

Expert Roundtable on Transitioning Young People with Intellectual Disability and Mental Illness to Adult Health Services

Summary Report

The Agency for Clinical Innovation (ACI) works with clinicians, consumers and managers to design and promote better healthcare for NSW. It does this by:

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Glossary

GP	General practitioner
ID	Intellectual disability
LHD	Local health district
NDIS	National Disability Insurance Scheme
PHN	Public health network

Executive summary

The aim of the Expert Roundtable on Transitioning Young People with Intellectual Disability (ID) and Mental Illness to Adult Health Services was to develop a consensus statement to guide policy and systems and assist managers and clinicians with implementing a co-designed and expert informed model.

This summary report discusses the need for change, the challenges with current transitioning practices for young people with ID and mental illness and the consensus points gathered from the Expert Roundtable held in July 2017. It suggests actions and areas for change.

‘Don’t underestimate the role and depth of skill of the GP. With access to expert support and consultation pathways, we can play a key role in supporting the person with intellectual disability and their family.’

General Practitioner

The NSW *Disability Inclusion Act* enshrines the rights of people with disability to equitable access to health services.¹ However, the system is not working as it should for people with ID according to patient satisfaction results, data linkage reports and reports from the NSW Ombudsman.^{2,3,4}

This work is underway during a period of disability reform as the National Disability Insurance Scheme (NDIS) is being rolled out across NSW and people with ID and their carers are empowered to assess their needs and interactions with service providers. It is pushing up against an absence of a NSW Health policy on transitioning within mainstream health services. There is current NSW Health policy to support transitioning young people within mental health services (GL2018_022).⁵ Tertiary level paediatric services have developed their own local policies and services to assist the process.

Systemic and structural barriers impact on ease of access to health services in the transitioning phase for young people with ID and mental illness. The transition pathway for this group of young people, who will not attain independence and have difficulty communicating needs and preferences, is not certain and requires links with service providers, general practitioners (GPs), mental health services and interagency partners.

‘Belinda is now 16, I’m worried that there are not many people with skills and interest to move onto. This is the first time I have heard about a transition person at the hospital.’

Kassie and Belinda, Real People, Real Lives.

A person-centred, wrap-around model in the community is required but it relies on a systems response with funding support to enable better communication between professionals and service providers.

The opinions of the experts attending the roundtable are collated under themes and suggestions. It is from this that the expert consensus statement is developed to guide health services as they seek to transition young people with ID and mental illness to adult health services.

‘The issue of transition to adult services is one that has not been resolved yet.’

Magda and Susie, Real People, Real Lives.

The work has included consultation with directors and managers of Aboriginal health services, the ACI GP Advisory Group, NSW carers and consumers, non-government organisations, public health networks (PHNs), Trapeze and the ACI Transition Care Network.

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Background

The ACI Intellectual Disability Health Network Model of Care subcommittee (the subcommittee) has a focus on youth transitioning to adult health services within the context of the Tiered Service Framework (see Appendix 1) and [the Essentials website](#).^{6,7} Approximately 1.8% of the population has an ID. In NSW that equates to about 92,000 people and around 40% of this number have a mental illness at any point in time.

The subcommittee decided to consult with experts to develop a consensus statement on transitioning to adult health services for this patient group. The period when young people transition is a busy life stage, involving school and post-school programs, family and friendship developments, possibly changes to living and financial arrangements and moving to adult health services from paediatric services. The Expert Roundtable occurred following the launch of *the Essentials*, a website giving guidance to NSW health services on providing services for people with intellectual disability.

The Expert Roundtable is an attempt to build on the work of the Transition Care Network and Trapeze to address the specific needs of youth with ID and mental health co-morbidity, who will not attain independence.⁸ It is in response to reports from families and paediatric and adolescent health services experiencing challenges in transitioning young people with ID, including people with ID and mental illness, to adult health services.⁹ The process and discussions begin at 13-15 years of age, but often with repercussions on health outcomes, unplanned emergency department presentations and consumer and carer stress.²

The NSW *Disability Inclusion Act* enshrines the rights of people with disability to equitable access to health services.¹ Equity of access and rights-based service provision occurs through working collaboratively with consumers and carers and across agencies. To do so there is a need to address attitudes and barriers in a systematic way. This consensus statement was developed as the NDIS was being rolled out in NSW and people with disability and their carers are negotiating with agencies and providers for funding and services to best meet their needs. NSW Health has no policy on transitioning within mainstream health services. Adult health services have no local policies on how they process the transition for young people with ID, although tertiary level paediatric services have developed their own local policies and services to assist the process.

