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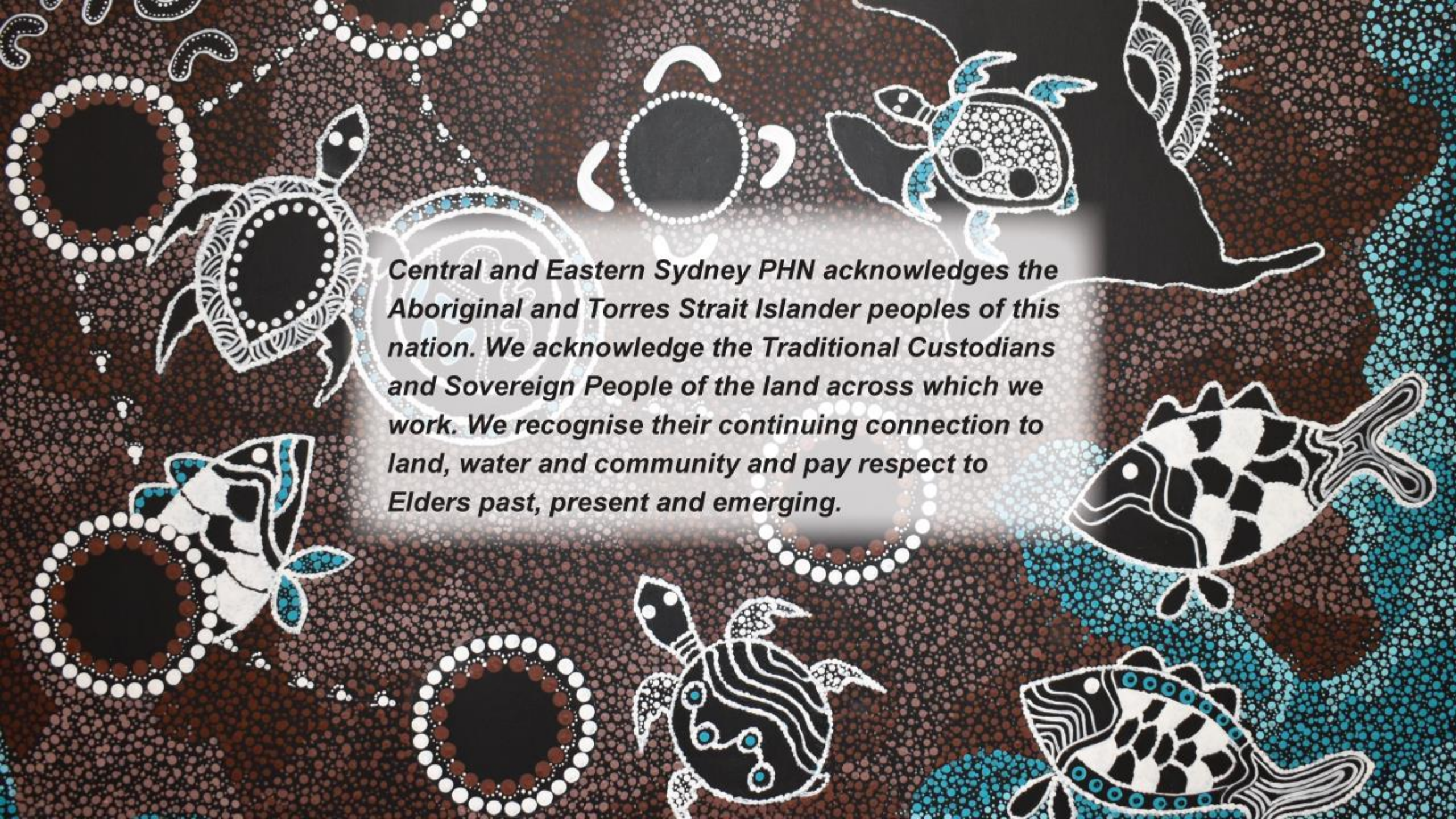
Together We're Better - Training Workshop

Working together to improve health outcomes for people with intellectual disability

2nd June 2025


Central and Eastern Sydney PHN acknowledges the Aboriginal and Torres Strait Islander peoples of this nation. We acknowledge the Traditional Custodians and Sovereign People of the land across which we work. We recognise their continuing connection to land, water and community and pay respect to Elders past, present and emerging.

Housekeeping

- Please ensure your phone is switched off or on silent
- Bathrooms are located outside the training rooms
- In the event of an emergency, please follow CESPHN staff instructions
- Sign on sheet
- Introductions

CESPHN and Project GROW

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GROW
Supporting people with intellectual disability

Session Plan & Learning Outcomes:

Session 1	• Health issues experienced by people with intellectual disability in Australia • Increase understanding of preventive health for people with intellectual disability • Understand the Roles and responsibilities of the support team	*9.30*
	Morning tea	*10:45*
Session 2	• Learn what reasonable adjustment means and develop a one- page health profile to include this information • Case Study Activity: Create a one-page health profile based on a provided scenario • The Annual Health Assessment Process	*11:00*
	Lunch and networking	*1:00*
Session 3	• Learn about the Intellectual Disability Health Service with Gavin Begbie • Engage in a session with Dr. Jess Murphy to learn how to work collaboratively with GPs and GP practices • Better understand GP appointment types	*1:30*
	Afternoon tea	*2:15*
Session 4	• Explore approaches to palliative and end of life care with Maria Heaton • Panel Discussion: Q&A	*2:25*

Compared to the general population, People with intellectual disability experience

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more than twice the rate of avoidable deaths;

twice the rate of emergency department and hospital admissions;

substantially higher rates of physical and mental health conditions; and

significantly lower rates of preventative healthcare.

What we know about People with intellectual disability

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- More likely to be overweight or obese
- Consume diets higher in fat and sugar (fast food!)
- Don’t get enough exercise
- Are more likely to have substantial oral health problems
- Likely to have multiple health issues
- Take multiple medication
- Higher rates of mental health issues

Chronic diseases that people with disability commonly experience

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DIABETES

HEART DISEASE

LUNG DISEASES

TOOTH/GUM DISEASE

HIGH BLOOD PRESSURE

GASTRO-INTESTINAL CONDITIONS

MENTAL ILLNESS

Activity

Review the list of specific health issues provided and pick out the health issues that the people you support experience.

Take 5 minutes to discuss with your group, collate your responses and place on the whiteboard.

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What is preventive health?

Preventive Health

Looking after our body and mind by eating well, being active, getting vaccinated and avoiding risky behaviours – like smoking or drinking too much – can prevent many diseases and keep us healthy and well.

We work to enable healthy living through supportive environments.

https://www.health.gov.au/topics/preventive-health/about

It’s what we do each day to stay healthy and well and reduce the risk of illness

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We exercise, eat a healthy diet, we drink less, stop smoking

We have regular health check with our GP and screening when needed

We have our vaccinations

We take medication for identified health issues

We look after our mental health

Preventative Health Screening

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- **Cancer Screening:** Breast, cervical, bowel (with accommodations).
- **Cardiovascular Health:** Blood pressure, cholesterol, and diabetes screening.
- **Immunizations:** Routine vaccinations (influenza, etc.).
- **Vision & Hearing Tests:** Regular checks.
- **Dental Check-ups:** Preventative dental care.
- **Mental Health Checks:** Assessment for depression and anxiety

Preventative healthcare for people with intellectual disability

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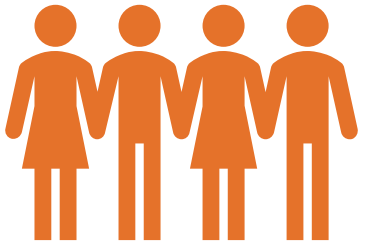
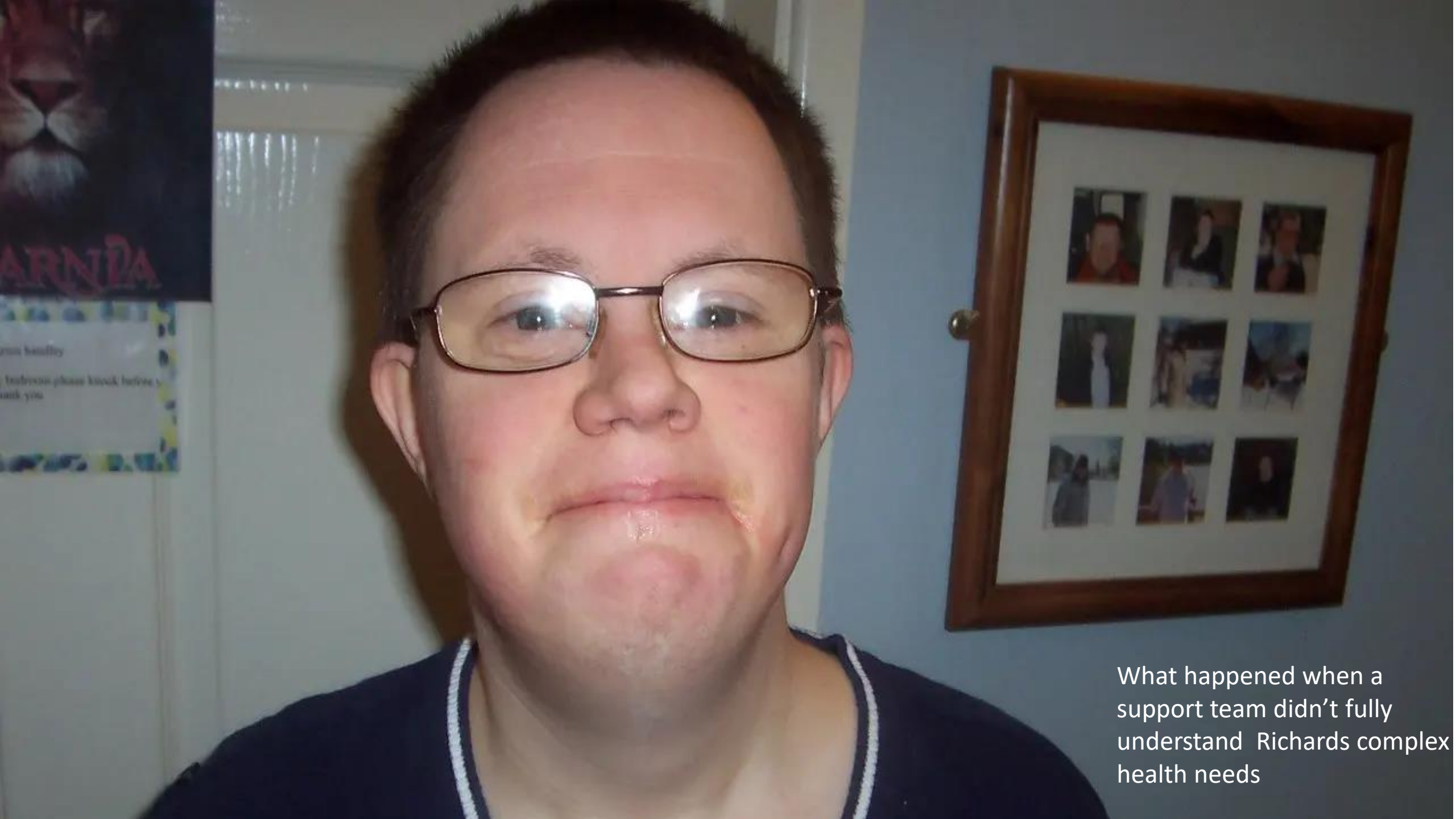


How do you know if the people you support have access to

Preventative Health Screening?



What happened when a support team didn’t fully understand Richards complex health needs

First ever scoping review of causes and contributors to deaths of people with disability in Australia

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Lead by:

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NDIS Quality and Safeguards Commission

UNSW SYDNEY

3DN DEPARTMENT OF DEVELOPMENTAL DISABILITY NEUROPSYCHIATRY

Risk and vulnerabilities of people who died

Mental Health Concerns: Depression, self-harming behaviours and anxiety

Physical health problems: Dental problems, epilepsy, constipation, urinary incontinence and Gastro Oesophageal Reflux Disease (GORD).

