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## Acknowledgement Of Country



The Sydney North Health Network wishes to acknowledge Australia's Aboriginal peoples – the traditional custodians of the land on which we meet and work.

We pay our respects and recognise their continued connection to land, water and community and honour their ancestors, Elders past, present and emerging.



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## Housekeeping



- ◆ **To change your displayed name** - Click on the 'participants' icon at the bottom of your screen, then click the 'more' option next to your name, then click 'rename'. Your microphone and video will be disabled during this webinar.
- ◆ **Interact with each other and submit questions via the chat box** - In your controls at the bottom window, click Chat. If you are on a mobile device, tap Participants, then Chat. Select who you would like to send the message to by clicking on the drop down next to "To" e.g. All Panelists and Attendees
- ◆ **Please be respectful** of other participants and behave as you would at a face-to-face meeting.
- ◆ **If your screen freezes** during the presentation, it could be your WiFi connection is limited – try moving closer to your WiFi router
- ◆ **Evaluation** – This will be available via QR code at the completion of this webinar. Please ensure that you submit this to ensure that we can adhere to our RACGP reporting requirements



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# health navigators

NORTHERN SYDNEY

Health Navigators is a completely free to access hotline which is staffed by experienced nurses. Health Navigators makes it easy for health, aged and social care professionals to find local services for their frail, older or vulnerable patients/clients.

**For more information visit**

[snhn.org.au/health-navigators](http://snhn.org.au/health-navigators)

**Or call 1800 271 212**

Phone lines are open Monday to Friday, from 8am to 6pm.



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## HealthPathways

### A WAY FORWARD



HealthPathways is an online health information website which supports GPs, hospital doctors, nurse practitioners, pharmacists, allied health and other clinicians.

**HealthPathways supports:**

- ✓ Condition management
- ✓ Service navigation
- ✓ Referral to specialists, facilities, public and private services
- ✓ Access to reference materials
- ✓ Access to patient educational resources



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## HealthPathways

### BENEFITS

#### Patient benefits

- ◆ Improved coordination of care
- ◆ Referral to specialists when appropriate

#### Clinician benefits

- ◆ Better communication with primary care and hospital services
- ◆ Clearer management options

#### Local Health District benefits

- ◆ Hospital avoidance due to better managed care in the community
- ◆ Appropriate use of tertiary resources



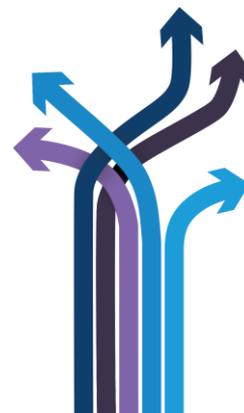
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## Sydney North HealthPathways Snapshot



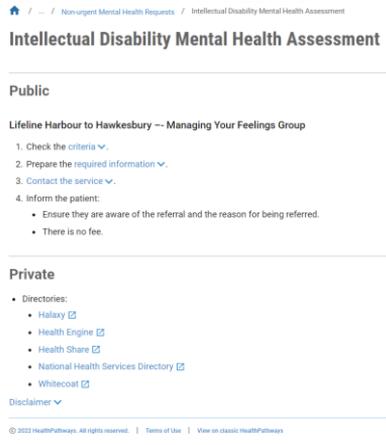
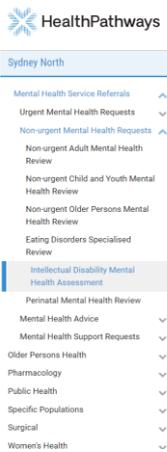
### February, 2022:

Launched May 2017  
 458 Pathways live  
 27 Pathways in progress  
 10,550 Average page views per month  
 12,195 Accumulative new users



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## Sydney North HealthPathways



<https://sydneynorth.communityhealthpathways.org/440942.htm>

**Visit:**  
<https://sydneynorth.communityhealthpathways.org>  
 General Practice Username: **healthpathways**  
 Allied Health Username: **healthpathwaysAH**  
 Password: **gateway**



**HEAD TO HEALTH**

## Head to Health

Head to Health is a free mental health service for anyone in NSW (of any age) whose mental health is suffering due to the pandemic.

### How does it work?

1. Patients phone 1800 595 212 (Mon-Fri, 8:30am-5:00pm except public holidays) from anywhere in NSW, then enter their postcode.
  2. A trained mental health professional will guide them to the right local mental health support for their needs.
  3. The intake clinician may refer them to an existing service or, if appropriate, to receive care from a trained mental health professional at a Head to Health Pop Up hub (via telehealth or COVIDsafe in-person appointments).
- No referrals needed.
  - Not a crisis service – phone 000 in an emergency.
  - Find details and resources at:

[snhn.org.au/h2h](https://snhn.org.au/h2h)