There is a current NSW Health policy to support transitioning young people within mental health services (GL2018_022).⁵ *NSW Youth Health Framework 2017-24; PD 2017_019* acknowledges the vulnerability of young people with chronic and complex health concerns and disability in this life stage.¹⁰ The ACI and Trapeze have developed an information sheet.¹¹ It is in this context that an expert consensus statement is being built and seeks to give guidance to the system and service developers.¹²

Aim of the Expert Roundtable

The aim was to develop a consensus statement for transitioning for young people with ID and mental illness to guide health service delivery at a systems level as well as at clinical and corporate level. It is based on the opinions of a group of NSW-based content experts from across agencies and includes carers as well. See Appendix 2 for a full list of attendees at the Expert Roundtable.

Method

The Expert Roundtable was hosted by the ACI ID Health Network and was convened in July 2017. Invited experts, including carers, met to assist in the development of a consensus statement. Professor Les White convened the Roundtable which was hosted by co-chairs of the subcommittee, Associate Professor David Dossetor and Dr Robert Leitner.

The expert advice gathered formed the basis of the consensus statement.

Format

Three models were presented.

1. The specialist paediatric ID clinic based multidisciplinary approach which includes assessment, presented by Dr Natalie Ong.
2. The school clinic based model which focuses on assessment, including psychosocial assessment presented by Dr Alexis Berry. Dr Berry also presented on the emerging role of a welcoming adult specialist service in the school transition clinic model.¹³
3. The specialist GP supported model which concentrates on the partnerships and processes and does not include a health assessment. There is a six month follow up and referral to adult services with an annual visit back to the clinic for medical review. The aim is to better support GPs in the community and referring specialists. This was presented by Dr Seeta Durvasula.

Dr Ong presented two complex case studies involving young people with ID, mental illness, challenging behaviour, complex and chronic health conditions and social situations requiring additional support. Interpreter services were needed and specialist referrals required but not always available. Dr Ong described how her team sought to meet the patient's needs.

The gathered experts were asked to discuss the model as presented by Dr Ong from each of the tiers of the service framework as well as from a regional and rural perspective.

Discussion questions

- What would be the perspective of the young person and their carer about the proposed model?
- How do we make the model as proposed in the case scenario of receiving the young person with ID and their carer to adult health services more welcoming? This included management of health (physical and mental) and behavioural aspects in interagency environment.
- How is it possible and sustainable to support the key role of the GP and their staff in providing health services for the person with ID?

Analysis

The Expert Roundtable saw a need for a hybrid model of transitioning which better supports people with ID and mental illness who are not able to attain independence and would need to rely on supports to communicate their needs and live in the community.

Experts saw the need for a change of focus in transition discussions to adult services. A discussion at system, corporate and clinician level is required to enable a fluid transition.

Underpinning the discussion was a recurrent theme of an individualised and co-designed pathway for young people with ID and mental illness and their carers that aligns with their needs in the community. This requires better collaboration and communication between professionals and service providers and support from the systems they work within. It also requires policy to drive it. See Appendix 1 for the relationship between tiers of service.

The adult model of healthcare based around the GP, underlined the need for primary health involvement from a young age. There was general agreement that the GP is a key player and one who is possibly already experienced and skilled in ID through GP registrar training programs. Additional supports, referral pathways and access to expert consultation, as well as better communication channels would enable the GP, practice nurse and allied health staff to support the person with ID and mental illness in the community for most of their needs, most of the time. This led to a discussion about a potential model whereby specialist ID services offer expert consultative support, including an out of hours service to adequately support GPs and mainstream clinicians (see Appendix 1). This tiered level of support was not disputed. Aboriginal medical services were seen as important partners.