Swallowing & mealtime support: People who died experienced issues that may have impacted how and/or what they ate. For example: missing teeth and other dental problems, swallowing problems related to GORD, medications and disease processes

High Rates of polypharmacy were noted: Psychotropic medications were commonly prescribed to people with disability who had died, <u>often in the absence of a diagnosed mental illness</u>

Mobility &Communication: People with limited communication/mobility support

Weight, exercise and lifestyle risks: Over ½ the people who died were outside the healthy weight range

NDIS Practice Alerts

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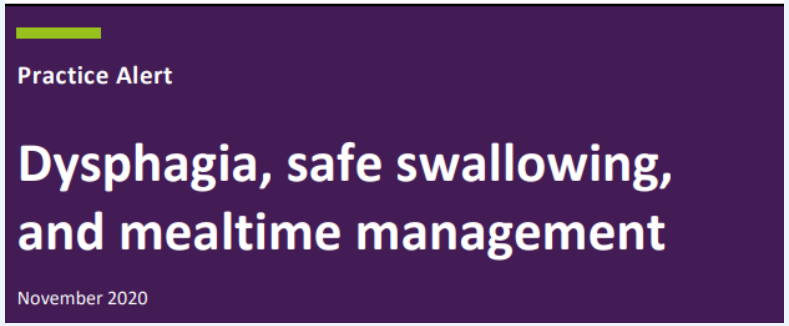

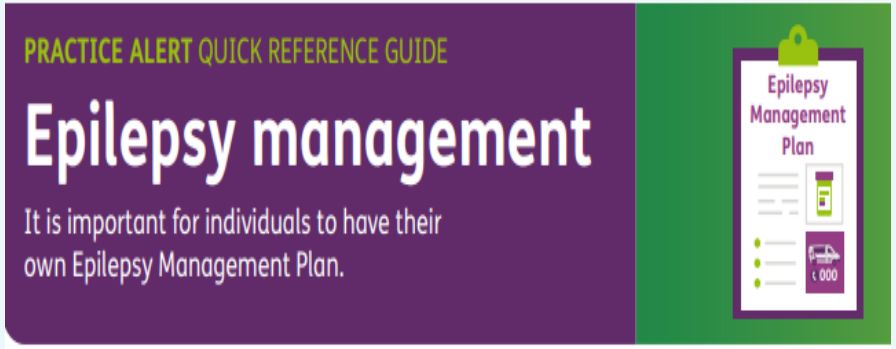

NDIS Practice Alerts
quick reference guides

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PRACTICE ALERT QUICK REFERENCE GUIDE

Polypharmacy

Polypharmacy is taking multiple medications at the same time for one or many conditions.

What medications does polypharmacy include?

It includes prescription medicines, over-the-counter medicines and complementary medicines.

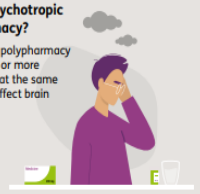
Who does polypharmacy affect?

Polypharmacy is more common among people with disability, as they are more likely to have multiple health conditions.

- Epilepsy
- Stroke
- Arthritis
- High blood pressure
- Heart problems
- Diabetes
- Mental health conditions

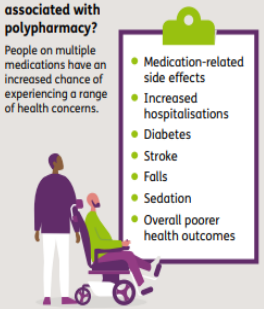
What is psychotropic polypharmacy?

Psychotropic polypharmacy is taking two or more medications at the same time which affect brain function.



What are the risks associated with polypharmacy?

People on multiple medications have an increased chance of experiencing a range of health concerns.



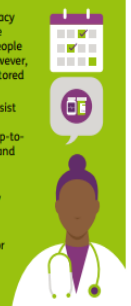
- Medication-related side effects
- Increased hospitalisations
- Diabetes
- Stroke
- Falls
- Sedation
- Overall poorer health outcomes

What is the treatment?

Despite the risks, polypharmacy may be the most appropriate treatment, particularly for people with multiple conditions. However, it needs to be carefully monitored and reviewed regularly.

NDIS support workers can assist participants with arranging appointments and keeping up-to-date lists of all medications and review dates.

- review medications with a doctor every 3-6 months by appointment
- review medications with a pharmacist every 2 years (or earlier) through the Home Medicines Review program.



Find out more
For full details on this practice alert and the obligations for NDIS support workers, and access to other training and resources, please visit **ndiscommission.gov.au/workerresources**

NDIS Quality and Safeguards Commission

PRACTICE ALERT QUICK REFERENCE GUIDE

Lifestyle risk factors

Lifestyle risk factors are ways in which people live that can be harmful to their health.

What types of lifestyle risks factors are there?

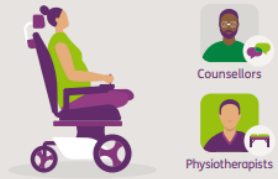
People with disability are more likely to have poor physical and mental health and can be a direct effect or made worse by lifestyle risk factors. Lifestyle risk factors include: poor nutrition, lack of exercise, smoking, stress, loneliness and isolation.

How can risk factors be reduced?

Lifestyle risk factors can be reduced by eating healthier food, increasing exercise and connection with others, maintaining a healthy weight, reducing stress, alcohol consumption and stopping smoking.

What other services can assist?

Providers can support participants to access other services that can help them with lifestyle changes. For example: dietitians, counsellors, physiotherapists.



Ongoing support

Providers should always support participants to make informed choices and encourage them to live a healthy life.

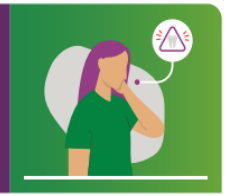
Find out more
For full details on this practice alert and the obligations for NDIS support workers, and access to other training and resources, please visit **ndiscommission.gov.au/workerresources**

NDIS Quality and Safeguards Commission

PRACTICE ALERT QUICK REFERENCE GUIDE

Oral health

People with disability are at a higher risk of poor oral (or dental) health and more likely to develop conditions such as gum disease, tooth decay, loss of teeth and related illnesses.



Is oral health important?

Diseases of the mouth can affect the health of the whole body and can have a negative effect on wellbeing and quality of life.

What if oral health is ignored?

If oral diseases are not treated, it can also lead to difficulty eating certain foods, severe pain or illness, and even hospitalisation.

What does good oral health look like?

Good oral health includes twice daily brushing, using a fluoride toothpaste, and flossing teeth and gums. Good nutrition, yearly dental check-ups, and treatment, if required, is also important.

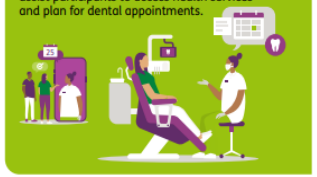
- Twice daily brushing
- Fluoride toothpaste
- Dental floss
- Good nutrition
- Annual dental check-ups

Monitoring and support

Participants should be supported to look after their teeth and gums. This might include asking them about their mouth and if they have any worries or pain.

Ongoing care

Providers are required to monitor participants' health, safety and wellbeing and support them in maintaining their health. Providers can also assist participants to access health services and plan for dental appointments.



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https://www.ndiscommission.gov.au/workerresources

Two New Practice Alerts Launched. I will talk about these later

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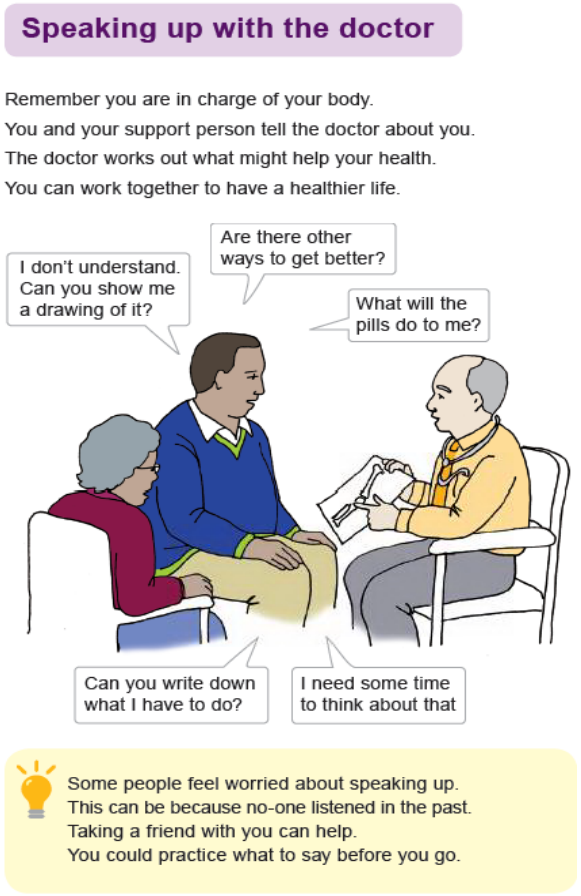
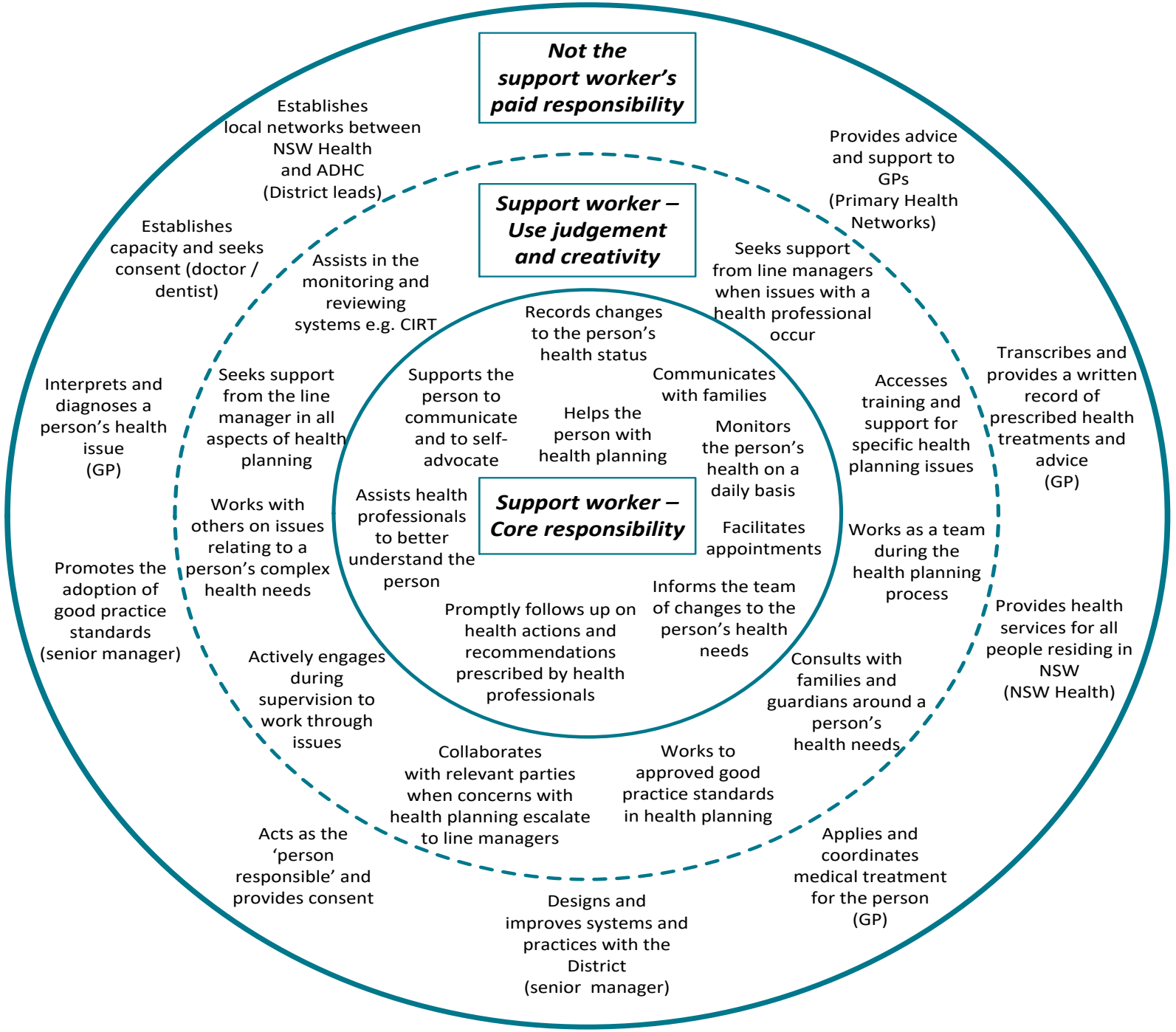
Role of Support team