## Speaker introduction



- ◆ **DR YVETTE VELLA | BAPPSC (OCC THERAPY) MBBS FRACP DCH MPH**  
Developmental and General Paediatrician at the NSIDHS and Hornsby Ku-ring-gai Child and Family Health within the Northern Sydney Local Health District. She has expertise in managing complex behaviours of concern in children and adolescents with ID and autism and works in collaboration with schools for specific purposes in the Local Health District. Dr Vella also has a special interest in working with children in out of home care.
- ◆ **LEAH BALLIN | BA (Psych & Ed), GradDipSci (Psych) MPsy (Ed & Dev), MAPS, FCEDP**  
Educational and developmental psychologist at NSIDHS. Leah has experience providing psychology services across a range of settings having previously worked as a school psychologist, in private practice, as well as with NGOs as part of a multidisciplinary team. Leah also has particular experience in working with children who present with autism spectrum disorder, intellectual disability and cerebral palsy.
- ◆ **ANGIE MYLES | Registered Nurse & Registered Sick Children’s Nurse (UK)**  
Angie has worked in Adolescent Health Services for 20years at Royal North Shore Hospital, John Hunter Children’s Hospital and as ACI Transition Care Coordinator since 2011.
- ◆ **CAMERON WHEELER | Uniting, a provider for the NDIS in the Northern Sydney region**  
Information Linkages and Capacity Building Project Officer – Operations, Local Area Coordination, Partners in the Community on behalf of National Disability Insurance Scheme (NDIS)



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# Transition to adult care for adolescents with intellectual disability



**Dr Yvette Vella Developmental Paediatrician**  
**Leah Ballin Psychologist**

Northern Sydney Intellectual Disability Health Service

**Angie Myles**

Transition Care Coordinator Northern  
ACI Transition Care Network / HNEKidshealth HNELHD



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## Learning objectives

1. Recognise the complexity of the transition process for an individual with intellectual disability and their family
2. Consider models of collaborative care for transition to adult services
3. Identify the role of key practitioners and services for a supported transition experience
4. Increase awareness of existing transition services for young adults with intellectual disability in NSW



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- Deficits in intellectual function
  - e.g. reasoning, problem solving, abstract thinking
  - (Clinical assessment, IQ testing)
- and**
- Deficits in adaptive functioning
  - e.g. independent living, communication, social participation
- Onset in developmental period – before age 18 years

*DSM V, 2013*



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## Complex presentations and transition

- There are additional challenges for adolescents with an intellectual disability and their families as they make the transition to adult life.
- Those with a dual diagnosis of intellectual disability and autism or mental health condition generally have a more complex presentation, as do adolescents with intellectual disability and a physical disability.



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## Complex presentations and transition

- Parents of adolescents with a more severe intellectual disability were found to be more anxious about moving on from paediatric services.
- Adolescents with an intellectual disability have typically shown poorer outcomes as they transition to adult life.
- Problems with transition negatively affects adolescents general health and wellbeing, relationships and social inclusion, and successful engagement in programs/education/employment.



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## The transition experience - carer and patient anxiety

- Confusion about services and difficulty accessing adult care and supports.
  - ❖ Accessing and using services for the first time
  - ❖ Increased reliance on GP to coordinate care
- Parent concerns about their child's ability to adjust to adult life
  - ❖ Loss of familiar school routine, treating practitioners and supports
  - ❖ Changing social supports and peer network
  - ❖ Expectations of increased independence



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## The transition experience - the family system

- Grieving the changing parent-child relationship
  - ❖ Parents can experience mixed feelings during the process of transition. For example, loss of the childhood years as well as fear about the future.
- Increased demands on parents to care for their children into adulthood.
  - ❖ Many adolescents remain living at home
  - ❖ The shift from full time schooling may mean adolescents are not automatically engaged in post school options full time.



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# The transition experience - the family system

- Impact on the family system
  - ❖ Increased stress, social, financial pressure
  - ❖ Potential for parent burnout and capacity to provide ongoing care highlight the need for a planned transition to support family health and wellbeing



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Maintaining community connection

Shared decision making

Creating a voice

Recognising important relationships

Personalised and individual goals

Meaningful roles and routines



Adjusting supports

Physical health

Planned handover and information sharing



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## Strategies to promote effective transition

- **Planned** - early and not at crisis points
  - ❖ Consider health care, social, accommodation and financial (NDIS funded) supports that will be required over the next few years.
  - ❖ Commence early referrals to specialist services and post school programs.
- **Collaborative** – communication between adolescent, family, education, health, disability services
  - ❖ Seek feedback from treating practitioners, allied health therapists and school.
- **Coordinated** – shared timeline between adolescent and stakeholders



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## Strategies to promote effective transition

- **Personal** – goal setting and achieving personal best outcomes
  - ❖ Setting goals that are realistic and meaningful
  - ❖ Having shared decision making with adolescents and their family, involve the adolescent.
  - ❖ Goals consider the impact on an adolescent's emotional wellbeing and social connection
  - ❖ Plan for regular medical follow up with an adolescent's GP who can assist in monitoring progress and satisfaction with transition.
- **Gradual** – stages of shifting care responsibility
  - ❖ Introducing new roles and new routines, e.g. work experience/TAFE, accommodation services
  - ❖ Overlap of support workers



