independent living) with an onset during the developmental period (before the age of 18). DSM-5-TR*

Borderline	**IQ 70-75**	
Mild ID	IQ 55-70	~75% people with ID
Moderate ID	IQ 30-55	~20% people with ID
Severe ID	IQ <30	~5% people with ID

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Comprehensive health assessment – why?

- PWID have substantially higher rates of many chronic health conditions than the general population
  - Epilepsy
  - Mental illness
  - Respiratory and Cardiovascular disease
  - Gastrointestinal disorders
  - Hearing and Vision impairments
  - Obesity

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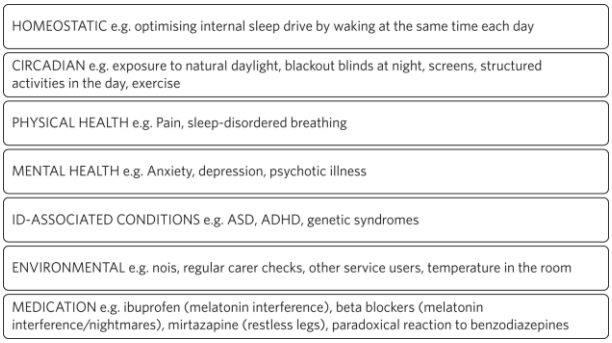
Comprehensive Paediatric Assessment

- Physical health
  - Sleep problems in children- 24% to 84%, and adults up to 34% (Korb et al., 2023)
  - Appetite/ diet
    - ASD related restricted diet
    - ARFID
    - Iron deficiency
  - Gastrointestinal – GOR/ Constipation



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Comprehensive Paediatric Assessment

- Physical health
  - Growth
  - Puberty
  - Vision and Hearing
  - Dental
  - Blood tests
    - Smileyscope (DHM)
    - Paediatric sedation pathway
      - Royal North Shore Hospital
      - NSLHD-RNS-CASSY@health.nsw.gov.au

- Genetic tests / Genetics referral
  - CGH microarray/ Fragile X / UMS
  - Trio Whole Exome Sequencing (WES)
    - Medicare funded
    - Parents + child (trio)
    - Paediatricians can order for children <10 years, dysmorphic features and one or more major structural congenital anomaly OR
    - ID/ GDD of at least moderate severity
    - Approx 40% rate

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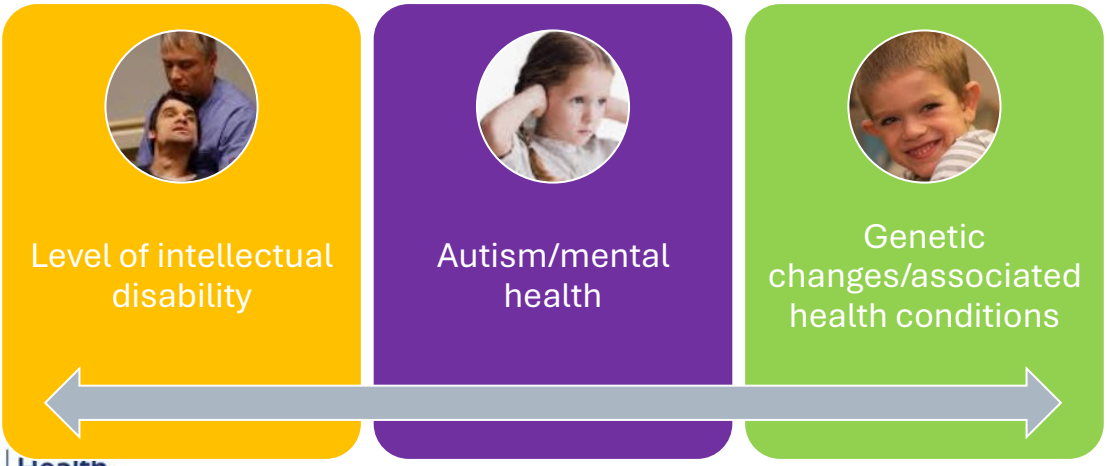
Aspects of the disability can assist in understanding behaviour



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Comorbid mental health conditions

- 40% of individuals with ID have a concurrent significant behavioural and emotional disturbance
- 31% have a diagnosable psychiatric condition
- Anxiety
- Depression
- ADHD
- ASD
- Few receive treatment for it (10%)

- Diagnostic overshadowing – all that presents is not singularly secondary to ID
- These assessments take a long time
- These are the MBS item numbers you can use.....