"The provision of high-quality health care to people with disabilities requires effective, respectful three-way collaboration between the person concerned, carers (those supporting the person - usually Disability Support Workers and/or family members) and healthcare professionals"

Recommendations from the Health Matters A submission to the Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability


Not the support worker's paid responsibility
Establishes local networks between NSW Health and ADHC (District leads)
Provides advice and support to GPs (Primary Health Networks)
Support worker – Use judgement and creativity
Establishes capacity and seeks consent (doctor / dentist)
Assists in the monitoring and reviewing systems e.g. CIRT
Seeks support from line managers when issues with a health professional occur
Records changes to the person's health status
Interprets and diagnoses a person's health issue (GP)
Seeks support from the line manager in all aspects of health planning
Supports the person to communicate and to self-advocate
Communicates with families
Helps the person with health planning
Monitors the person's health on a daily basis
Accesses training and support for specific health planning issues
Transcribes and provides a written record of prescribed health treatments and advice (GP)
Support worker – Core responsibility
Assists health professionals to better understand the person
Facilitates appointments
Works with others on issues relating to a person's complex health needs
Works as a team during the health planning process
Promotes the adoption of good practice standards (senior manager)
Informs the team of changes to the person's health needs
Promptly follows up on health actions and recommendations prescribed by health professionals
Provides health services for all people residing in NSW (NSW Health)
Actively engages during supervision to work through issues
Consults with families and guardians around a person's health needs
Collaborates with relevant parties when concerns with health planning escalate to line managers
Works to approved good practice standards in health planning
Acts as the 'person responsible' and provides consent
Applies and coordinates medical treatment for the person (GP)
Designs and improves systems and practices with the District (senior manager)

Role of disability support team

- **Understand** the person and their specific support needs
- **Prepare** the person for their Annual Health Assessment.
- **Inform** the GP practice about the person's support needs and if reasonable adjustments are necessary.
- **Update** the person's health plan following the Annual Health Assessment, and ensure the disability support team understands the goals and actions agreed on by the GP and the person
- **Monitor** the person's health, record and report any changes to the team,
- **Know** what to do in a medical emergency

Role of GP and GP Practice

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- **Understand** the preventable causes of death of people living in care and take necessary action to prevent these issues.
- **Know** the person, understand their disability and the specific health conditions related to that disability.
- **Make** any reasonable adjustments necessary to facilitate medical appointments and interventions.
- **Conduct** Annual Health Assessments - diagnose, prescribe, and coordinate treatment for health issues.
- **Refer** to specialists as needed and ensure clarity around who is responsible for making appointments and following-up actions.
- **Understand** the role of the person's support team in healthcare planning

How to work together

- **Develop** a shared understanding of the person's health and support needs
- **Appreciate** each other's knowledge and skills, and the shared responsibility for optimising the person's health and well-being
- **Support** the person to participate as fully as possible during their appointment
- **Seek** to understand the challenges people with disability experience in the health system and work together to improve health outcomes
- **Develop** good relationships with all those concerned with the persons health

ROLES AND RESPONSIBILITIES

Disability Support Team

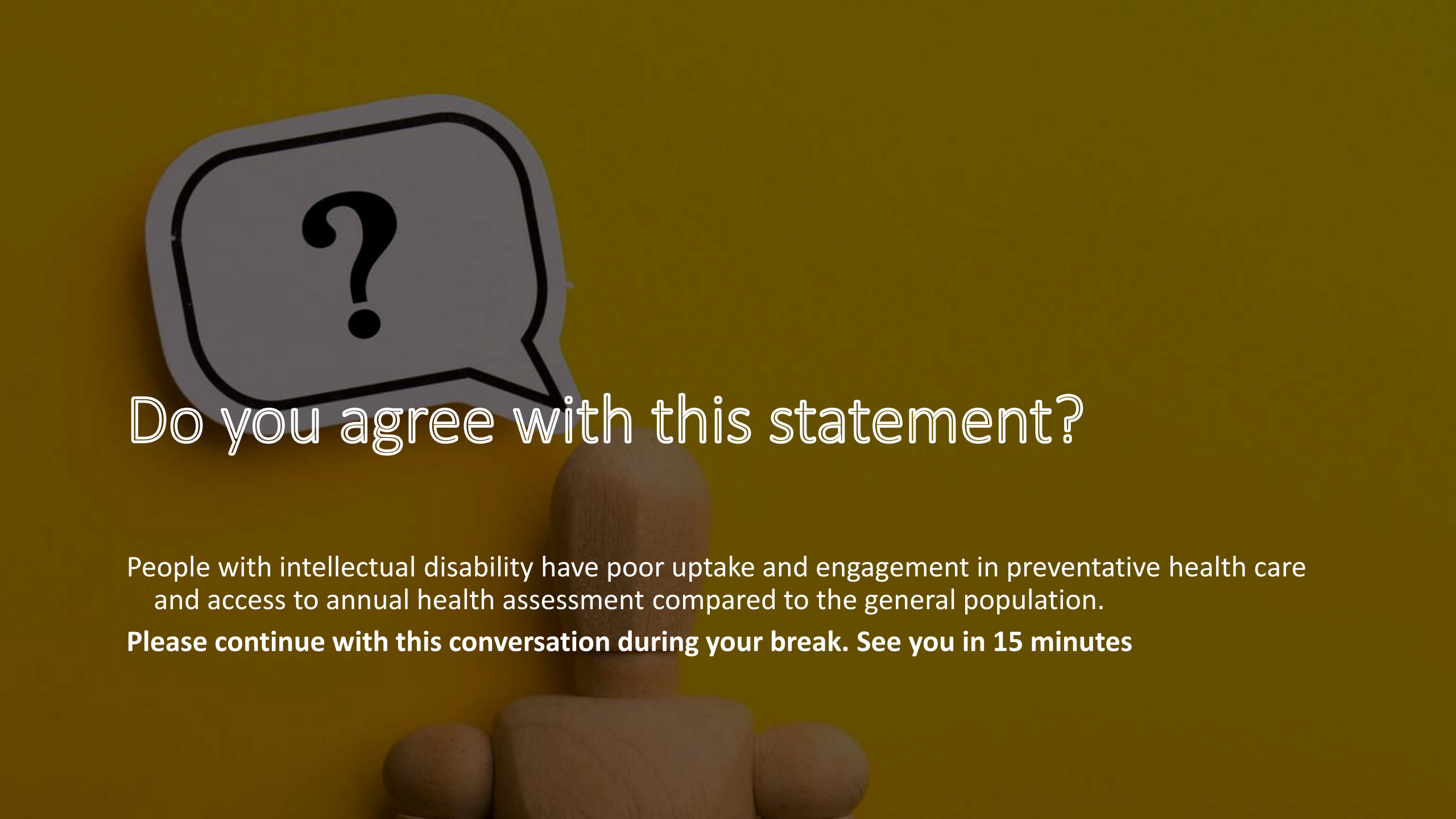
- Only send individuals to appointments with a support person who knows them well, including their specific health, support, and communication needs.
- Update an individual's health plan with new goals and actions after each GP appointment and communicate these updates to all relevant parties.
- Follow through on referrals and medical advice in a timely manner.
- Monitor an individual's health and record and report any changes to the team, family/guardian, and GP.
- Inform the GP practice about an individual's support and adjustment needs prior to all appointments.
- Prepare an individual for appointments by helping them understand why they are going and identify the supports needed throughout the process.
- Know how to support an individual in a medical emergency.

Role of GP and Practice

- Understand an individual, their disability, specific health conditions related to their disability, and healthcare needs.
- Understand the high-risk health factors for people living with intellectual disability and take necessary action to prevent these issues from occurring.
- Put in the effort to understand and implement specific support needs to improve medical appointments, correspondence, and communication.
- Understand the support team's role in healthcare planning for the individual.
- Refer to specialists as needed. Clearly assign responsibility for following up on post-appointment actions.
- Conduct Annual Health Assessments, diagnose, prescribe, and coordinate treatment for health issues, and provide guidance on medical conditions and preventative health interventions.

GP and Disability Support Team

- Respect each other's knowledge and skills and acknowledge the shared responsibility for optimising an individual's health and well-being.
- Develop communication channels that support information sharing.
- Work together to provide the support/ adjustments for an individual to attend and participate during their appointments.
- Facilitate access to quality health care for individuals with intellectual disability.



Do you agree with this statement?

People with intellectual disability have poor uptake and engagement in preventative health care and access to annual health assessment compared to the general population.

Please continue with this conversation during your break. See you in 15 minutes

Break

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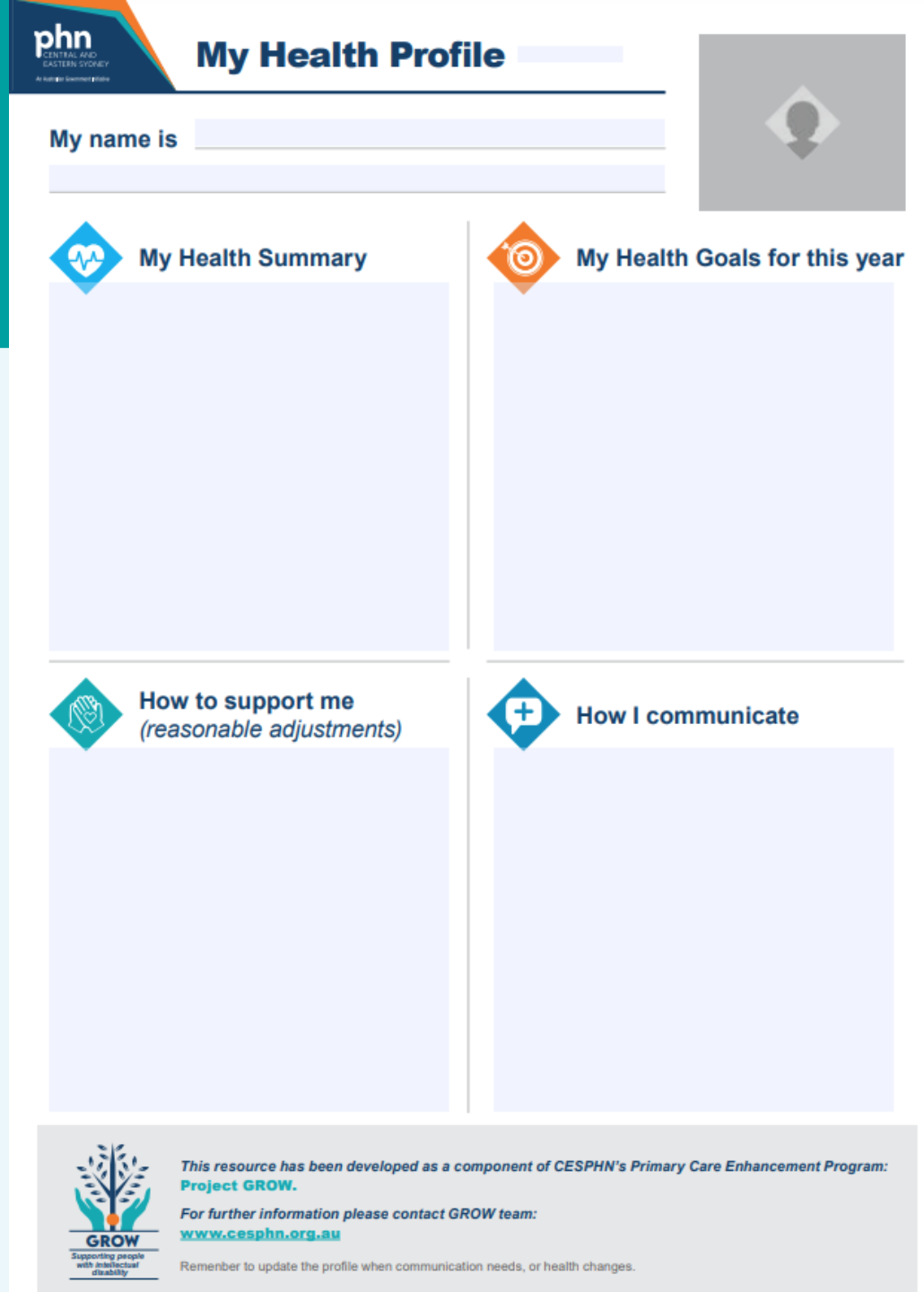
What is My Health Profile?
What are Reasonable Adjustments?