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## William - 16 years old

- Autistic and with a moderate intellectual disability
- Some verbal communication, key word sign and can make choices with gesture and visual support
- Increasing anxiety, absconding, destructive and self harm behaviour from early teenage years
- School for specific purposes, behaviour support practitioner, speech and occupational therapy engaged
- Psychiatry and specialist Intellectual Disability Health Service management
- Family supports exhausted with parent depression and separation
- Weekly overnight respite introduced but unsettled by unpredictable routine
- Family decision to request for voluntary out of home care



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## William

Following an adjustment period of several months with a new living arrangement -

- Physically well
- Sleeping well
- Behaviours of concern better understood and supported
- Regular medication for anxiety able to be rationalised
- Parent relationship improved
- Build skills and capacity for future opportunities



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## Collaboration

- Initially monthly meetings: parents, paediatrician, psychologist, school, disability accommodation provider and therapists
- Less frequent meetings after a successful adjustment period
- Regular communication between NSIDHS and general practitioner
- Plan for handover of medical care
- Accommodation and post school program options
- Opportunity to make shared decisions
- Parents supported



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## Paediatric medical handover

Handover around 18 years from paediatrician to general practitioner

Some public paediatric outpatient services may handover at 16 years

Continue with child and adult psychiatrist or handover to an adult psychiatrist

Some adult psychiatrists will see patients from 16 years of age



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## Shared care model of transition

- Essential to establish a relationship with GP
- Strong partnership and communication between clinicians is needed
- Recognise variation with GP knowledge and confidence managing the needs of patients with intellectual disability
- Recognise varied prescribing experience and capacity
- Recognising the extent of carer demands through adolescence particularly for those young people with autism and behaviour support needs
- Transition planning commencing from early to mid adolescence



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## Fearless, Tearless Transition Model

Culnane E, Loftus H, Efron F, Williams K, Iorio N, Shepherd R, Marraffa, C, Lubitz L, Antolovich G & Prakash C (2020).

- Model of care developed from the shared transition experiences of:
  - ❖ young adults with a dual disability (intellectual disability and mental health concerns)
  - ❖ paediatricians,
  - ❖ general practitioners,
  - ❖ policy makers



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## Key concerns raised

Existing variation in transition planning

Time and resources constraints

Lack of coordination support

Disconnect between health and disability services

Patient, family and clinician frustration about accessing the right service

Lack of appropriate and available community services

A need to build capacity in general practitioners

Parent anxiety with unrealistic expectations of adult services



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## Fearless, Tearless Transition

12 years: begin to discuss transition with paediatrician, identify GP and encourage annual or more frequent visits

15 years: meet with the transition coordinator to discuss transition needs

From 15 years: co management with planned alternating visits between paediatrician and GP

18 years: Paediatrician ensure all services are in place before GP takes over continuing care



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## Outcomes

- Transition would likely be improved by a structured, centralised and family centred transition process
- This model requires a well established transition service with capacity to maintain links between clinicians, family and disability services



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## In every day practice

- Developing a shared care arrangement
  - ❖ consultation with the patient, family, general practitioner and paediatrician
- Family centred approach
- Use of clinical assessment tools and resources to complement clinician experience
- Continued capacity building of paediatricians and general practitioners



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## Existing resources

- School information can contribute to shared family discussion about post school activities and supports
- NDIS Support Coordinator to plan for adequate funding for transition planning
  - ❖ Accommodation options
  - ❖ Work/community activity programs
  - ❖ Skilled disability support for community participation at the appropriate ratio

## Transition planning – key practitioners and services involvement

Key Practitioners also supporting transition	Role and services provided
Allied health (Occupational Therapy, Speech Pathology, Psychology/BSP, Physiotherapy)	Inform discussion about transition Potential for same provider to continue into adulthood
High School	Informs discussion about post school options
Post-School Options	TAFE, Vocational training and employment, community participation programs, accommodation/independent living.
NDIS Coordinator	Adequate NDIS supports for transition planning

## Existing resources

Identify potential adult medical specialists and plan for waiting periods

Psychiatry services – telepsychiatry platforms for assessment and continuing care

Specialist Intellectual Disability Health Service for patient consultation, clinician case discussion and education needs



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## Transition planning – key practitioners and services involvement

Key Practitioners to support mental health services	Role and services provided
SCHN Mental Health Intellectual Disability Hub	Specialist mental health advice for adolescents <18
Statewide Intellectual Disability Mental Health Outreach Service (SIDMHOS)	Specialist mental health advice once individuals turn 18



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## Local ideas

### Build relationships and clinician capacity

- Use of shared case discussion meetings between paediatricians and general practitioners
- Build upon established professional connections to link patients with well suited clinicians