Einfeld, S.L. et al (2006)

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Medicare item numbers

- Chronic Condition Management (CCM) Plan
  Provides access to 5 partially rebated allied health sessions
- Better Access Mental Health Treatment Plan
  Provides access to 10 individual and/or 10 group partially rebated sessions with a psychologist

Both once per calendar year

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Medicare item numbers

- Multidisciplinary diagnostic assessment
- GP attendance - through items 3 to 47 or telehealth items 91790, 91800 to 91802 (video), 91890 and 91891 (phone)
- Up to 8 sessions with allied health clinician

- Treatment and Management Plan – 139 --> M10 pathway
- Treatment session referrals
  - Up to 20 sessions in total
  - Eligible disabilities including:
    - Vision and hearing impairment
    - Syndromes (e.g. Down, Fragile X, Angelmans)
    - Microcephaly and ID
    - FASD
    - Speech Sound Disorders, cleft lip
    - Refer to MBS online

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Case conference numbers

MBS Online
Medicare Benefits Schedule

Item	GP item number	Prescribed medical practitioner item number
	Organise and coordinate	
At least 15 minutes but less than 20 minutes	735	235
At least 20 minutes but less than 40 minutes	739	236
At least 40 minutes	743	237
	Participate	
At least 15 minutes but less than 20 minutes	747	238
At least 20 minutes but less than 40 minutes	750	239
At least 40 minutes	758	240

ELIGIBLE PRACTITIONERS

This note covers services for general practitioners, and prescribed medical practitioners to organise and coordinate, or participate in, time-tiered multidisciplinary case conferences for:

- patients in the community, or
- patients being discharged into the community from hospital, or
- care recipients in residential aged care facilities.

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Thriving Kids

Thriving Kids Australia - Information Hub
www.thrivingkidsinfo.com.au/medical

- National early intervention initiative for children aged 0–8 years with developmental delay/intellectual disability and/or autism with low to moderate support needs, and their families, carers
- Due to start roll out October 2026
- Foundational supports – for services (outside of the NDIS) to provide
  - Trusted information and advice for families
  - Evidence-based developmental supports
  - Access to allied health professionals
  - Supports tailored to each child's needs and circumstances

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Case discussion- Lisa (10 years)

- Only child – single mother
- Parental separation with no ongoing contact with father. Alleged domestic violence during pregnancy and Lisa's early life
- Assessed at 4 years old through CHW Child Development Unit, diagnosed with ASD- Level 3, and Mild Intellectual Disability
- Attending a mainstream school, with individualised education plan
- Gradually increasing anxiety and limited attendance at school, significant difficulties going to new places
- Regular therapists involved including speech therapy, psychology- reports reviewed

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Case discussion- Lisa (10 years)

- Reasonable adjustments made for clinic day
  - Social stories including pictures of clinicians
  - Visual schedule used to support communication during appointment
  - Flexibility in use of clinic room - able to leave to safe space when anxious/ overwhelmed
- With adjustments able to complete face to face clinic appointment including physical examination
- Concerns re: ?seizures- referral made for EEG, as well as cardiology review as history of congenital heart disease
- Significant anxiety (Anxiety Scale for Children- Autism Spectrum Disorder- ASC-ASD) – commenced trial of SSRI

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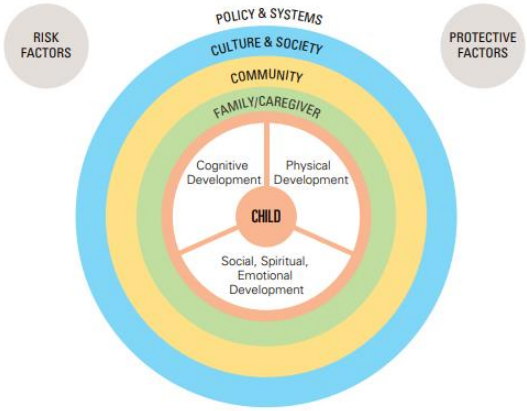
The Social Ecological Model (SEM)

Figure 1.
Social Ecological Model



UNICEF: https://knowledge.unicef.org/mental-health-and-psychosocial-support/resource/unicefs-brief-social-ecological-model

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Putting it into practice

- Parent awareness and understanding of varied presentation of children with intellectual disability
- Consistency with positive behaviour support strategies across care environments to provide structure, routine and anticipate triggers
- Reinforcement of the need for early intervention including parent capacity building and psychoeducation
- Impact of grief and loss, and impact on parent-child relationship
- Monitor carer stress and parent mental health and wellbeing
- Variable capacity of parents to co-regulate and support behaviour
- Family tolerance and accommodation for physicality changes as child grows
- Monitor siblings emotional and physical wellbeing
- Multiple transitions between carers and care environments can be confusing