My Health Profile

- 1 Page Health profile that is developed between week 2-3 of the planning.
- It is summary of the person's health issues, newly identified health concerns, health goals
- It includes information about how best to support the person before, during and after their appointment(reasonable adjustments)
- How the person communicates
- It is sent to the GP practice before the appointment



Reasonable Adjustments

Time – take time to get to know the individual.

Environment – alter the environment e.g. physical access, sensory access.

Attitude – have a positive solution orientated focus.

Communication –What's the best way to communicate with the individual, how do they communicate. How do you communicate this to others.

Help – what assistance does the individual need and how can you support them best.

Reasonable Adjustments

Other adjustments:

- Work with parents or carers - consulting the people who know the individual best to figure out what accommodations the individual needs. For example: When A is triggered by X, Y calms the individual down.
- Team communication - It helps individuals to have all staff across reasonable adjustments.
- Systems and processes.

My Health Profile

SAMPLE

- My health profile- this includes reasonable adjustments person may need.
- What do you think might be your role in conveying reasonable adjustments.

My Health Profile

My name is Margaret Brown

My Health Summary

Summary of my health issues:
Type 2 diabetes
Complex PTSD
GORD
Chronic Paranoid psychosis
Osteoarthritis
R hip replacement
Lower back pain
Reduced mobility.
Stroke
Constipation
Vit D deficiency

My Health Goals for this year

My health goals for the year:

This year I would like to:

Loose 10kgs so I can feel good.
Eat a healthy diet so my diabetes doesn't play up.
Have more physiotherapy so I can walk better and stop falling.
Get and OT assessment so I can get a recliner chair to help my mobility.
Have my vitamin D levels checked.
Have my eyes tested- I used to wear glasses.

How to support me *(reasonable adjustments)*

How best to support me during my health appointments (reasonable adjustments):

I can get anxious if I need to have bloods taken so please discuss this with me and my support team as I may need to have a calming tablet.
Please reassure me that everything will be ok as I worry sometimes, and this can make me very anxious.
Please explain to me what my appointment is for and ask me to repeat what you said so you know that I understand.
Please speak to me first before talking to my

How I communicate

How I communicate when I am sick, in pain, unwell, or feeling a bit down:

I can usually tell people when I am unwell or in pain.
Sometimes I get a bit upset (when they are tormenting me) so you might need to ask me a few times how I'm feeling as I get a bit confused.
It is good to ask the staff who know me well to also tell you what is going on with me.

This resource has been developed as a component of CESPHN's Primary Care Enhancement Program: Project GROW.

For further information please contact GROW team:
www.cesphn.org.au

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SGH Disability Inclusion Committee

- Patient Story -

My Health Profile

My name is

My Health Summary

My Health Goals for this year

How to support me
(reasonable adjustments)

How I communicate

GROW
Supporting people with intellectual disability

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www.cesphn.org.au

Remember to update the profile when communication needs, or health changes.

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Background…

- 59yo person living in supported accommodation:
  - » Moderate-severe ID
  - » Major depressive disorder
  - » Anxiety
- Difficult engagement due to behaviours
  - » Biting, banging, throwing items in reach
- Required colonoscopy

NSW GOVERNMENT

Pre-planning…

- Received hospital care plan from the group home which included My Health Profile
  - Included communication style, care requirements, behaviours, personal preferences
- Admission 2 Discharge Together (A2DT) tool completed, identified:
  - At risk of displaying challenging behaviours
  - Diversion and reassurance required
  - Limited, repetitive verbal communication
- Stakeholder meeting to prepare for admission, including reps from all disciplines and group home
- Devised care plan of patient needs and resources required

NSW GOVERNMENT

On the day…

- Psychiatrist prescribed Clonidine – given before coming in for procedure
- Used a car park out the back of the hospital for a less stimulating environment
- Patient was more comfortable being around males
- 2 x males greeted patient with a coffee and toys to celebrate her recent birthday and to remove the anxiety of being in an unfamiliar environment.
- Transported up to 3 South using uncrowded access
- Set her room up for her birthday including more toys/games
- Arranged carer comforts including recliner chair, hospital meals
- MDT arranged a change in theatre time, pt placed first on the list

NSW GOVERNMENT

Lessons…

- Getting to know her likes, dislikes and fears helped a successful admission and discharge
- MDT approach– not doing it in silos
- Thinking outside the square – be creative i.e. entrance into hospital
- Discharged straight from recovery = shorter admission due to good pre-planning
- Having pre-admission staff flag early gave time to plan

NSW GOVERNMENT

How Someone with an Intellectual Disability May Present When Experiencing a Mental Health Problem

- Recognising the Signs and Supporting Early Intervention

Common Mental Health Issues & Barriers

- **Key Points:**
- People with ID have higher rates of:
  - Anxiety
  - Depression
  - Psychosis
  - PTSD
  - OCD
- **Barriers to recognition:**
  - Diagnostic overshadowing (attributing symptoms to ID)
  - Limited self-reporting
  - Misinterpreted behaviours
  - Limited social supports/isolation

Signs to Look For

Behavioural:

- Aggression, self-injury, withdrawal, sleep/appetite changes, sexualised behaviours

Emotional:

- Tearfulness, irritability, fearfulness, mood swings

Cognitive/Communication:

- Confusion, regression, increased repetition, talking to self

Physical:

- Headaches, fatigue, nausea without clear medical cause

Responding to Concerns

- Be proactive!
- Observe and document changes clearly
- Communicate with family/carers
- Seek specialist input (GP, psychiatry, psychology, OT, BSP)
- Support communication needs
- Develop a safety plan if risk is identified

Risk Indicators & Importance of Baseline

Serious Signs:

- Expressions of hopelessness, suicidal thoughts, severe withdrawal
- Escalation in aggressive/self-harm behaviours

Baseline Knowledge:

- Know what's *normal* for the individual
- Small changes can be significant

Behaviours of Concern vs Mental Health Disorders

- Behaviours of concern do **not always** indicate a mental health disorder.
- Changes in behaviour may be due to **environmental**, **physical health**, **communication difficulties**, or **sensory factors**.
- A **functional and behavioural assessment** must be completed to explore the cause of behaviours.
- Understanding an individual's **baseline functioning** is essential to accurately identify changes that might suggest mental health issues.

What is an Annual Health Assessment

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The health assessment is the primary source of health information the GP uses to guide the person and their support team on person's health goals for the year. The annual health assessment aim:

- **Gather** information about the person's current and long-term health needs
- **Identify** health risks/ record diagnoses
- **Record** actions and treatment to manage current and chronic health conditions
- **Monitor** a person's medication
- **Discuss** preventative health care actions (e.g. diet plan, vaccines, screening)
- **Develop** an annual healthcare plan in consultation with the person and their support team
- **Provide** a financial incentive to the GP with its completion.

Annual Health Assessments

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Group discussion with Dr. Jess Murphy

What are the current issues/challenges/barriers with annual health assessment process for the people you support?

Annual Health Assessments Tools

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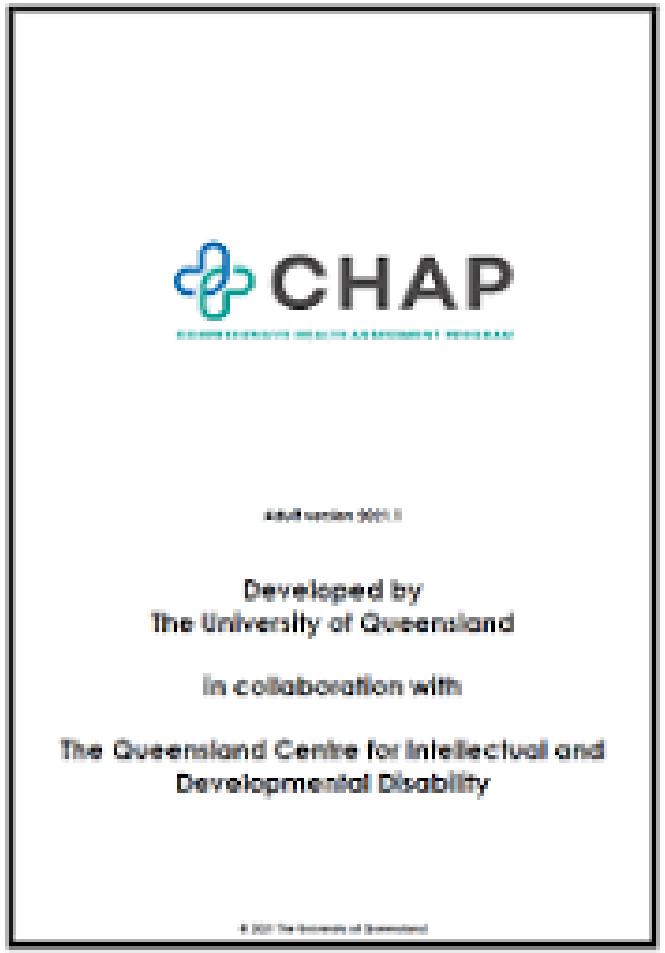
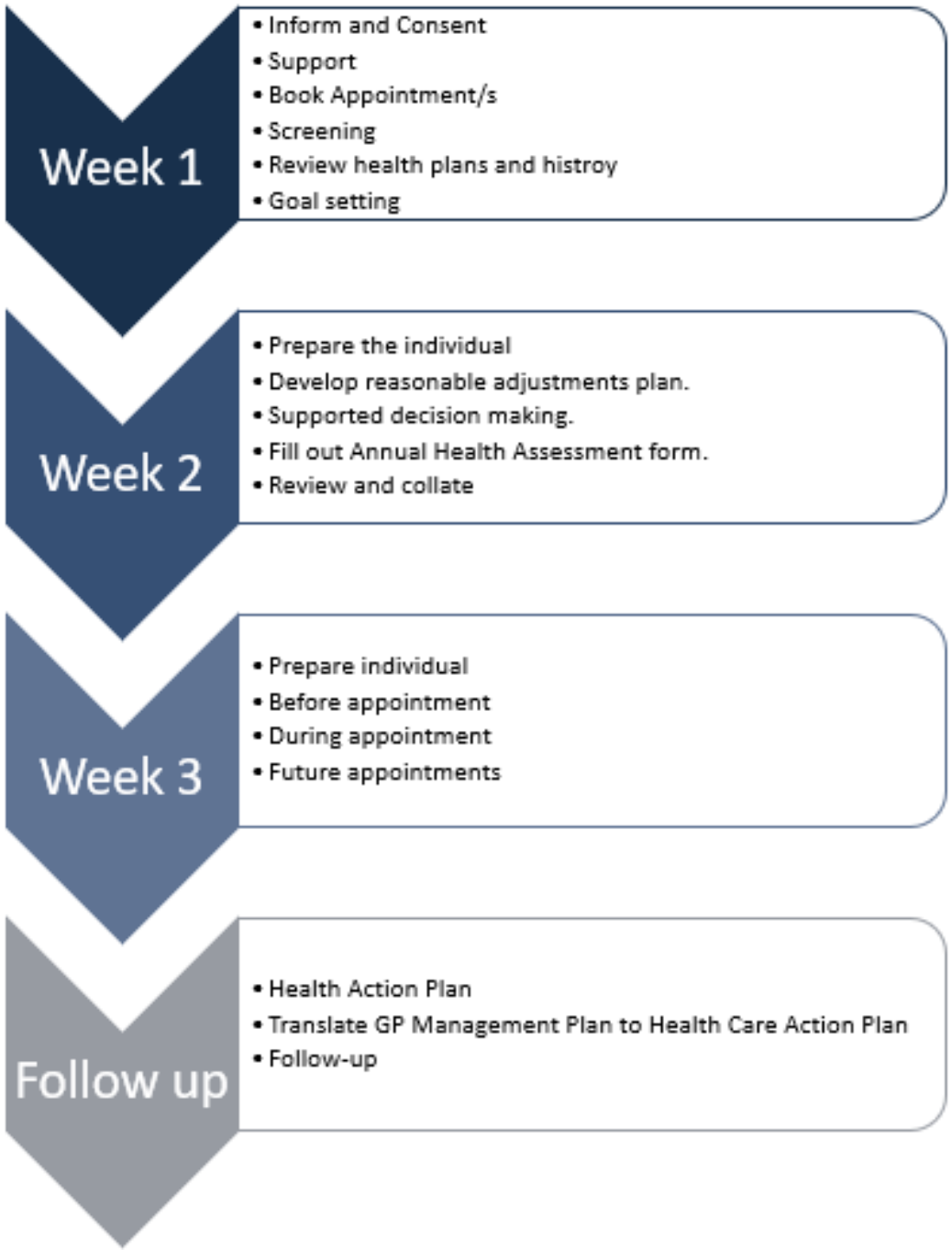
- CHAP Tool
- Medicare Department of Health Annual Health Assessment
- GPs or SIL providers may have developed their own templates

Are you keen to better understand

Annual Health Assessments



Introducing the Annual Health Assessment Process



Annual Health Process

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Week 1

- Inform and Consent
- Support
- Book Appointment/s
- Screening
- Review health plans and history
- Goal setting

Annual Health Process

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Week 2

- Prepare the individual
- Develop reasonable adjustments plan.
- Supported decision making.
- Fill out Annual Health Assessment form.
- Review and collate

Annual Health Process

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Week 3

- Prepare individual
- Before appointment
- During appointment
- Future appointments

Annual Health Process

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Follow up

- Health Action Plan
- Translate GP Management Plan to Health Care Action Plan
- Follow-up

NDIS Practice Alert for health assessments

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PRACTICE ALERT QUICK REFERENCE GUIDE

Comprehensive health assessments

Helping to monitor the health of people with disability can reduce the risk of poor health, chronic disease and premature death from potentially preventable causes.