### For Paediatric outpatient services

- Scheduled alternating appointment with paediatrician and identified GP
- Joint consultation transition appointments or case conference with GP and paediatrician +/- support coordinator prior to handover of care

### ACI transition services to give advice on supports and contacts



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## Puberty and sexuality

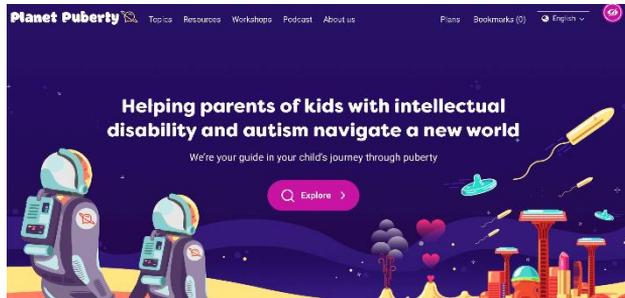
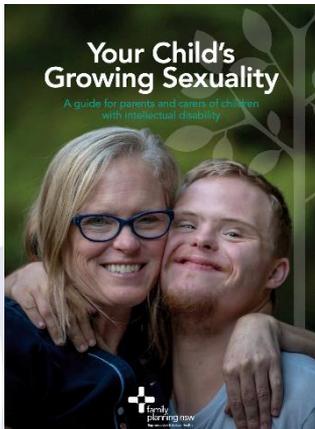
- Family and young person support and guidance
  - ❖ Protective behaviours
  - ❖ Teaching adolescents with intellectual disability about body changes
  - ❖ Safe and meaningful relationships
- Capacity to attend appointments on their own and give consent for sexual health
- Family Planning NSW Sexuality and Disability Service and resources
- Northcott - Learning about relationships, consent and sexuality



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## Family Planning NSW



<https://www.planetpuberty.org.au/>



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## FPNSW Clinician resources – supported decision making

- <https://www.fpnsw.org.au/factsheets/health-professionals/resources/supporting-decision-making-reproductive-and-sexual-health>
- Whether to have sexual intercourse
- Whether to have STI testing today
- What type of contraception to use
- Whether to have a cervical screening test today
- Whether to become a mother
- What to do about an unintended pregnancy



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## Northcott Sexuality and Relationship Education



### Sexuality and Relationship Education

Our Sexuality and Relationship Education service for people with disability is the first of its kind to be offered by an Australian disability organisation. Developed following customer demand to lift the lid on taboo topics, our educational services have been created to support people with disability to achieve their sexuality and relationship goals and desires.

[Get in touch](#)  
[Call us on 1300 605 996](tel:1300605996)

### A film and education resource about bravery in relationships

VALIANT is joint project by [Bus Stop Films](#) and Northcott, supported by the Australian Department of Social Services.



- <https://northcott.com.au/sexuality-and-relationship-education/valiantfilm/>



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## RNS Sexual Health Clinic

- Clinic 16 Royal North Shore Community Health Centre Level 5, 2C Herbert Street, St Leonards 2065  
 Phone: (02) 9462 9500  
 Web: [www.clinic16.com.au](http://www.clinic16.com.au)



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## How to support decision making

- The NSW Health Capacity Manual states:

... a patient with an intellectual disability may have capacity to make decisions about their own health treatment if information is provided to them in an appropriate manner or with appropriate assistance ..

... 'reasonable adjustments' (can) ... support inclusive and accessible services to people with a disability. Essentially, information should be provided in the format that is more typically used by the client – for example, picture symbols, large print. Patients should be assisted or supported to make their own decisions as far as possible.



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## Principles regarding supported decision making

Client health needs can be very complex

Dignity of risk

Those who know client best and for longest period should be consulted

Clients may have a history of trauma that hospital staff may not be aware of if regular supports not consulted

Conducting capacity assessments during critical moments or in strange surroundings eg. hospitals not ideal.



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## If client cannot give consent - person responsible

- A person responsible is a term used in the NSW Guardianship Act about consent in regards to medical or dental treatment
- If a client is over 16 and cannot give consent, a medical or dental practitioner must seek consent from the person responsible before giving treatment
- There is a hierarchy of who is the person responsible if the client cannot make a decision:
  - ❖ A legally appointed guardian, if any
  - ❖ If no legal guardian, then a spouse, if any
  - ❖ If no spouse, then an unpaid carer of the person
  - ❖ If no carer, then a close friend or relative of the person.
- A practitioner does not have to seek consent to save a client's life.



