

# Healthcare transition for young people with intellectual disability

## Information for families and carers

This resource is for families and carers of young people with an intellectual disability who are transitioning from paediatric to adult health services.

It provides guidance on some of the common practical issues that need to be addressed before and during transition. Also listed are the many services and organisations that are available to help you and your young person navigate this time of change.

### What is transition?

Transition is a process of moving from children's (0–18) healthcare services to adult (18+) healthcare services and often coincides with other significant changes, like finishing school. Preparing for transition involves equipping you and your young person with the knowledge to manage this process. All decisions should be centred on your young person, what is in their best interest and their right to live a full life, while also respecting your role as their carer.

Transition is ideally a gradual process that starts early to give you time to plan and prepare. Discussing transition with your healthcare teams can start from the age of 14. Many of the services mentioned are based in NSW, but there may be equivalent services if you live elsewhere.

Please visit our two websites for transition tips and resources:

- Trapeze [www.trapeze.org.au](http://www.trapeze.org.au)
- NSW Agency for Clinical Innovation (ACI) Transition Care Service  
[www.aci.health.nsw.gov.au/networks/transition-care/about/transition-care-service](http://www.aci.health.nsw.gov.au/networks/transition-care/about/transition-care-service)

If you haven't accessed Trapeze or the ACI Transition Care Service for the transition of health services for your young person, your main point of contact could be your general practitioner (GP) or specialist doctors.

### In this resource

What is transition?	1
In this resource	1
Finding support	2
Private health insurance	3
Before leaving children's or adolescent services	3
Carer and patient experience	4
Medication	4
Equipment and resources	4
Reproductive and sexual health	4
Decision-making	5
Government services	6
School and post-school options	7

## Finding support

As a parent or carer of a young person with intellectual disability, knowing where you can find support is useful. You are not alone, and it is helpful to turn to others for additional support.

### Useful people or organisations

- Family and friends
- Your GP and your young person's healthcare team members
- Support workers or social workers
- Psychologists or counsellors
- Cultural and language support – through diversity health workers or healthcare interpreters
- Aboriginal liaison officers or Aboriginal health workers within the local health district or Aboriginal health services.

### Carer support

- **Carer Gateway**  
Produced by the Australian Dept of Social Services, Carers Gateway provides practical information and advice, free counselling services and coaching as well as connection with other carers through a community forum.  
Tel: 1800 422 737 | [www.carergateway.gov.au](http://www.carergateway.gov.au)
- **Carers NSW**  
The peak non-government organisation for carers in NSW. It focuses on improving the lives of carers.  
Tel: 1800 242 636 | [www.carersnsw.org.au](http://www.carersnsw.org.au)

### Disability advocacy

- **Disability Advocacy agencies NSW**  
[www.dss.gov.au/disability-and-carers/programmes-services/for-people-with-disability/national-disability-advocacy-program/models-of-disability-advocacy/national-disability-advocacy-agencies-funded-by-the-commonwealth-by-state-or-territory/disability-advocacy-agencies-new](http://www.dss.gov.au/disability-and-carers/programmes-services/for-people-with-disability/national-disability-advocacy-program/models-of-disability-advocacy/national-disability-advocacy-agencies-funded-by-the-commonwealth-by-state-or-territory/disability-advocacy-agencies-new)

- The Department of Social Services has an online **Disability Advocacy Finder** that includes state-and-territory-funded advocacy providers. The finder will also help people with a disability find National Disability Advocacy Program services across Australia.  
[disabilityadvocacyfinder.dss.gov.au/disability/ndap/](http://disabilityadvocacyfinder.dss.gov.au/disability/ndap/)

### Community support organisations

- **Ability Links** is a way of connecting people with disability, their families and carers in the community. Linkers work closely with people with disability, their families and carers to support them to fulfil their goals, hopes and dreams. [www.abilitylinksnsw.org.au](http://www.abilitylinksnsw.org.au)
- The **Council for Intellectual Disability** works with and for all people with intellectual disability to advocate for their rights and make life better in all aspects where possible.  
[cid.org.au](http://cid.org.au)
- **IDEAS (Information on Disability Education and Awareness Services)**  
Tel: 1800 029 904 | [www.ideas.org.au](http://www.ideas.org.au)
- **Intellectual Disability Rights Service**  
A disability advocacy service and a community legal centre. They work alongside people with disability to promote and protect their rights.  
[www.idrs.org.au](http://www.idrs.org.au)

### Adolescent transition clinics in children's or adult hospitals

- **NSW ACI Transition Care Service**, includes details of area coordinators  
[www.aci.health.nsw.gov.au/networks/transition-care/about/transition-care-service](http://www.aci.health.nsw.gov.au/networks/transition-care/about/transition-care-service)
  - Northern Area  
Tel: 02 4925 7866 or 0434 361 202
  - Western Area  
Tel: 02 8890 7787 or 0436 323 321
  - South Eastern Area  
Tel: 02 9382 5455 or 0425 232 128
- Sydney Children's Hospital Network Trapeze Service Tel: 02 9382 5457  
[www.trapeze.org.au](http://www.trapeze.org.au)