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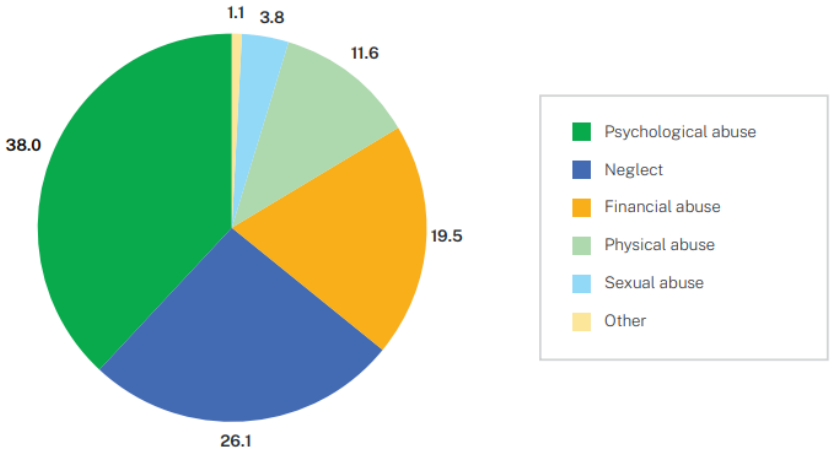
Figure 14: Percentage of allegations by type of abuse, reports to the ADC about adults with disability, 2023-24



https://ageingdisabilitycommission.nsw.gov.au/documents/reports-and-submissions/adc-annual-reports/ADC-Annual-Report_2023-2024_-_final.pdf

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What do I do if I suspect an adult with ID is the victim of Abuse and Neglect?

Police

NSW Police Force
www.police.nsw.gov.au

NDIS Quality and Safeguards Commission
Government agency
ndiscommission.gov.au

Ageing & Disability Commission
https://www.ageingdisabilitycommission.nsw.gov.au

NSW Ageing and Disability Commission

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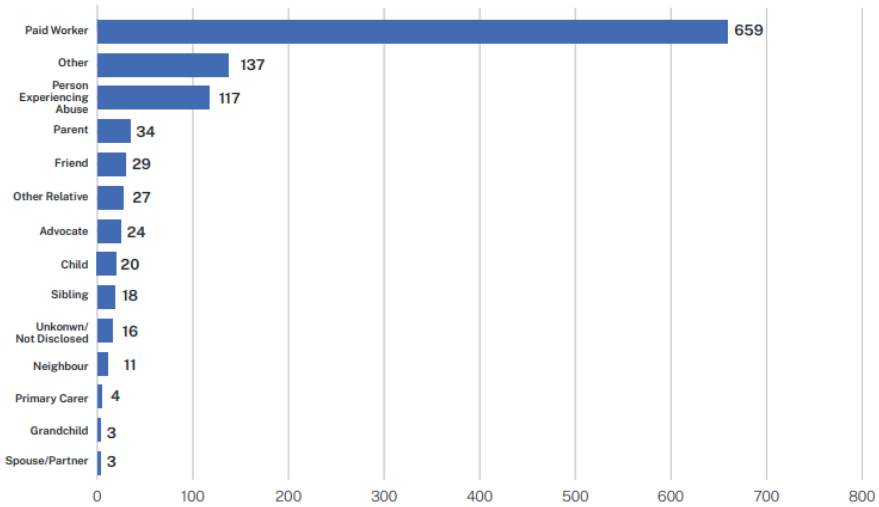
Figure 10: Relationship of reporter to the adult with disability in reports to the ADC, 2023-24



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Official Community Visitors

- Visit people with disabilities living in accommodation supported full time by NDIS providers (2475 services, home to 9,228 people (2022/2023))
- Rights of access without notice, to examine records and to interview staff and residents in private.
- Identify and seek to resolve issues of concern.
- Provide information about access to advocacy services
- In 2022/2023 they visited 46% of visitable services (also includes boarding houses and out of home care).
- 2023/2024:

3,396 visitable services in NSW known to the OCV scheme

11,277 residents accommodated

1,864 (55%) were allocated to an OCV in 2023-24

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Resources: domestic family & sexual violence

1800RESPECT

Disability Support Toolkit

- Collaboration between Women with Disabilities Australia and 1800 RESPECT
- Information for people responding to or supporting someone who has experienced violence
- Easy Read tools

neve

Neve

- By WWDA
- Easy read website navigation
- Resources for women and gender diverse clients
- Resources for clinicians e.g. Teaching people with intellectual disabilities about sexual consent | Guides | For professionals | neve