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## NCAT Guardianship Division

### NCAT Guardianship Division required to give consent

- without a 'person responsible'
- without a guardian an application should be made by the doctor or dentist to the to treat the person
- To special medical treatments including sterilisation and termination of pregnancy

### Treatment cannot be given without this consent



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# Transition

## A Clinician's Guide

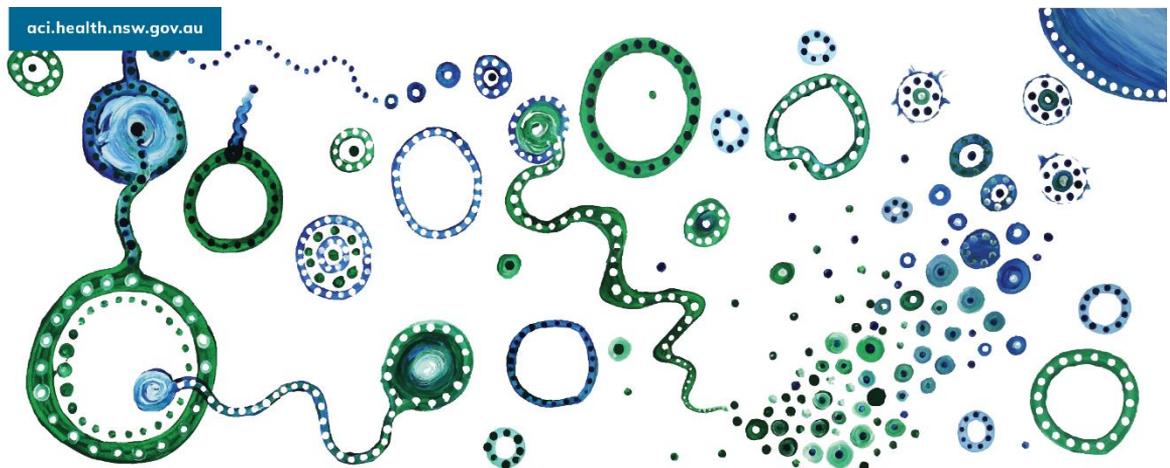
Angie Myles | Transition Care Coordinator Northern | ACI Transition Care Network / HNEKIDShEALTH HNELHD

15<sup>th</sup> March 2022 | Virtual Event NSW Clinicians



The slide features a dark teal background with white and light blue curved lines. At the top left is the URL 'aci.health.nsw.gov.au'. The main title 'Transition' is in large white font, followed by the subtitle 'A Clinician's Guide'. Below that is the presenter's name and affiliation. The date and event name are listed next. At the bottom, there are four logos: the NSW Government logo, the Agency for Clinical Innovation logo, the HNEKIDShEALTH logo with the tagline 'Children, Young People & Families', and the Twitter handle '@nswaci'.

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**ACI acknowledges the traditional owners of the land that we work on.  
We pay our respect to Elders past and present and extend that respect  
to other Aboriginal peoples present here today.**

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I recognise and appreciate consumers, patients, carers, supporters and loved ones. The voices of people with lived experience are powerful.

Their contribution is vital to enabling decision-making for health system change



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## Objectives

- Where does ACI fit within NSW Health?
- Statistics - young people and transition
- Differences between paediatric and adult services
- Key principles for transition and practical strategies
- NSW Transition Services
- Non medical things to consider
- Takeaway message

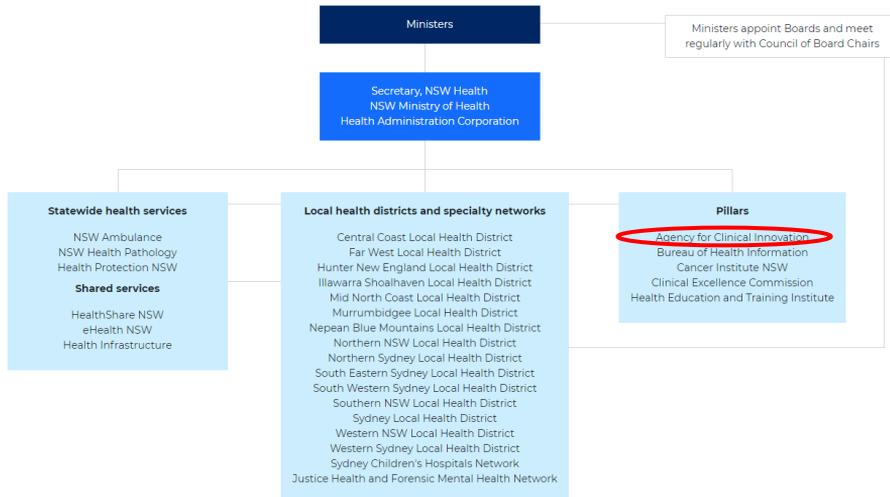
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## NSW Health organisation chart



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## More young people transitioning

In 2020, there were 3.2 million young people aged 15-24 in Australia representing 12% of the total population

- 31% of young people aged 15-24 years live in NSW
- Across Australia 5.1% of young people are Aboriginal or Torres Strait Islander
- 1 in 11 (9.3%) have a disability
- Approximately 12% reported at least one chronic condition/disability  
(Australian Institute of Health and Welfare 2021, Australia's youth: in brief. Cat. no. CWS 89. Canberra: AIHW).