## A general practitioner for your young person

- Your GP is the central medical coordinator in your young person's healthcare and can connect you to health providers.
- Your GP should be your first point of call if your young person is unwell (except for emergencies).
- It is important to find a GP practice that meets your needs. Things to consider are accessibility and availability of appointments.
- When requesting a first appointment with the GP consider if quiet space is required and available to improve the waiting room experience.
- Your GP can perform an annual health check to enable comprehensive review and planning of your young person's health needs (Chronic Disease Management Plan). Looking after yourself as a carer is important too, so chat to your GP about having an annual health check for yourself.
- Consider asking for a longer appointment to enable your GP enough time to examine and discuss your young person.
- Ask your GP about referrals to psychology and other allied health services if required. A referral from a GP can unlock Medicare funding for these services.
- If your young person has a My Health Record, encourage your GP to upload your young person's health information to facilitate the sharing of information with other health professionals.
- **National Home Doctor Service**  
After hours GP home visits bulk billed  
Tel: 13 74 25 (13 SICK) | [homedoctor.com.au](http://homedoctor.com.au)
- **Health Direct**  
Government-funded service for 24 hour health advice  
Tel: 1800 022 222 | [www.healthdirect.gov.au](http://www.healthdirect.gov.au)

## Private health insurance

If your family has private health insurance, please check with your insurer for the age to which your young person may be considered a dependent on the insurance policy.

## Before leaving children's or adolescent services

- ✓ From about the age of 14 talk with your healthcare teams about transition.
- ✓ From the age of 15, consider if your young person should have a Medicare card.
- ✓ From about the age of 16 ask your healthcare teams or specialists who they recommend your young person to see in the adult healthcare setting and develop a transition plan.
- ✓ Discuss with your healthcare team if a period of overlap between children's and adult services might be an option to ease the health transition. The timing of when this happens should be discussed with your healthcare teams. It might be around the age of 17.
- ✓ Make contact with Aboriginal health services if appropriate.
- ✓ Ask for copies of clinical letters, summary of care, relevant reports and imaging.
- ✓ Speak to your healthcare team about access to medication, equipment or allied health services supplied through the children's hospital, as it may be different at the adult hospital.
- ✓ Allow for possible long waiting times for first appointments in adult healthcare and talk to your healthcare providers about how to manage emergency situations during the time between the last children's health appointment and the first adult appointment.
- ✓ Consider discussing with your healthcare team whether a nurse's time should be included in the NDIS plan if your young person has high medical requirements or is unable to manage their health issues on their own.
- ✓ Consider creating person-centred profile with your healthcare team around how best care could be managed in an adult setting to assist adult teams to learn about your young person and how they respond to a health encounter.

Trapeze and the ACI transition care coordinators are available to assist you through the healthcare transition process.

## Carer and patient experience

The care provided in an adult hospital or service may be different to what was provided in children's healthcare services.

Adult health services recognise the important role of the family and carers when your young person is admitted to hospital. Speak with staff, like the nursing unit manager, about how to best meet your young person's needs (e.g. a family member staying by the bedside during admission). The carer representative or patient friend can help with this initial advocacy, if you need assistance. Every person has a right to appropriate healthcare. There are resources available to support the communication with health professionals on what is relevant and appropriate for your young person.

- **Admission2Discharge Together** was developed to improve the hospital experiences of people with a cognitive impairment, their carers, families and disability support staff. Through improved communication and sharing of relevant and current information, hospital staff are better equipped to meet the needs of people with a cognitive impairment.  
[a2d.healthcare](http://a2d.healthcare)
- **My Health Matters folder** developed by Council for Intellectual Disability.  
[cid.org.au/resource/my-health-matters-folder](http://cid.org.au/resource/my-health-matters-folder)
- ACI's **Say Less, Show More** seeks to provide this support with a series of simple photo stories (visuals) that illustrate what will happen during a physical examination or blood test.  
[www.aci.health.nsw.gov.au/resources/intellectual-disability/hospitalisation/say-less-show-more](http://www.aci.health.nsw.gov.au/resources/intellectual-disability/hospitalisation/say-less-show-more)
- Clinical Excellence Commission **Top 5 Initiative – Engaging Carers** simple process that encourages health professionals to engage with carers to gain valuable non-clinical information to help personalise care.  
[www.cec.health.nsw.gov.au/quality-improvement/people-and-culture/person-centred-care/top5](http://www.cec.health.nsw.gov.au/quality-improvement/people-and-culture/person-centred-care/top5)

## Medication

Most medications used in Australia are subsidised through the Pharmaceutical Benefits Scheme (PBS). To access this subsidy, you need to have a Medicare card. A Health Care Card (HCC) can further lower the cost of medication for your young person. Once your medication costs in a calendar year pass a certain threshold, you and your family may be eligible for the PBS Safety Net.