Sexual Assault Services Victoria

Sexual Assault Services Victoria

- Resources and practice tools

Making Rights Reality

- Easy Read Booklets by South Easter Centre Against Sexual Assault (SECASA)

NSW Health Education Centre Against Violence

NSW Health Education Centre Against Violence

Resources

- Co-designed resources for people who have been sexually assaulted
- Easy-read guides
- Plain English booklets
- Informational videos in Easy Read

Legal Aid NSW

Legal Aid

Easy-Read Resources

NSW Ageing & Disability Commission

NSW Ageing and Disability Abuse Helpline

Resources

- Guides, assessment tools, training modules, resources, e.g.:
- Identifying abuse types and signs
- DFSV of older women with disability

SHFPACT Safer Girls Safer Women

Responding to a disclosure

- by safer me safer you and Sexual Health and Family Planning ACT
- Responding to a disclosure of sexual violence in a safe and supportive way

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Transition Experience

- Changing Roles and Expectations
  - Parent/Carer stepping back
  - Young person stepping forward
- Finishing School
- Navigating new services
- Stabilising role
  - Primary care

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Transition

- ACI Transition Care Network

Moving to adult health services for young people with intellectual disability | Agency for Clinical Innovation

- Trapeze (SCHN)

Transition Care Co-ordinators

- ACI or Trapeze

How the Transition Care Service can help | Agency for Clinical Innovation

- NDIS funded clinicians / Support Co-ordinator

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Case Study: Sam is 19y.o with mild ID

- Lives with father who is a single parent and 3 younger siblings in private residence. Mother passed away suddenly after late diagnosis of cancer
- Attended support unit in mainstream school
- Grandparents provided additional support, father works full time

- Medical Background
  - Mild ID- post autoimmune encephalitis age 8
  - Epilepsy
  - ADHD
  - Cerebral Palsy GMFCS II
  - Spasticity

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Case Study: Sam is 19y.o with mild ID

- ADHD
- Sam was using medication in the school setting but not during holidays
- Transitioning to part time TAFE

- Epilepsy
- Sam was linked to adult services
- Discussed increasing his independence: webster pack, medi-alert , photo of medications

- Spasticity
- Last injection 5 years ago but reviewed yearly. In hand clinic/ spasticity clinic
- Adult service saw him once, discharged and referred him to NDIS OT

- Orthopaedic
- Yearly hip surveillance but not referred to adult ortho

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Issues discussed

Financial

- Sam was not on Disability Support Pension
  - At age 16 a child may be eligible for their own income support including Disability Support Pension (application can start 13 weeks before they turn 16)

  Before age 16 parents can start getting ready by
  - Setting up a bank account in their child's name
  - Getting a tax file number
  - Ensuring they have a copy of the birth certificate

- Carer allowance/ payment- new form required >16 years

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Issues discussed

Decision Making

- Sam is verbal and able to make decisions/ consent for himself with support
  - Father significant caring responsibility
  - Brothers young carer responsibility
  - Carer support discussed

- At age 18 NSW law presumes the person has capacity to make decisions unless they are assessed not to. This includes a person with ID.
- In most cases decisions can be made informally (person responsible) for someone who does not have 'capacity', and formal guardian/ power of attorney is not required

Guardianship application

- Required if there are restrictive practices required
- No person responsible available and person cannot safely make decisions for themselves, or informal carers disagree
- Private guardian or Public guardian

Guardianship Orders | NSW Government

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'Jack' 22 y.o

- Jack is 22y.o. with severe ID. He has a very short attention span and struggles with transitions of activities. He can be aggressive towards others when his needs are not met and has recently started refusing some of his preferred foods and hitting his head. His GP has not been able to examine him or perform blood testing. Although he has always had some Behaviours of Concern they are much worse at the moment.

- His parents will support him to attend the appointment but don't think he will stay in the consult room for very long. They will bring his iPAD, snacks and comfort items to keep him settled.

- Since transitioning from paediatrics he has no regular clinician, besides his GP

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‘Jack’

Jack has lost 3kg in 1month. He is not sleeping. He is not eating as much (but still drinking). He has hit his mother (causing bruising) as well as hitting his head against the wall causing a laceration. After previous traumatic hospital visits his parents want to try an avoid a hospital admission if possible.

There is no significant medical background.

His only medication is Risperidone 1mg BD.