Over 90% of young people with chronic conditions arising in childhood are estimated to survive into adulthood (Blum et al 2002).

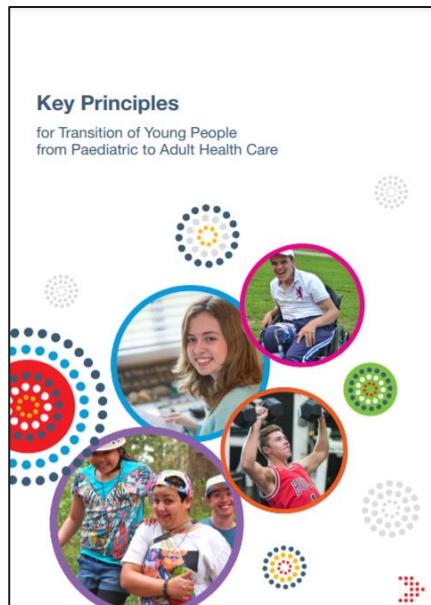
Adolescents are transitioning at an increasing rate from paediatric services into mainstream adult services which are often ill equipped to meet their needs

Providing appropriate transition services can impact positively on the young person's ability to manage their health & achieve improved health outcomes

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## Differences between paediatric and adult health services

Paediatric Services	Adult Services
Paediatrician often has a coordination role	Expectation that the GP will have a coordination role and take over the prescribing of medications
Encourage families and carers to be present in consultations	Encourage the young person to see the clinician independently
Free or reduced cost of medications, equipment and treatments	May need to pay for medications, Treatments and resources
Provide multidisciplinary team & 'one stop shop' often with specialist knowledge about rare conditions	Greater choice of medical specialties around adult health issues e.g., Drug and Alcohol, Sexual Health and Fertility, Mental Health services



[https://aci.health.nsw.gov.au/\\_data/assets/pdf\\_file/0011/251696/Key\\_Principles\\_for\\_Transition.pdf](https://aci.health.nsw.gov.au/_data/assets/pdf_file/0011/251696/Key_Principles_for_Transition.pdf)

## Aims of the key principles

1. Better functional outcomes
  - Increased adherence
  - Improved self - management
  - Knowledge of their condition
  - Improved wellbeing
2. Better access to appropriate health services for young people with a chronic condition
3. Improved morbidity & mortality rates
4. A reduction in avoidable hospital admissions

## 7 Key principles for transition



- 1 A Systematic and Formal Transition Process**  
 A systematic and formal transition process is required. This should be underpinned by formal guidelines and policies outlining the transition process.
- 2 Early Preparation**  
 Transition is a process not an event. Education on transition and empowerment around self-management will commence with the young person at the age of 14.
- 3 Identification of a Transition Coordinator/ Facilitator**  
 A designated Transition Coordinator/Facilitator from the young person's paediatric and adult specialty teams should be identified to coordinate the transition.
- 4 Good Communication**  
 Communication processes and tools will support person-centred care for the young person throughout their transition journey. Openness, transparency, collaboration and a willingness to work together underpins all good communication.
- 5 Individual Transition Plan**  
 All young people should have an individualised transition plan which focuses on all aspects of their life.
- 6 Empower, Encourage and Enable Young People to Self-Manage**  
 Responsibility for decision-making should be increased gradually and adolescent friendly transition services should be put in place. Where the young person has complex needs, it is particularly important to involve their family/carer.
- 7 Follow up and Evaluation**  
 Follow up may be required for several years to ensure that young people have engaged effectively with adult health care services. Evaluation of the transition process must be undertaken to inform future planning and policy.

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## Principle 2: Early preparation

### Things for all clinicians to consider:

1. Do you currently **identify** all young people aged 14 and over for transition planning?
2. Do you **talk about transition** to young people and their carers at regular intervals (normalising the process)?
3. Do you allocate **1:1 time** in your apt for the young people to see the you independently? (where developmentally appropriate)
4. Does the young person have a **GP** that they have a good rapport with? does the young person see their GP?
5. Does the young person / carer know they can have their own **Medicare Card**

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## Early preparation

### Are you aware of the transition:

- **services** available for young people with complex health care requirements and how to refer?
- **resources** and **apps** available to clinicians, young people and carers?
- **education sessions** available throughout the year for young people and their carers?