How health assessments reduce risk

Increased health risks occur for a range of reasons. Some people with disability have difficulty accessing health care services and this puts them at greater risk.

A regular comprehensive health assessment helps identify health issues early.

How to support participants

Arranging for participants to have an annual comprehensive health assessment with a GP can help prevent health risks through:

- early identification of changes in a participant's health and wellbeing
- ensuring participants are supported to promptly access a GP when unwell
- being proactive with chronic illness.

Early detection

Prompt access to a GP

Proactive management

How to provide ongoing support

Providers are required to support participant health, safety and wellbeing by assisting with access to appropriate health services. This can include arranging annual comprehensive health assessments and developing a health care plan.

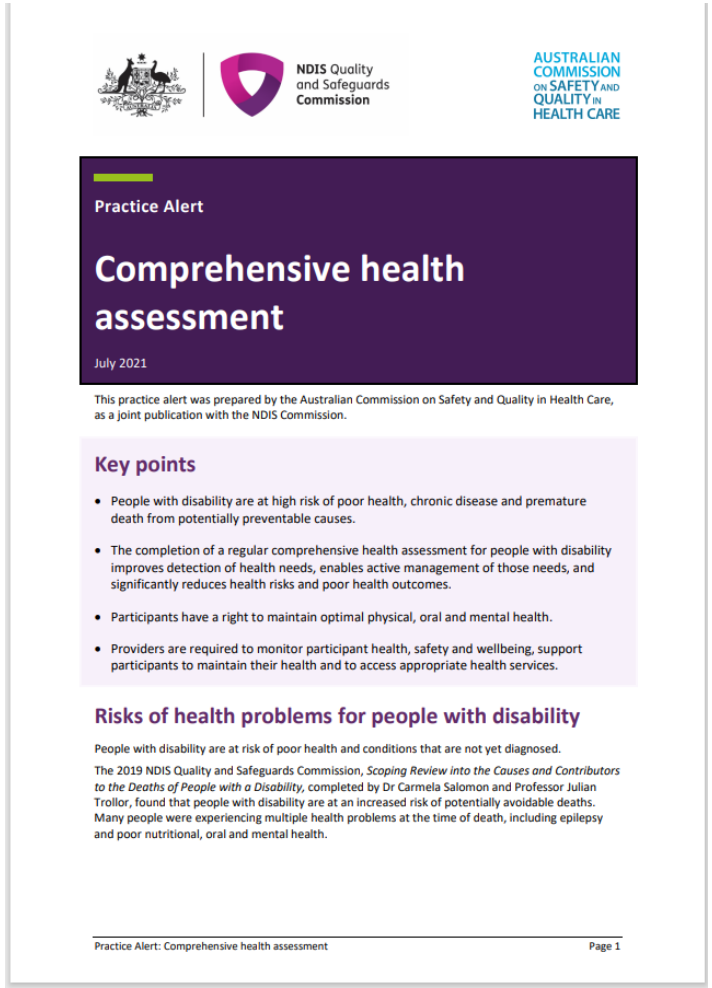
Find out more

For full details on this practice alert and the obligations for NDIS support workers, and access to other training and resources, please visit **ndiscommission.gov.au/workerresources**

NDIS Quality and Safeguards Commission

Refer to the website for the full document

https://www.ndiscommission.gov.au/workerresources


NDIS Quality and Safeguards Commission

AUSTRALIAN COMMISSION ON SAFETY AND QUALITY IN HEALTH CARE

Practice Alert

Comprehensive health assessment

July 2021

This practice alert was prepared by the Australian Commission on Safety and Quality in Health Care, as a joint publication with the NDIS Commission.

Key points

- People with disability are at high risk of poor health, chronic disease and premature death from potentially preventable causes.
- The completion of a regular comprehensive health assessment for people with disability improves detection of health needs, enables active management of those needs, and significantly reduces health risks and poor health outcomes.
- Participants have a right to maintain optimal physical, oral and mental health.
- Providers are required to monitor participant health, safety and wellbeing, support participants to maintain their health and to access appropriate health services.

Risks of health problems for people with disability

People with disability are at risk of poor health and conditions that are not yet diagnosed.

The 2019 NDIS Quality and Safeguards Commission, *Scoping Review into the Causes and Contributors to the Deaths of People with a Disability*, completed by Dr Carmela Salomon and Professor Julian Trollor, found that people with disability are at an increased risk of potentially avoidable deaths. Many people were experiencing multiple health problems at the time of death, including epilepsy and poor nutritional, oral and mental health.

AHA Activity
Please read Charlie's Story

Do	Group 1: What do you need to do in Week 1 and what else do you think about .
Do	Group 2: What do you need to do in Week 2 and what else do you think about or do.
Do	Group 3: What do you need to do in Week 3 &4 and what else do you think about or do
Develop	Group 4: Develop the person's 1 page health profile
Do	Group 5: identify any other issues that may not have been addressed in the process that could potentially impact the person's overall wellbeing.
Present	Each Group will present to the rest of the team

Top 5 tips to improve the annual health assessment

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Involve the person and the people who know them well when collecting information and preparing documentation.

Be prepared: use the checklist and start the assessment process at least three weeks before the appointment - longer if the individual has complex needs.

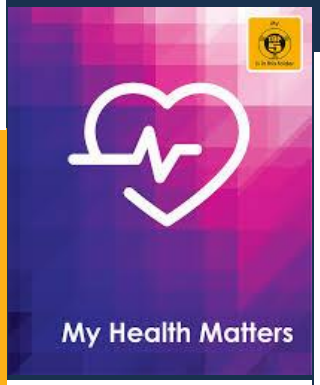
Be clear what reasonable adjustments are needed if the person is known to get upset due to medical triggers, past trauma, challenging behaviours etc.

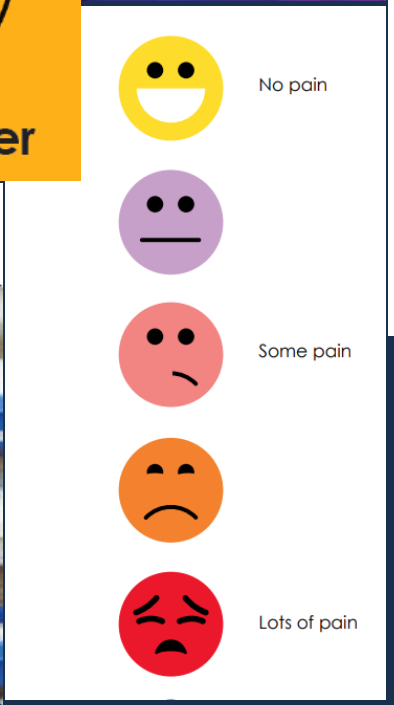
Alert the GP and the GP practice about any reasonable adjustments needed. This will insure the person has a reasonably positive experience.

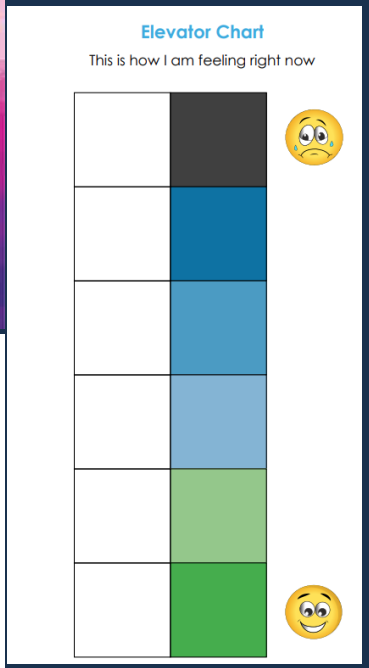
Understand the different types of appointments a GP can bill for. Use telehealth when possible and ask for the AHA appointment to be split over a few appointments if best for the individual.

Communication Resources

- End of life tool kit
- My Health Matters folder
- Admission to Discharge (A2D)
- Say Less, Show More







- 2 new Practice Alerts

PRACTICE ALERT QUICK REFERENCE GUIDE

Transitions of care

The movement of people between places or services providing care, such as disability support services and hospitals.

How to prepare for a safe transition

Safe transition requires early, clear and ongoing communication with the participant, health care staff and support networks, to ensure critical medical information is not lost during transition.

How to support participants

There are several ways NDIS support workers can assist participants during transitions of care:

- be prepared to go to hospital, both for planned and emergency visits
- keep participant's health and medication information accurate and up-to-date
- bring essential items for hospital admission.

What to do in an emergency

Support the participant by having someone familiar stay with them during the admission, and as needed while in hospital. For planned hospital visits, communicate with hospital staff beforehand.

How to prepare for discharge and ongoing care

- plan for the participant's discharge in consultation with health professionals as early as possible
- ensure any new support needs are understood and in the plan before discharge.

Find out more

For full details on this practice alert and the obligations for NDIS support workers, and access to other training and resources, please visit **ndiscommission.gov.au/workerresources**

NDIS Quality and Safeguards Commission

PRACTICE ALERT QUICK REFERENCE GUIDE

Pain management

Different types of pain require different types of management and monitoring.

Pain in people with disability

Pain is more common in people with disability than the general population and can often go unrecognised. Untreated pain can also have negative physical and mental health effects and can be a cause of behaviours of concern.

What are the most common pains?

Common causes of pain in people with disability can include: muscle spasm, headache, dental pain, earache, constipation, stomach pain, and menstrual pain.

Who can help manage pain?

Different types of pain require management by different health professionals such as a doctor, physiotherapist or dentist.

What is a pain management plan?

A GP can develop a pain management plan with people who have ongoing pain that might include: physical, psychological and pharmacological interventions. Regular dental checks are also important.

Ongoing care

NDIS providers are required to monitor NDIS participants' health, safety and wellbeing and support them to maintain their health and to access appropriate health services when required.

Find out more

For full details on this practice alert and the obligations for NDIS support workers, and access to other training and resources, please visit **ndiscommission.gov.au/workerresources**

NDIS Quality and Safeguards Commission

Resources for Health Professionals working with people with intellectual disability

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Resources for Health Professionals working with people with intellectual disability

Read more

Good Appointments, Better Health

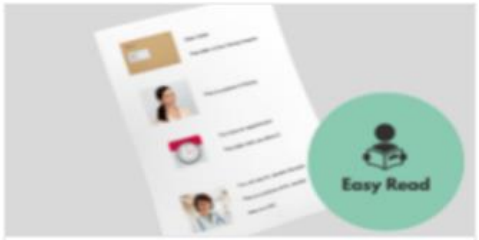
Read more

Tailorable Easy Read Appointment Letter

Read more

Tailorable Easy Read How to Find Us sheet

Read more



Sample Easy Read appointment letter

Read more

What not to miss by Professor Nick Lennox

Read more

cid.org.au/health/resources-health-professionals/

Feedback from the AHA Activity

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What did you learn by doing this activity together?

Did you find this activity helpful?

What will you do differently when you go back to your workplace?