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Preliminary Plan

- Health issues must be excluded first: Dental, Pain, Constipation, GIT

- Use of PRN medication to allow for:
  - Physical Examination
  - baseline bloods [FBC, EUC, Ca/Mg/PO4, LFT, Iron Studies, TFT, Vit D, Vit B12, HbA1C, fasting glucose/ lipids, H.Pylori, coeliac serology +/- genetics (if relevant/ consent available)]
  - radiology

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‘Jack’

- Constipation
- Extremely poor dentition with oral caries
- H.Pylori positive
- Possible GORD responded well to a PPI trial after eradication therapy: referred to Gastro
- Iron deficient
- Diabetes

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A word about Dental

- Tooth decay is almost 3x more common.
- Higher rates of extraction and decay leading to higher rates of missing teeth.
- Earlier and more extensive periodontal disease.
- Few specialised oral health services

AND

- *Dental needs often underestimated by caregivers/ clinicians*
- *Non verbal indicators of pain and perhaps altered threshold*

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Behaviours of Concern

A behaviour that:

1. Is a barrier to a person participating in, and contributing to their community
2. Directly or indirectly undermines a person's rights, dignity, or quality of life
3. Poses a risk to the health and safety of a person and those around them

Behaviours of concern are not a medical condition to treat. Instead, they indicate aspects of a person's life that are causing them distress. Behaviour as communication.

HELP Framework

- **Health** = Check for physical pain, illness, sensory loss or medication side effects
- **Environment** = Look at physical or social triggers that cause stress or escalation.
- **Lived Experiences** = Explore past or present trauma, life changes or attachment issues.
- **Psychiatric** = Consider mental health conditions only after ruling out other causes, ensuring safe use of medications.

https://ddprimarycare.surreyplace.ca/tools-2/mental-health/guide-to-understanding-behaviour/

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What do people with intellectual disability want from their health care provider?

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Accessing care for a patient with intellectual disability

https://vimeo.com/99300668?fl=pl&fe=sh#end=5m18s

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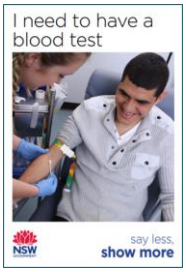
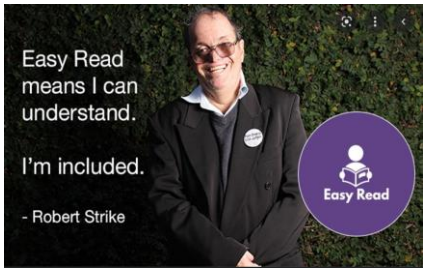
intellectual disability: a retrospective cohort study from New South Wales, Australia. BMJ Open, 16(2), e110184. https://doi.org/10.1136/bmjopen-2025-110184 [bmjopen.bmj.com]

What is Reasonable Adjustment?

Reasonable adjustments are **removing barriers** that people with an intellectual disability face, or **providing additional support** to enable them to **access the healthcare** they need.

'Within a health context reasonable adjustment requires services provided to people with disability to be inclusive, patient centred and accessible'.
Commonwealth Disability Discrimination Act 1992





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Environmental considerations

Reasonable Adjustments

Communication methods

Waiting space and consult location

Appointment timing

Involving support persons – including NDIS team

Consider sensory differences

Pre Appointment reminders

Leading with the persons interests

Image: Royal College of Nurses Institute (RCNi)
https://dm3omg1n1n7zx.cloudfront.net/rcni/static/journals/cnp/16/7/cnp.16.7.12.s17/graphic/cnp_v16_n7_17_0002.jpg

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Strategies to support communication

See resource slide

- Time – allow more time than usual for response
- Simple language – Easy Read, use pictures, break down big ideas, repeat new information
- Ask – how does the patient communicate? Level of understanding?
- Explain procedures – demonstrate with pictures or equipment, explain ahead of time, social story
- Monitor – changes that indicate experience of pain
- Observe – non-verbal cues, body language, lower intensity emotions
- Summary of recommendations

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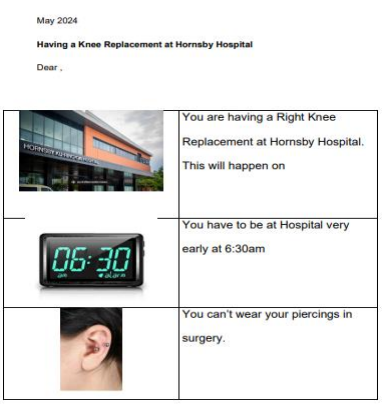
Easy Read

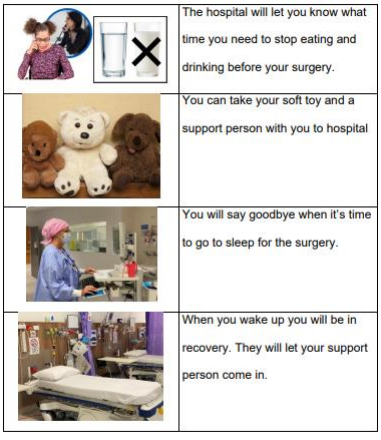


May 2024

Having a Knee Replacement at Hornsby Hospital

Dear ,

	You are having a Right Knee Replacement at Hornsby Hospital. This will happen on
	You have to be at Hospital very early at 6:30am
	You can't wear your piercings in surgery.