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Transition Support services in NSW			
 	 	 	
<b>Trapeze</b>	<b>Agency for Clinical Innovation Transition Care Service</b>	<b>South Western Sydney Local Health District Paediatric to Adult Care (SWSLHD P2A)</b>	<b>Spina Bifida Adult Resource Team (SBART)</b>
<ul style="list-style-type: none"> <li>• Paediatric setting</li> <li>• Supports YP <b>known</b> to the SCHN (CHW or SCH) to transition from the paediatric to adult healthcare system</li> <li>• <a href="http://www.trapeze.org.au/">http://www.trapeze.org.au/</a></li> </ul>	<ul style="list-style-type: none"> <li>• Paediatric &amp; adult setting</li> <li>• State-wide care coordination service</li> <li>• <a href="https://aci.health.nsw.gov.au/_data/assets/pdf_file/0008/665702/ACI-Transition-Care-Service.pdf">https://aci.health.nsw.gov.au/_data/assets/pdf_file/0008/665702/ACI-Transition-Care-Service.pdf</a></li> </ul>	<ul style="list-style-type: none"> <li>• Paediatric &amp; adult setting</li> <li>• LHD- based service</li> </ul>	<ul style="list-style-type: none"> <li>• Life-long adult service from 18 years</li> <li>• State-wide service funded by NSW Health</li> <li>• Specific referral criteria: spinal bifida, neural tube defects, congenital spinal anomalies (no SCI)</li> <li>• <a href="https://northcott.com.au/spina-bifida-adult-resource-team/">https://northcott.com.au/spina-bifida-adult-resource-team/</a></li> </ul>

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## Referral criteria & referring



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## Accepts referrals for young people living in NSW or ACT:

- Aged 14 – 25 years
- Living with a chronic illness / disability (excluding a primary diagnosis of mental illness or eating disorders)
- Requires complex case coordination to transition to adult specialist health services
- Transition Service Referral Form [https://aci.health.nsw.gov.au/\\_data/assets/word\\_doc/0009/165870/ACI-Referral-Form.docx](https://aci.health.nsw.gov.au/_data/assets/word_doc/0009/165870/ACI-Referral-Form.docx)

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## ACI transition care service – what we do....



### Help young people, their families, carers and their health professionals by:

- Plan the **transfer of care** and assist in the **development of transition plans**
- Provide **information about adult health services** and services in the community
- Help to sort out any **difficulties in finding or attending** an adult health service
  - no clear pathways
  - access issues & different local health districts
  - available resources

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## ACI transition care service – what we do....



- Provide guidance & support to attend clinics – **first adult appointments**
- Assist the young person / carer to **adjust to new adult teams and services** and the different ways things may be done in the adult health services
- **Regular follow-up** - contacting the young person, their family and carers to make sure they have successfully engaged with an adult health service
- Follow through and **provide feedback** once young people have moved to adult services

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## Factsheets for young people, health professionals & carers

- ✓ Finding a good GP
- ✓ Medicare & paying for health services
- ✓ How to prepare for your transition
- ✓ Stages of healthcare transition
- ✓ Transition...getting ready to move to adult health services
- ✓ Ideas for parents and carers to support young people with chronic conditions with their transition
- ✓ Your rights in accessing health care
- ✓ **Healthcare transition for young people with intellectual disability**

### Easy read information for young people

- ✓ **Being in charge of your healthcare**
- ✓ **Costs in adult health services**
- ✓ **Finding a good GP**
- ✓ **Getting ready to move**
- ✓ **Stages of transition**

Also available in Arabic and Vietnamese

<http://www.trapeze.org.au/content/factsheets>

<https://aci.health.nsw.gov.au/networks/transition-care/resources>

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## Early preparation

### Checklists for:

- Young people
- Transition readiness
- Clinicians
- Parents & carers

### Websites Relevant to Young People

[https://aci.health.nsw.gov.au/\\_data/assets/pdf\\_file/0003/596073/List-of-websites-relevant-to-young-people.pdf](https://aci.health.nsw.gov.au/_data/assets/pdf_file/0003/596073/List-of-websites-relevant-to-young-people.pdf)

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## MyTransition App



<p>Calendar: assists in keeping track of appointments and prescriptions</p>	<p>Tips: provides ideas to improve transition readiness linked to each of the 14 TRANSITION-Q items</p>	<p>TRANSITION-Q history: shows whether you have improved overall on the TRANSITION-Q</p>

<https://www.canchild.ca/en/research-in-practice/current-studies/apply-the-mytransition-app-in-transition-applyit-study/mytransition-app>

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## Preparing for health care transition

Online events conducted via Zoom must register through **Eventbrite**  
<https://www.eventbrite.com.au/e/preparing-for-transition-to-adult-healthcare-tickets-210811491847?aff=ebdssbeac>

- Friday 22 April 2022, 10 -11am
- Thursday 30 June 2022, 7:30 – 8:30pm
- Friday 26 August 2022, 10 – 11am
- Thursday 27 October 2022, 7:30 – 8:30pm
- Friday 9 December 2022, 10 – 11am

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## Principle 6: Empower, encourage and enable young people to self manage

### Things to consider:

Encourage the young person to develop skills if appropriate:

- Know and describe their medical condition(s)
- Know their medications, doses & where to obtain scripts
- Know and participate in their treatment
- Booking & rescheduling appointments
- Speaking with specialists independently or with support
- Knowing what to do and being prepared for emergencies? Examples: having Medical identification (ID) on their phone, carrying an Epipen

Health fact sheets available on Council for Intellectual Disability website

<https://cid.org.au/wp-content/uploads/2019/10/Health-Fact-Sheets-2019-All.pdf>

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## Principle 6: Empower, encourage and enable young people to self manage

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### Non Medical things for YP and carers to consider

Is the young person and/or carer aware of their eligibility for **Centrelink** entitlements, **taxi subsidy scheme**, **companion card**?