Lunch

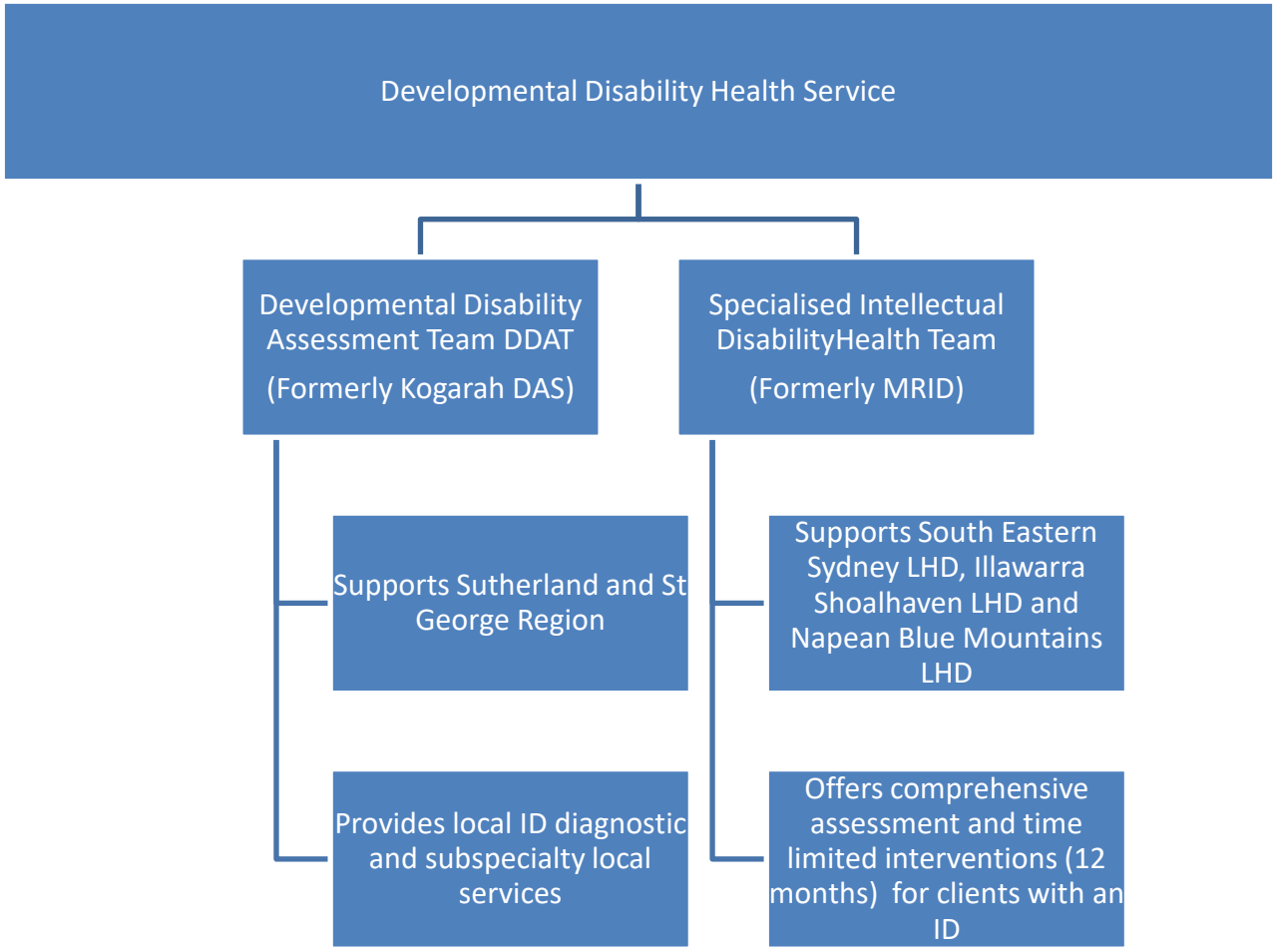
Intellectual Disability Health Service

South Eastern Sydney Local Health District

Who are we?

- We are a multidisciplinary team, consisting of
  - Team Leader & Clinical Nurse Consultant Gavin Begbie
  - Social Worker – Michael Morgan
  - MHID clinician - Vacant
  - Psychiatrist – Dr Keller
  - Rehabilitation physician – Dr Taskin
  - Developmental Paediatrician – Dr Piper
  - Child and Adolescent psychiatrist – Dr Bickerton

Where do we sit?



NSW GOVERNMENT

What is our Role?

- Clinical assessment/development comprehensive case management plans
  - People with an Intellectual Disability and complex unmet health needs
- Capacity Building
  - Hospital, community health and primary health professionals
- Reporting and accountability
- Multidisciplinary teams

Why is there a need for the team?

- People with intellectual disability have a higher prevalence of physical and psychiatric conditions, higher levels of morbidity and experience poorer health outcomes than the general population.
- Life expectancy is significantly reduced for people with Intellectual Disability as detailed below (2010)
- People with Intellectual Disabilities experience significant health inequalities compared with the general population

	People with ID	People without ID
Male	63 year	79 years
Female	65 years	83 years

Important points

- Client must have an Intellectual Disability
- Client must have a current unresolved health concern
- Complex health conditions
- Time limited – short recommendation based service
- Within the correct geographical region

Referral process!

- Community Referrals
  - Contact SIDHT office (phone or email)
  - Complete referral form or provide GP referral
  - Once returned referral will be triaged
- In-Patients referrals
  - Contact SIDHT office (phone or email)

How to contact us?

- We are based at Burbangana, 2 Belgrave St, Kogarah
- Email: SESLHD-SIDHT@health.nsw.gov.au
- Phone Number: 8566 1222 (DDHS reception)

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How to work collaboratively with GPs

Dr Jessica Murphy

First Steps

- Foster a relationship with the GP

- Introduce yourself to them as SIL team leader & to key contacts at your facility who they can contact
- Let them know the best contact method for you/your facility
- Ask the GP to introduce you to their key contacts – practice manager/key admin person
- Ask how they would best like to be contacted with info – phone/email/fax

Booking Appointments

- Discuss with the GP/practice how best to book in appointments

- Particular time/day?
- Take into account reasonable adjustments needed for the patient
- Online/phone/via key contact person

- Also discuss how to organise recalls/reminders
- Who will they be sent to?
- What format works best for the patient?
- Need to ensure patient consent documented!

Preparing for Appointments

- Ensure you alert staff/GP in advance of reasonable adjustments needed – again how would they like this information? Who best to communicate to at the practice re this? **May need to re-send this information**

- Provide My Health Profile in advance & ensure this kept up to date – living document

- Discuss as a team before the appointment what are **your** agendas/needs for the patient? What are the patient's needs? Family requests

During Appointments

- GP agenda vs your & patients' agenda
- **Vital to send somebody with the patient who knows their needs, background & issues to be discussed**
- Please understand there is limited time – most standard appointments are only set for 10-15 minutes
- **We can't sign/discuss paperwork & deal with medical problems all in one consult – try to organise this for a separate appointment if possible or book a long appointment**

- Appointments don't always run on time – if the patient is becoming distressed in the waiting room please alert someone – a decision can then be made how to handle it

You are the advocate for the patient!

After the appointment

- Ensure information re management plans effectively communicated & documented
- Ensure plans kept up to date – living document
- Ensure follow up appointments booked in advance – always plan opportunity for review

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Q&A

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Understanding Appointment Types, Medicare & Billing

A bit of context…

- GPs are under a lot of pressure
- Want to support patients but time is limited!!
- Medicare billing is restrictive & doesn't support providing complex care

- Bulk Billed Standard appointment (up to 20 mins) - $42.85

– 30% goes to the practice for fees = $29.99

- **Only get paid for consultation time – Additional admin is done without pay!**

- NDIS requirements not always understood by GPs
- Additional administrative burden
- GPs can sometimes feel they are being made to do additional “free work” on behalf of others

Appointment Types

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General Consults

- Standard appointment is 10-15 mins – only really suitable for straightforward or minor problems
- Likely best to always book a long consultation for these patients

Telehealth

- Ideal to be used for simple things in between consults
- Repeat Scripts
- Signing forms (can be sent via fax/email then returned)

Annual Health Assessments

- Billed depending on time spent with the patient as a whole
- This can be done over several appointments & parts can be done with the nurse
- Makes it easier for the GP
- Think about your patient – what works best for them?

GP Management Plan

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- What is a GP Management Plan?
- For patients with chronic medical conditions (present >6m)
- Opportunity to review & co-ordinate care for next 12 months – what are the needs/goals for the patient?

- What is a Team Care Arrangement? ****
- Done in conjunction with the GPMP – can use to refer to allied health professionals
- Allows up to 5 visits per calendar year with a Medicare rebate

- The plans can be reviewed on a 3-6 monthly basis (depending on complexity)
- Opportunity to review if goals are being achieved & what else needs to be done?

Case Conference

- Complex medical issues
- Can be organised by the GP or by another health professional – you can organise!
- Billed per time spent on the case conference (Allied health can bill medicare too for this)
- GPs may not be aware of this as an option

Continuity of Care

- Stick to one regular GP for review appointments – Health assessments, GP Management plans, medication reviews
- If that GP is away on leave then best to defer it until they're back – ensures continuity of care
- Acute problems with any available GP

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Thank you for listening to the GP perspective!

Any Questions/Comments?

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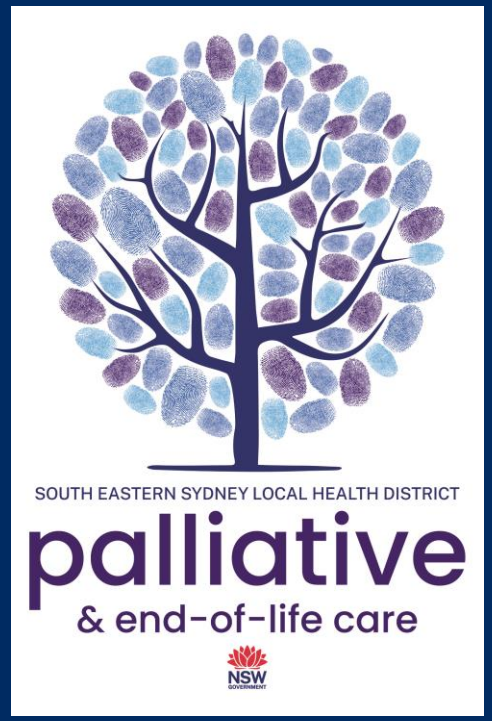
Break

Maria Heaton TBC Content

Intellectual Disability Palliative Care



Maria Heaton

SESLHD Intellectual Disability Palliative Care Clinical Nurse Consultant

ATTENTION!

- This content is sensitive and emotional.
- The intention is not to upset anyone but to provide information.
- Please feel free to step outside if you are finding it difficult and seek support from your manager.

ACKNOWLEDGEMENT OF COUNTRY

We acknowledge the Traditional Custodians of country throughout Australia and their connections to land, sea and community.

We pay our respect to their Elders past and present and extend that respect to all Aboriginal and Torres Strait Islander peoples today.

SOUTH EASTERN SYDNEY LOCAL HEALTH DISTRICT
palliative
& end-of-life care
NSW

Acknowledgement of Lived Experience

I would like to acknowledge people with lived experience of intellectual disability and the carers who support them.

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NSW

What is Palliative Care

Palliative care is an approach that improves the ***quality of life of patients*** (adults and children) and their families who are facing problems associated with ***life-threatening illness.***

It prevents and ***relieves suffering*** through the early identification, correct assessment and treatment of pain and other problems, whether ***physical, psychosocial or spiritual***.