- **Concession and health care cards**  
[www.servicesaustralia.gov.au/individuals/subjects/concession-and-health-care-cards](http://www.servicesaustralia.gov.au/individuals/subjects/concession-and-health-care-cards)
- **Information on the PBS Safety Net**  
[www.humanservices.gov.au/individuals/steps/when-you-spend-lot-pbs-medicines/51177](http://www.humanservices.gov.au/individuals/steps/when-you-spend-lot-pbs-medicines/51177)
- If you obtain your medications through a children's hospital pharmacy, check whether this can continue at the adult hospital. Talk to your children's or adult healthcare team, transition coordinator or hospital pharmacist.

## Equipment and resources

Equipment that has been loaned from the children's hospital, such as pumps, humidifiers and oxygen tanks will have to be returned when your young person transitions. If your young person has resources such as feeding tubes, connections, special feeds or formula, you will need to find out whether your supplier will continue to provide these after transition, or if a new referral and prescription will be required.

Your GP, specialist or your healthcare team will help you apply for these resources or direct you to the appropriate people to help you. Look at the NDIS pathways that could facilitate this.

## Reproductive and sexual health

Young people with intellectual disability may want to explore their sexuality and looking after your young person's reproductive and sexual health is a part of caring for their general health and wellbeing. Please talk with your GP if you have any questions and review these resources:

- **Family Planning NSW: disability resources**  
[www.fpnsw.org.au/who-we-help/disability/disability-resources](http://www.fpnsw.org.au/who-we-help/disability/disability-resources)

## Decision-making

After the age of 18, NSW law assumes your young person has the capacity to make decisions. Your young person may be able to be supported to make some decisions about their finances, health and life choices. Their wishes guide this process.

If your young person has decision-making ability, they can and should continue to make decisions. They can appoint an enduring guardian (for medical, health and lifestyle decisions) or a power of attorney (for property and financial matters) to manage their affairs while they are alive (e.g. in case of illness or travel). This can be revoked at any time as long as they have capacity.

If your young person is not able to make important life decisions even with support, then it may be appropriate for other people who have a close and trusted relationship to make these decisions, that is, a 'person responsible'.

A person responsible can be a family member, friend or neighbour, however it is important to note that anyone who is paid to provide support services is ineligible.

Sometimes a formal process is necessary where the Guardianship Division of the NSW Civil and Administrative Tribunal can appoint a guardian for medical, health and lifestyle decisions or a financial manager for financial affairs. This may be needed if there is disagreement, or if the young person has no one able to act as a person responsible.

Please contact the resources listed below to guide your individual situation.

- **Aboriginal Legal Services NSW/ACT**  
[www.alsnswact.org.au](http://www.alsnswact.org.au)
- Dept of Communities and Justice:  
**Capacity Toolkit.** Information for government and community workers, professionals, families and carers in NSW  
[www.justice.nsw.gov.au/diversityservices/Pages/divserv/ds\\_capacity\\_tool/ds\\_capacity\\_tool.aspx](http://www.justice.nsw.gov.au/diversityservices/Pages/divserv/ds_capacity_tool/ds_capacity_tool.aspx)
- **Guardianship Division NSW Civil and Administrative Tribunal**  
[www.ncat.nsw.gov.au/Pages/guardianship/guardianship.aspx](http://www.ncat.nsw.gov.au/Pages/guardianship/guardianship.aspx)
- **LawAccess NSW** gives information about the law and legal issues. It provides legal advice over the phone and links to relevant services  
Tel: 1300 888 529 |  
[www.lawaccess.nsw.gov.au](http://www.lawaccess.nsw.gov.au)
- **Legal Aid NSW**  
[www.legalaid.nsw.gov.au](http://www.legalaid.nsw.gov.au)
- **NSW Public Guardian**  
[www.publicguardian.justice.nsw.gov.au](http://www.publicguardian.justice.nsw.gov.au)
- **NSW Trustee and Guardian**  
[www.tag.nsw.gov.au](http://www.tag.nsw.gov.au)
- **Planning Ahead Tools** is a NSW government website with information about organising a will, power of attorney, enduring guardianship or advance care planning  
[www.planningaheadtools.com.au](http://www.planningaheadtools.com.au)
- **Youth Law Australia** is a community legal service that provides free, confidential legal information and help for young people under 25  
Tel: 02 9385 9588 | [yla.org.au](http://yla.org.au)

## Government services

### MyGov

MyGov is a way to access Australian government services online and all in one place.