	The hospital will let you know what time you need to stop eating and drinking before your surgery.
	You can take your soft toy and a support person with you to hospital
	You will say goodbye when it's time to go to sleep for the surgery.
	When you wake up you will be in recovery. They will let your support person come in.

	You might feel strange when you wake up. There will be a bandage and a drain on your knee.
	You will move to the hospital ward.
	Your support workers can stay with you during the day on the ward. You can have your soft toys.

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Tips for assessment/procedures

Support plans	Environment	Communication	Response
• Behaviour Support plan • Top 5 • Hospital Plan • Ask caregiver what has worked best in the past • Asking the persons family, support workers or behaviour support specialist about what is usual for the person – usual skills, ways of expressing pain and usual mental state	• Quiet space • Allow the person to sit where comfortable • Move slowly, perform exams distal to proximal	• Set expectations at the beginning of consult if physical examination is planned or discuss at visit prior to visit for exam. • Communicate with person before each step of exam • Explain prior to examining – demonstrate on staff/caregiver • Avoid terms of endearment when addressing the patient. Use their name.	• Let the patient know you can see they are upset and will take a break form the examination • Include the family/carer/support person to help calm and settle • Allow time and personal space, allow or offer soothing strategies to deescalate • Pain may be a common trigger for behavioural escalation – investigate early on

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Resources

It's Doctor Time!

Inclusion Australia

Easy read option for health checks and resources

Social story template
Yearly health check easy read
A quick guide to CHAP
Video scripts for GPs
Conversation cards

Reasonable Adjustments Checklist for Health Professionals

A checklist for health professionals to use before, during and after a person with intellectual disability presents for a health appointment.

Use this checklist as a guide for reasonable adjustments you can make. Be mindful that adjustments will be different for each person.

Review this checklist and tick the box if you have offered or completed the change.

Before an appointment

Considered if any background information is known about the person

Reviewed this person's medical history before the appointment to identify potential reasonable adjustments and indications about how to enhance the person's decision-making capabilities.

Considered whether the person needs to take medication before coming to the procedure.

If medication is needed, confirmed if it is taken at home or at the clinic to avoid waiting time.

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Resources: Intellectual Disability Health

Council for Intellectual Disability

Home page - Council for Intellectual Disability

Easy Read guides (including contraception, medication, appointments, sexual health)
- My Relationships Matter - Council for Intellectual Disability
- My Hormones series (New!)

Tailorable Easy Read Health Letters

Appointment tools e.g. My Body My Choices Conversation Cards

My Health Matters folder - Council for Intellectual Disability

National Centre of Excellence in Intellectual Disability Health

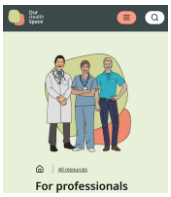
National Centre – Intellectual Disability Health

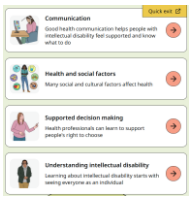
Intellectual Disability Health Capability Framework and education resources (webinars, podcasts, tools, etc)

Excellence in Practice: Voices for Better Care Podcast - care approaches

Website – Our Health Space - ID health topics

ID Clinicians network





Agency for Clinical Innovation – Intellectual Disability Network

The Essentials

Resources for Health Professionals

About Intellectual Disability – info sheet

Say Less Show More Easy Read Guides: Blood test, CT scan, Ultrasound/X-ray

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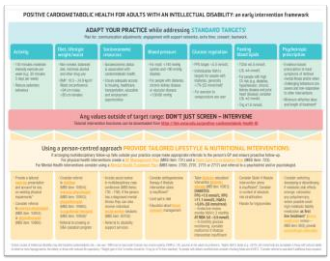
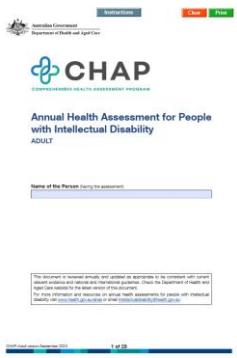
Prevention is better than cure





- Preventative Health care
- GP annual check-ups
  - Comprehensive health assessment program (CHAP)
  - Chronic Disease Management Plan
  - “My Health Matters Folder”
  - Age/ Condition appropriate check ups

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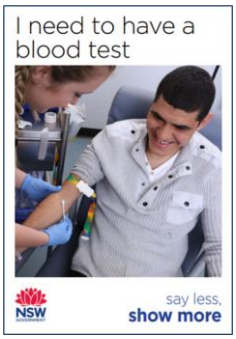
Desensitisation Process for visiting the doctor and pathology

Ms X is 23y.o.