(WHO, 2002)

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What is Palliative Care

"Palliative Care no longer means helping people die well, it means helping people and their families live well and then when the time is certain, helping them to die gently"

Mattie Stepanek (1990-2007)

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SESLHD Palliative Care Use Before Death

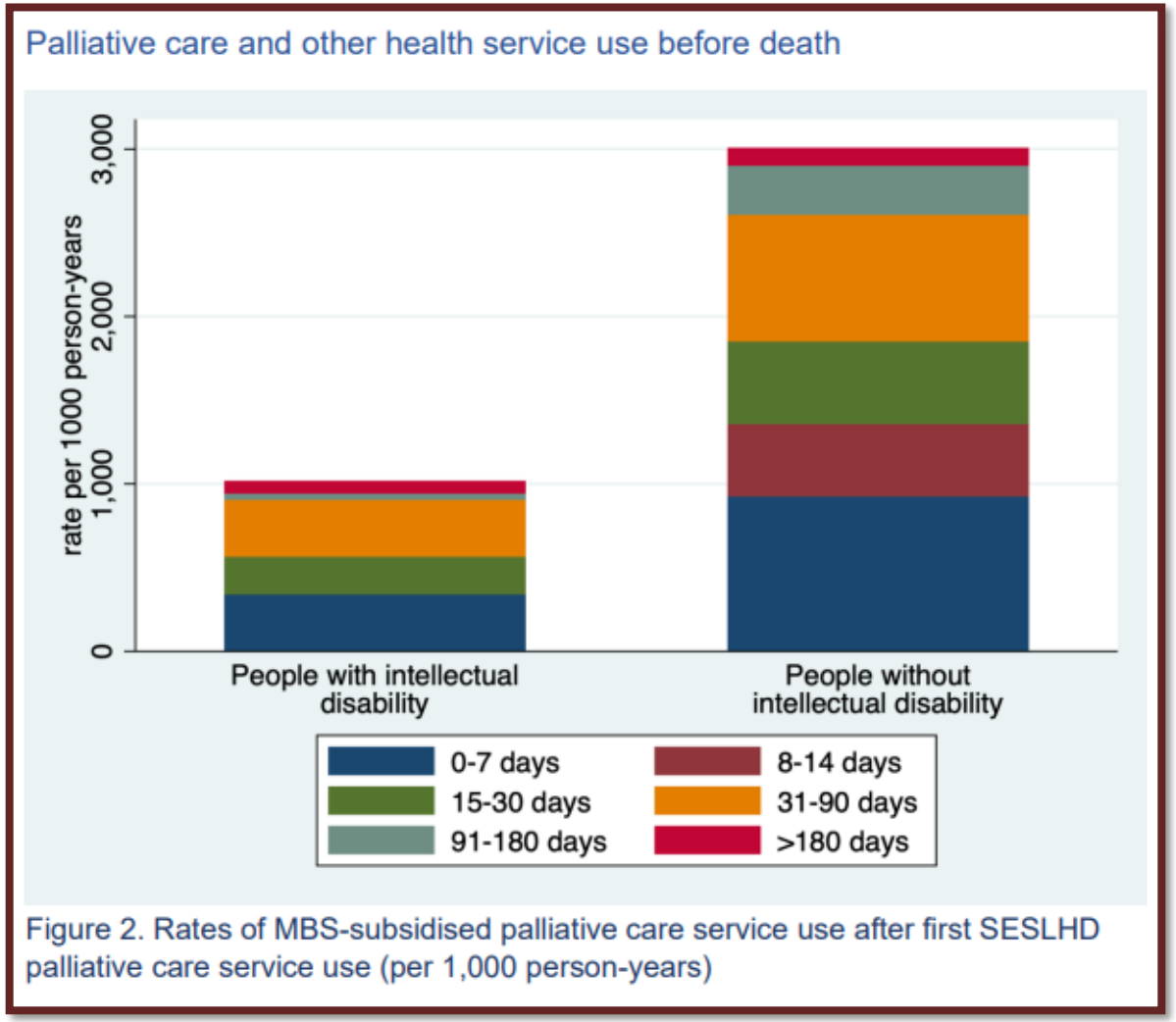


Figure 2. Rates of MBS-subsidised palliative care service use after first SESLHD palliative care service use (per 1,000 person-years)

Location of People with Intellectual Disability in SESLHD

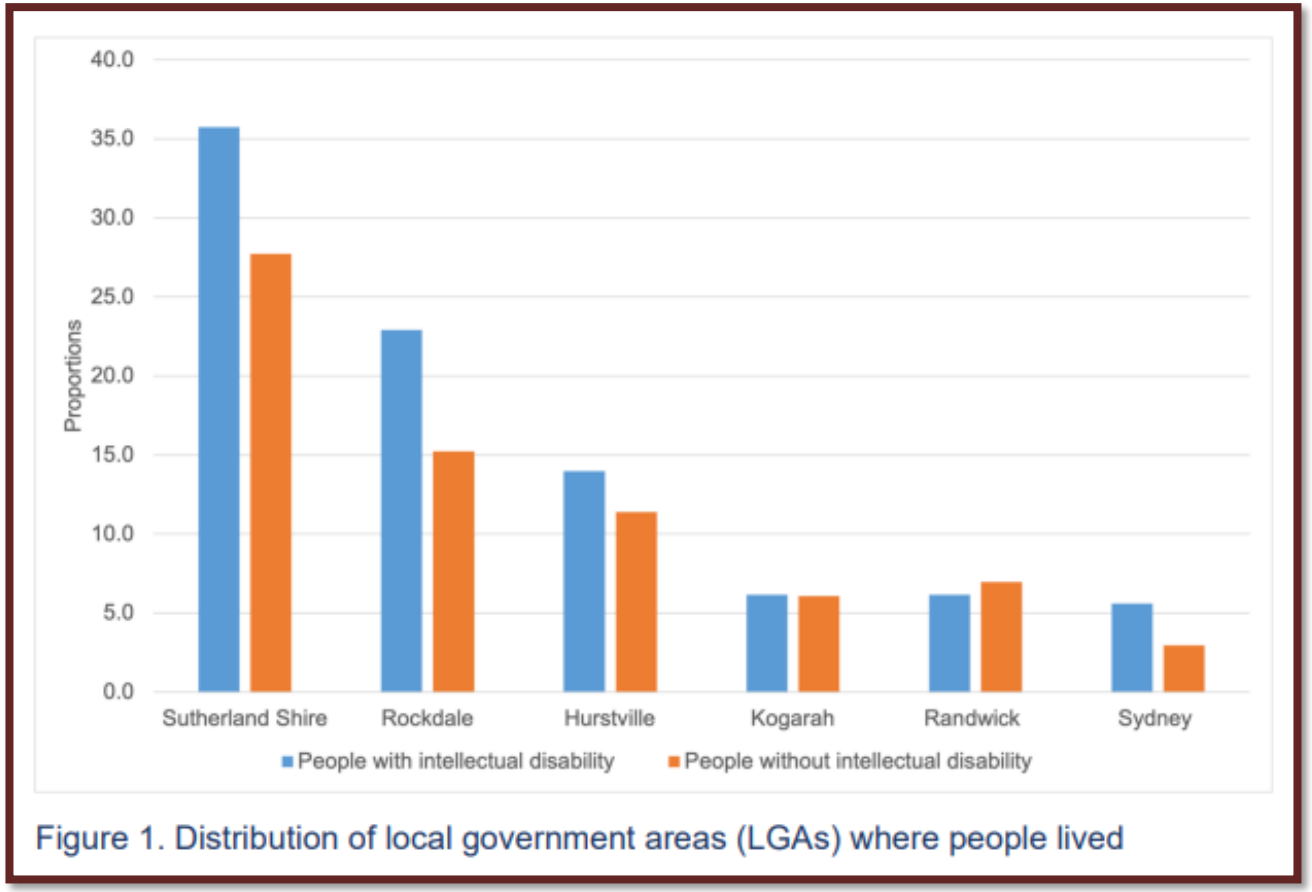
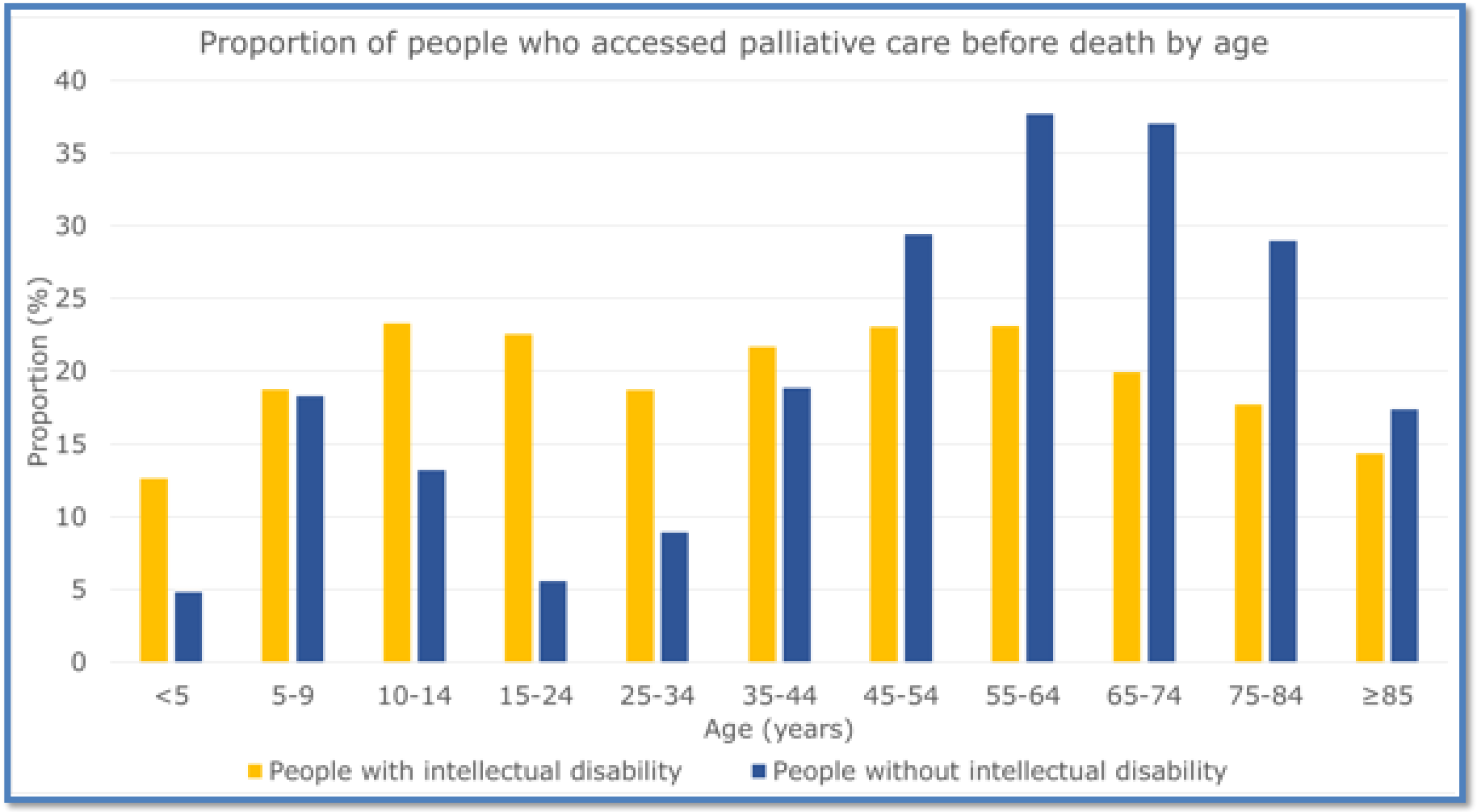


Figure 1. Distribution of local government areas (LGAs) where people lived

Data regarding Palliative Care use by age



Cvejic R, Srasuebkul P, Vajdic C et al, 2023, *Palliative care use by people with intellectual disability: A linked data study in NSW, Australia.* UNSW.

Changes as a person's health deteriorates

- Oral intake
- Output
- Tiredness
- Drowsiness
- Oral hygiene
- Pain

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Quality of Life

- **Physical** – How does the person feel? How independent and active are they?
- **Emotional** – How happy they are? Do they feel valued and respected?
- **Social** – Are they seeing the important people in their lives regularly? Do they feel valued by these people?
- **Spiritual** (not religious) – Do they feel connected to or a part of something bigger that adds value to their life?

When is the right time?