Is young person registered / or unregistered to **Vote** with the Australian Electoral Commission (AEC)?

### Disability Support Pension (DSP)

#### Eligibility

1. 16 years +, residency, for individuals who unable to work 15hours or more per week due to permanent illness/ disability. Income & assets test. Medical evidence required

<https://welfarerightscentre.org.au/legal-services> Free legal information & advice

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## Non Medical Things

### Companion Card NSW

Any Age, residency, live NSW and have significant permanent disability and require life long attendant care support to participate in activities or attend venues

<https://www.companioncard.nsw.gov.au/home>

### Voting & Commonwealth Electoral Role

Compulsory to enrol, can enrol from 16 years & vote from 18 years - physical disability & unable to write provisions. Easy read guides available

[https://www.aec.gov.au/About\\_AEC/Publications/easy-read/files](https://www.aec.gov.au/About_AEC/Publications/easy-read/files)

Objection claim that elector should not be enrolled- Medical Certificate required

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## Non Medical Things

### NSW Taxi Subsidy Scheme

Eligibility- severe and permanent disability (severe Intellectual Disability eligible category of disability) Not means tested

Eligible subsidy 50% up to \$60, resident NSW, be over school age

Supporting medical documents required

[https://www.aec.gov.au/About\\_AEC/Publications/easy-read/files/how-to-enrol-easy-eng.pdf](https://www.aec.gov.au/About_AEC/Publications/easy-read/files/how-to-enrol-easy-eng.pdf)

### School Leavers Expo's Disability & Support Teacher Transition (public schools)

Assistance for students with disability around transition to post school options

Annual Expo's

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## Useful Websites

Centrelink Payment and Service Finder Services NSW

[https://www.centrelink.gov.au/custsite\\_pfe/pymtfinderest/paymentFinderEstimatorPage.jsf?wec-appid=pymtfinderest&wec-locale=en\\_US#stay](https://www.centrelink.gov.au/custsite_pfe/pymtfinderest/paymentFinderEstimatorPage.jsf?wec-appid=pymtfinderest&wec-locale=en_US#stay)

The Intellectual Disability Rights Service (irds)

<https://irds.org.au/>

Say less, show more

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

Planet Puberty Family Planning NSW

<https://www.planetpuberty.org.au/about-us/>

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## Take away messages

- Identify the young persons transition needs early and communicate / liaise with GP and clinicians
- Identify young people who require complex care coordination and know how to refer to transition care services
- Paediatric clinicians should promote the role of the GP and encourage young people & their carers to build rapport with their GP
- Know what resources exist and how to access
- Consider the individual needs of the young person as an emerging young adult and promote independence and self management skills where appropriate

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## Contacting us

**HNEkidshealth**  
Children, Young People & Families

**NSW GOVERNMENT** | **AGENCY FOR CLINICAL INNOVATION**

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## Resources

- Transition advice for carer on preparing for appointments with GP and shared care templates for information sharing and goal setting)
- [https://www.rch.org.au/uploadedFiles/Main/Content/transition/180116%20DI%20LORI%20AT%20Transition%20A5%20book\\_5.pdf](https://www.rch.org.au/uploadedFiles/Main/Content/transition/180116%20DI%20LORI%20AT%20Transition%20A5%20book_5.pdf)
- Supported decision making
- [https://www.facs.nsw.gov.au/\\_data/assets/pdf\\_file/0010/590617/048-Decision-Making-and-Consent-Guidelines-accessible.pdf](https://www.facs.nsw.gov.au/_data/assets/pdf_file/0010/590617/048-Decision-Making-and-Consent-Guidelines-accessible.pdf)
- Sexual health
- <https://www.fpnsw.org.au/factsheets/health-professionals/resources/supporting-decision-making-reproductive-and-sexual-health>
- Puberty and sexual health fact sheets
- [https://www.fpnsw.org.au/sites/default/files/assets/FPNSW\\_GrowingSexuality\\_booklet.pdf](https://www.fpnsw.org.au/sites/default/files/assets/FPNSW_GrowingSexuality_booklet.pdf)
- <https://www.fpnsw.org.au/factsheets/individuals/disability>



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## Contact Details

- **Northern Intellectual Disability Health Service**

Ph: 02 8968 3400

Fax: 02 9904 1541

[NSLHD-Intellectualdisability@health.nsw.gov.au](mailto:NSLHD-Intellectualdisability@health.nsw.gov.au)

- **Local ID Clinicians**

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