- She has Autism Spectrum Disorder, Intellectual Disability-moderate severity and communicates verbally and with key word sign.
- Multiple previous traumatic health care experiences in childhood.
- Won't allow physical examination.
- Needs routine pathology and immunisation



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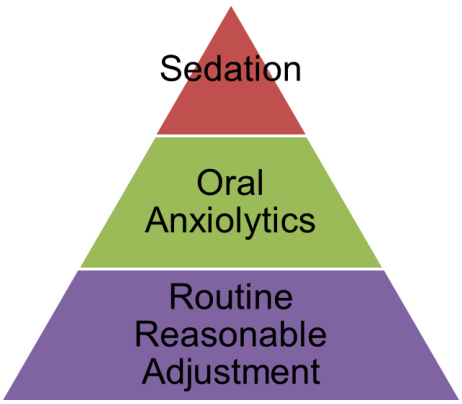
Tiered Approach



- Building Familiarisation with the location
- Building rapport
- Building on positive encounters
- Play based role playing
- Building on Success

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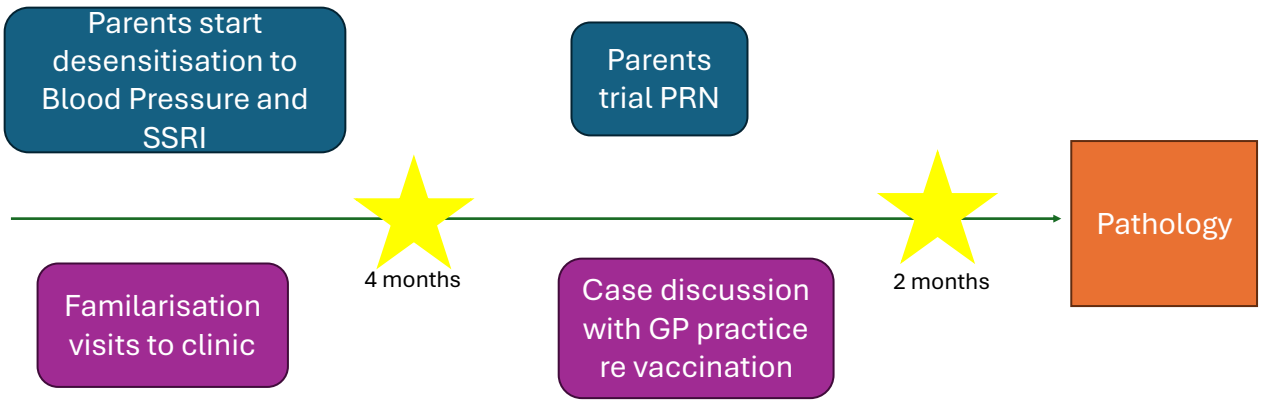
Ms X needs a health check, immunisation and pathology



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Case Study:
Ageing and Intellectual Disability

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Ms S: Referred for review of decline in function, cognition and mood

- **Baseline**: 40y.o
  Outgoing, independent woman working 3 days a week living semi-independently
- **Background**: 3/12 rapid decline across all functional domains
  - Unable to perform self-care activities
  - Unable to follow instructions
  - Flat mood, teary
  - Associated physical symptoms: headaches, dizziness

- PMHx: **Down Syndrome,** Anxiety, Bilateral cataracts, Sensorineural hearing loss

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Ix to date

- Baseline Bloods: Normal
- CT Brain: No acute intracranial pathology, interval cerebral volume loss and interval chronic infarcts since previous scan.
- Psychiatry review
- Neurology review

- DX: **Alzheimers Dementia**, Migraine, Anxiety, Menopause

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Diagnostic work-up

- On review: Repeat Imaging, Pathology, Sleep Study referral
- Brain MRI with PRN Diazepam: Evidence of further ischaemic events
- Urgent Referral to Stroke Clinic
  - Lupus Anticoagulant Positive
- Moderate OSA

Stroke NOT Dementia

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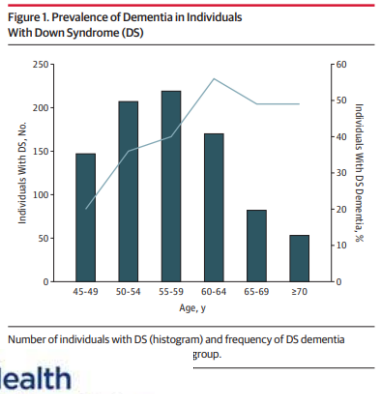
Dementia and the DS-ID Population