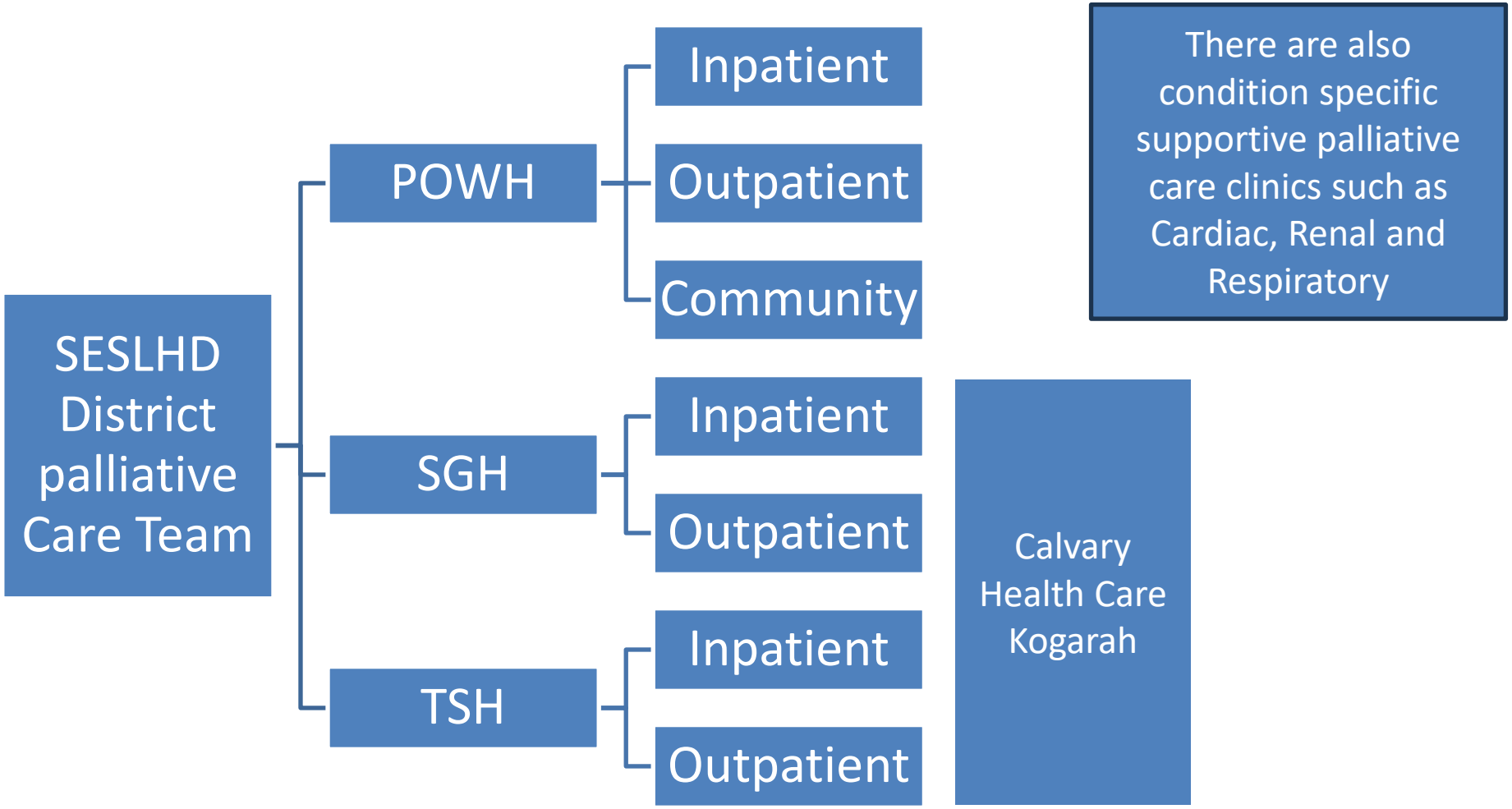
Palliative care is best introduced at time of diagnosis of a life limiting condition.

Palliative care can be provided alongside curative treatment.

How to decide if a client will benefit from palliative care?

- Will you be surprised if they died in the next two years?
- Has there been permanent functional decline?
- Are the treatments being done to the person rather than for the person?
- What are their/their family's wishes?

SESLHD Palliative Care Services



Community Supportive Care Clinic

- Must have at least one of the following general triggers:
  - Complex and increasing symptom burden
  - Persistent symptoms, despite optimal treatment of underlying condition(s)
  - Deterioration in functional performance status and increased support needs
  - Patient requires advance care planning
  - Progressive weight loss of more than 10% dry body mass, in last 6 months
  - Two or more unplanned acute admissions in the last 12 months
  - Patient or family requesting supportive and/or palliative care input
- The client must be able to attend the clinic at least for the first visit. Follow up can be done via telehealth or a home visit.

Questions?

Maria Heaton

Phone: 0461517088

Email:

seslhd-intellectual-disability-palliativecare@health.nsw.gov.au

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Q&A Session

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GROW

Supporting people with intellectual disability

Project GROW

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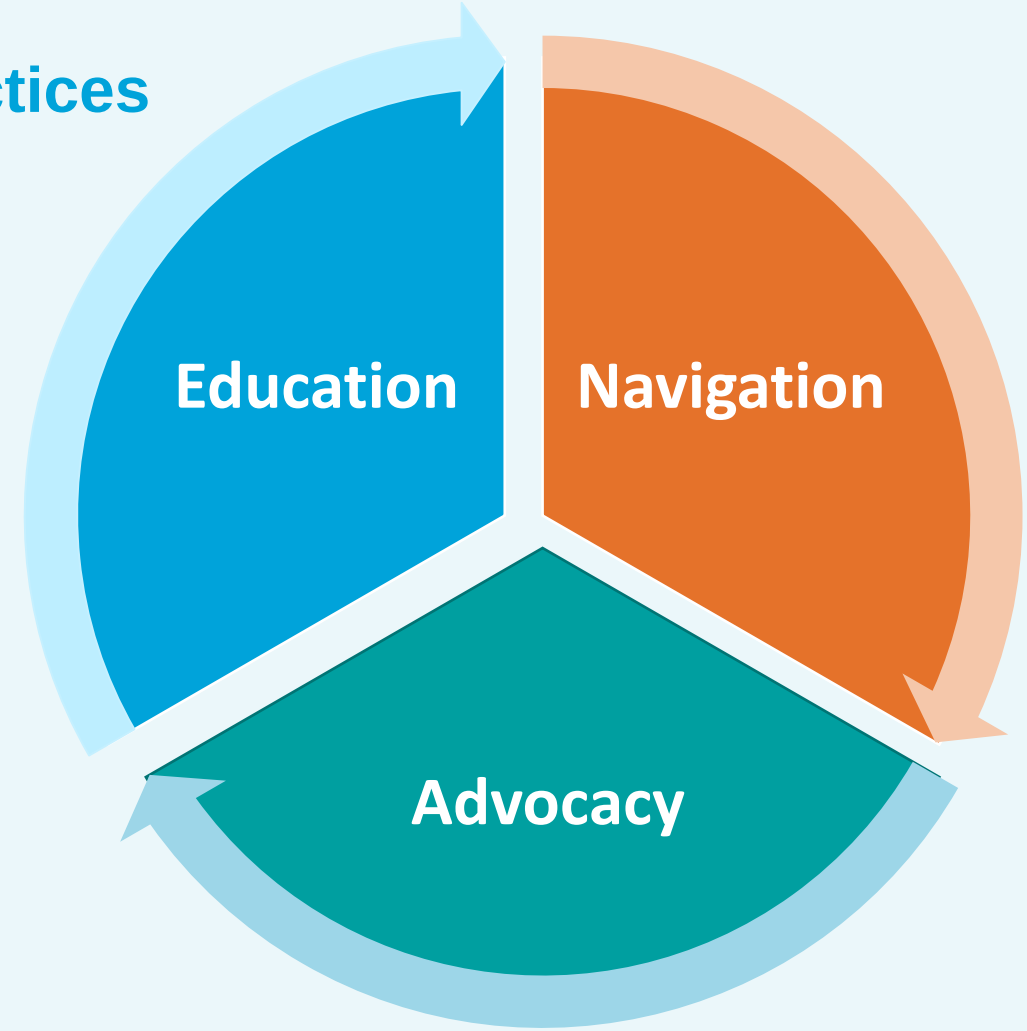
Training in general practices

SIL provider training

We will hold another workshop later in the year.

If you have colleagues who may be interested, please contact our team at intellectualdisability@cesphn.com.au.



GROW Service Navigators are available for ongoing support, referral pathways.

GROW Educators and Service Navigators

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Naomi Halligan
9304 8640

Dominique Abagi
9304 8739

intellectualdisability@cesphn.com.au

For more information about GROW visit, our Website:
https://www.cesphn.org.au/general-practice/help-my-patients-with/intellectual-disability

GROW
Supporting people with intellectual disability

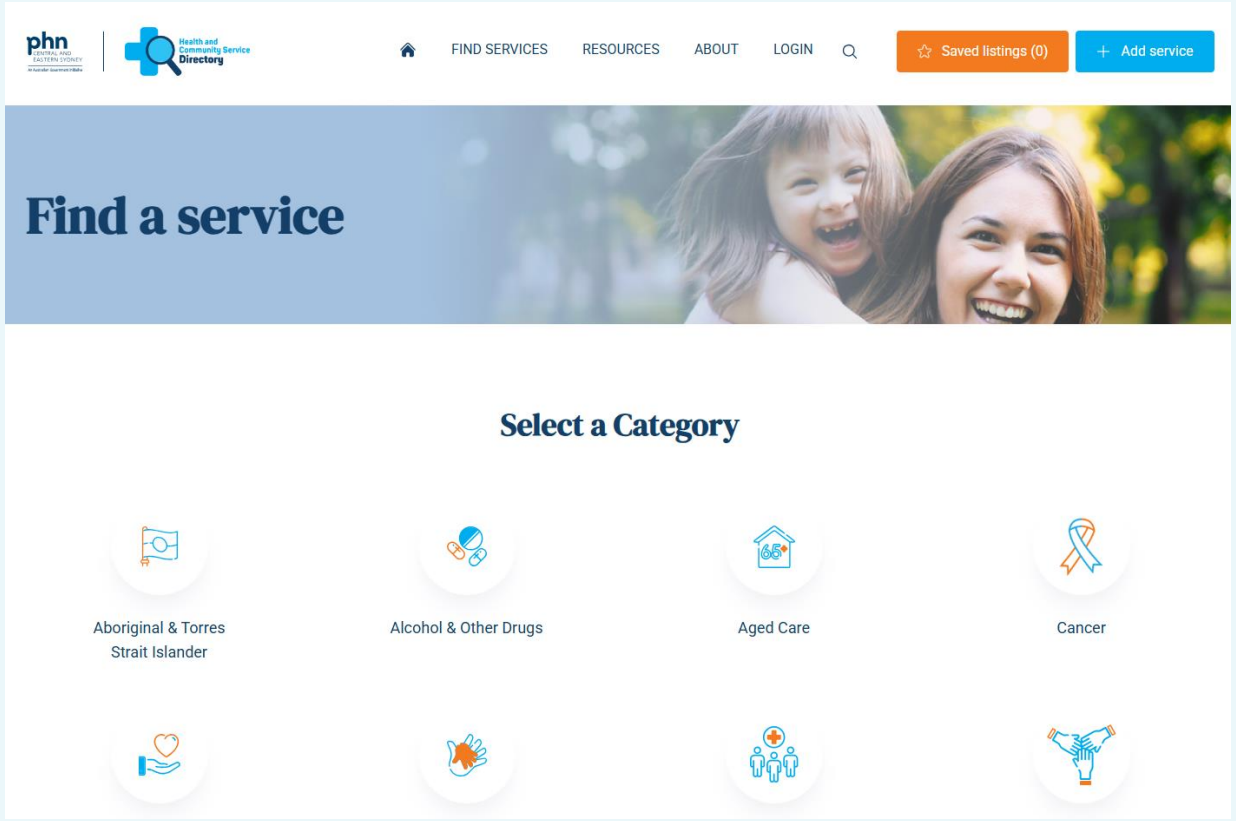
CESPHN Disability Network

The Network is a collaborative forum of representatives from across the **disability and health sectors.**

Our **goal** is to build connection between the sectors and support more integrated, inclusive approaches to care and support.

To join or find out more email, disability@cesphn.com.au

Community Service Directory



The purpose of the directory is to help people better understand what local health services are available to them.

To add your service to the directory or find out more, visit https://servicedirectory.cesphn.org.au/

Evaluation Survey: please complete via the QR Code

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Your feedback to us

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Thank you so much for your time today

Thank you for all you do for the people you support

What you do every day in your work can make a positive difference

Before you go, we have a few questions

GROW

Supporting people with intellectual disability

Do you have a better understanding of:

- What preventive healthcare is and the importance of the Annual Health Assessments.
- Your role and the roles and responsibilities of the person and their team to keep the person healthy and well and improve their health outcomes.

GROW

Supporting people with intellectual disability

Do you feel more confident to:

- Implement the annual health assessment process and develop a one- page health profile that includes what reasonable adjustments the person may need.

- Work in partnership with the person's GP and their family and foster relationships with GP practices.

Thank you and safe journey home

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Supporting people with intellectual disability

Together We're Better Training Workshop

Working together to improve health outcomes for people with intellectual disability

2 June 2025