Tel: 132 307 | [my.gov.au](http://my.gov.au)

Some of the government services include:

- Medicare
- Child Support
- Australian Tax Office
- Centrelink
- Australian JobSearch
- My Health Record
- National Disability Insurance Scheme

### Australian Department of Human Services (Centrelink)

Centrelink offers a range of payments to support Australian residents. **Payment and Service Finder** on the website can help determine what your young person is eligible for. There is also an Essential Medical Equipment payment available.

[www.servicesaustralia.gov.au/individuals/topics/payment-and-service-finder/28656](http://www.servicesaustralia.gov.au/individuals/topics/payment-and-service-finder/28656)

- Disabilities and Carers Line | Tel: 132 717
- Youth and Students Line | Tel: 132 490
- Multilingual support | Tel: 131 202

### Australian Taxation Office

The **Australian Taxation Office: People with a disability** provides support services to help people with disability and there may be tax and superannuation concessions and exemptions available. A bank account and tax file number are needed if your young person receives income (including Centrelink).

[www.ato.gov.au/Individuals/People-with-disability](http://www.ato.gov.au/Individuals/People-with-disability)

### National Disability Insurance Scheme

The National Disability Insurance Scheme (NDIS) provides support to eligible people with intellectual, physical, sensory, cognitive and psychosocial disability. Early intervention supports can also be provided for eligible people with disability or children with developmental delay. The NDIS can provide all people with disability with information and connections to services in their communities

such as doctors, sporting clubs, support groups, libraries and schools, as well as information about what support is provided by each state and territory government. [www.ndis.gov.au](http://www.ndis.gov.au)

### Enrolling to vote

It is compulsory in Australia for all Australian citizens over the age of 18 to enrol and vote in Federal elections and referendums.

Everyone has a right to vote. Some people may need additional support to enrol and vote. The Australian Electoral Commission provides a range of **Easy read guides** for people who have difficulty reading and understanding written information. If your young person cannot understand the voting process, you can request that they be exempt from enrolling and voting.

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

To do this, complete an **Objection claim that an elector should not be enrolled form** and get your GP to sign the form and return it to the Australian Electoral Commission.

[www.aec.gov.au/Enrolling\\_to\\_vote/pdf/forms/objection/er005aw.pdf](http://www.aec.gov.au/Enrolling_to_vote/pdf/forms/objection/er005aw.pdf)

### Photo ID card

There may be times when your young person needs to present proof of their identity. The **NSW Photo Card** provides photo identification for people who do not hold a current NSW driver licence or other form of photo identification. You can use it to open bank accounts or enter licensed premises. This card is available free of charge for young people who have a current Pensioner Concession Card issued by Centrelink (e.g. Disability Support Pension).

[www.rms.nsw.gov.au/roads/licence/nsw-photo-card.html](http://www.rms.nsw.gov.au/roads/licence/nsw-photo-card.html)

### NSW Companion Card

The **NSW Companion Card** program is for people with significant and permanent disability who have a lifelong need for a high level of care to participate in community events and activities. This card allows a person's carer free entry into participating venues and events.

[www.companioncard.nsw.gov.au](http://www.companioncard.nsw.gov.au)

## School and post-school options

Schools need to provide adjustments to teaching, learning and assessment activities for students with disability. Leaving school is a significant transition point in the life of a young person with a disability. Talk to your school about the annual school leavers' expo disability in your area. Your young person's school will provide you with information and will support you through post-school planning for day programs or supported working environments.

Remember that this will need to be planned for in your NDIS plan. There are a number of useful resources available to help navigate this process.

- **National Disability Coordination Officer Program** – works strategically to assist people with disability access and participate in tertiary education and subsequent employment, through a national network of regionally based NDCOs.  
[www.education.gov.au/national-disability-coordination-officer-programme](http://www.education.gov.au/national-disability-coordination-officer-programme)
- **NSW Education Standards Authority, Special Education**  
<https://educationstandards.nsw.edu.au/wps/portal/nesa/11-12/Diversity-in-learning/stage-6-special-education>

- **NSW Department of Education Transition Planning** – high school learning and support teams assist and support students, parents and carers with transition planning.  
<https://education.nsw.gov.au/teaching-and-learning/disability-learning-and-support/leaving-school/transition-planning>
- **TAFE NSW Disability Support Services**  
[www.tafensw.edu.au/student-services/disability-services](http://www.tafensw.edu.au/student-services/disability-services)
- **Training Services NSW, Apprenticeships and Traineeships**  
[www.training.nsw.gov.au/apprenticeships\\_traineeships/index.html](http://www.training.nsw.gov.au/apprenticeships_traineeships/index.html)
- **Universities** – each university will have their own Disability Support Service.
- **National Disability Insurance Scheme (NDIS)** commonly funds post-school services.  
Tel: 1800 800 110 | [www.ndis.gov.au](http://www.ndis.gov.au)