JAMA Neurology | Original Investigation

Prevalence of Aging, Dementia, and Multimorbidity in Older Adults With Down Syndrome

Eleonore Bayen, MD, PhD; Katherine L. Possin, PhD; Yingjia Chen, PhD; Laurent Cleret de Langavant, MD, PhD; Kristine Yaffe, MD

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Additional Considerations: Ageing and ID

- Younger onset of age-related health conditions
- Diagnostic Overshadowing i.e behaviours
- Challenges undertaking preventative health screening
  - Mammogram/ Cervical Screening
  - Bowel cancer/ FOBT
  - Bone Density
  - Routine pathology
- Long-term effects of medications (i.e psychotropic)
- Communication challenges
- Carer strain/ burn-out
- Decision making

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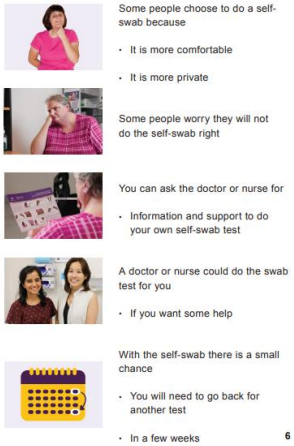
Easy Read



Excerpt from *The Cervical Screening Test*

Easy Read Resources - National Cervical Screening Program

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Immunisation Status

- Identify catch up and examine potential barriers to immunisations

Additional beyond schedule
Hep B primary series recommended for at risk - day program/group home.
- Born before 2000 has not been vaccinated
- Serology necessary if they are living in group home with someone positive.

Meningococcal B

Covid
- 18 -64 years - primary dose only
- Covid vaccination for over 65s every 12 months, over 75s every 6 months

Flu annually

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Genetic Testing

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Carer Gateway

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Disability Gateway

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Resources: Sexual health and relationships

Reproductive and Sexual Health Australia
In The Know
- Resources for people with disability about sexuality and sexual health, including topics like masturbation and sex work

Family Planning NSW
- Easy English Disability Page | Family Planning NSW
- Social stories | Family Planning NSW

Sexual Health Victoria
- Easy Read resources

Play Safe Pro
- Sexual Health Promotion with young people with disability
- Sexuality and Sexual Health Education for Students with Intellectual Disability

SECCA
Resources:
- Easy read guides, brochures, videos
- Relationships, sexuality, health, gender diversity, consent, and rights for people with disability

Booklet – Sexuality, Relationships and your rights
- PDF or order a physical copy

Feel Safe – SECCA - accessible, interactive and multi-media resource that explores Protective Behaviours concepts

Glossary – big words explained

SECCA APP - App with tiles and learning plans (see Manual)

Safer Me Safer You
National project to increase social and sexual safety of women, girls and gender diverse people with disability.
- Resource Library
- Extending the reach of existing SoSAFE! Programs

Planet Puberty
Resource hub – Planet Puberty
All about puberty for young people with Intellectual Disability and Autism

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Resources: parenting with Intellectual Disability

Intellectual Disability Rights Service
- Ability Rights Centre
- The Parents Project
- Resource sheet: Introduction to Intellectual Disability

The Bumpy Road – navigating child protection system
- Website/resources: made by and for parents with intellectual disability

Emerging Minds
- Podcast (27 mins): Improving the rights of parents with intellectual disability
- Podcast (35 mins): Parenting with a disability and responding to stigma

Australian Institute of Family Studies
- Webinar: How to support parents with intellectual disability to meet their parenting goals
- Snapshot (1 page handout): supporting parents with intellectual disability
- Article: Practices that support parenting by parents with intellectual disability

raisingchildren.net.au
the australian parenting website

Raising Children Network

Easy English Booklet: How your baby develops from 0 to 1 month

Browse additional Easy English Guides by Raising Children Network

See also – Videos re pregnancy & birth (not easy read, but may be appropriate for some parents).

Online resource: Parents with intellectual disability – support for parenting (Easy English version available)

NDIS resources for parents with ID

How your baby develops from 0 to 1 month

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Contact

NSLHD Specialist Intellectual Disability Health Service

RNS Community Health Centre, 2C Herbert St. St Leonards NSW

Clinic-Ground Floor, Offices-Level 5

Ph: 02 9926 5777

NSLHD-IntellectualDisability@health.nsw.gov.au

Referrals via Healthlink

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Questions

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