Additional considerations such as Aboriginality, culturally and linguistically diverse backgrounds, refugee status, out of home care and juvenile justice system involvement add layers of complexity which reinforce the need for a broader funded systems approach which includes health systems during the transition phase. The host or lead in such an interagency systems approach, enabling wrap around services was considered. Health is well positioned to provide this leadership but support from other systems was seen as a critical element.

The current health funded and hospital-based transition models (the Transition Care Network and Trapeze models) were set up in this sphere and are potentially well placed to trial such an approach and gather relevant data to drive change.

The regional and rural model was shown to be different at the paediatric and adult levels for people transitioning to adult services. The role of the carer and the GP was more embedded. The process was often carer driven.

There was agreement on the need for the young person, especially when they have ID and mental illness and perhaps other layers of complexity, to have developed a sense of trust in their health service providers and it was acknowledged that this takes time and exposure. Transition was seen as a process reliant on a key clinician with a good knowledge of the young person and an understanding of their wishes, decisions and background.

Policies and data to drive change at all levels were seen as a priority. There was agreement that this is not traditionally where transition discussions place emphasis. This was seen as an important shift to embed change.

Conclusions

In summary, the roundtable discussion suggested characteristics of a model for an improved co-designed transition process to adult health services for people with ID and mental health co-morbidity to guide the NSW Health system, services and clinicians.

The overarching theme was collaboration and communication. There was in principle support for a primary health model built around the young person and including their established connection to their GP. It was agreed that the GP and team would need access to mainstream and specialist ID teams and clinicians in a consultancy model, an established referral pathway and an after-hours key contact through a specialist service.

Alongside this GP focused model, there is a need for acknowledgement of responsibility for commitment by the involved key systems to support coordination of care for this vulnerable population during transition.

Key partners such as NSW Health, NSW Dept of Education, PHNs, Family and Community Services, Juvenile Justice and the National Disability Insurance Agency need a committed and collaborative response to enable system support for transition.

This consensus statement is based on expert opinion and the practice-based evidence of specialists in the field. Transitioning young people with ID and mental illness is complex and requires guidance which this consensus statement hopes to provide. Empirical evidence of outcomes and experience measures for young people and their carers and for the system is still needed. Data collection and standardised outcome measures to evaluate implementation of an individualised, GP supported coordinated approach might then form the basis of a clear NSW Health policy.

Although sections within the NSW health system, namely ACI and Trapeze, and some emerging local health district (LHD) initiatives, provide transition services, the current models and service deliveries do not support a coordinated approach for young people with ID and mental illness.

There is a growing awareness of the need and a strong rationale for an interagency model with a designated coordinator for this cohort of young people. There are examples of local initiatives including school transition clinics, post-school option transition clinics, specialist supports and pathways for GPs to enable transition, but there is no systematic approach. Without strong interagency commitment and support, the health of the young person will suffer and systems legislated to serve all, including young people with co-morbidities, will not fulfil their purpose. Commitment at all systems levels is required and could reasonably include resources and staff skilled to enable young people with ID and mental illness to transition to adult health services and live their lives in the community.

Key consensus points and actions

There was consensus for a hybrid model or adapted, co-designed and individualised model for young people with ID and mental illness who are dependent on carers and have complex health and support needs. The model proposed was flexible and responsive to service provision in local communities. It was grouped into four themes: key role of GP and practice nurse, communication, collaboration and policy and guidance to system.

Key role of GP and practice nurse

Consensus points

- Transition is a co-designed and individualised process requiring engagement with the young person and their carer based around their needs to maintain health and live life in the community.
- The young person with ID and mental illness relies on an established relationship with a GP or practice nurse over time.
- The GP will be able to support most young people with ID and mental illness most of the time if they have access to specialist ID and mental health support, referral pathways and an after-hours key contact through a specialist service.
- The PHNs are tasked to support local GPs and practice staff and present an opportunity for involvement in model development and promotion.
- Alongside the health concerns, and related to them, are aspects of the young person's life involving other agencies and support services.

Actions

- Use telehealth hosted by the GP with the young person and their carer to connect with paediatric and adult specialists.
- The GP transition model should build on each tier of the framework supporting the tier below (see Appendix 1). Support the GP with pathways, expert consultation access, specialist ID service hubs which includes after-hours support and key mainstream contacts.
- Build trust in the mind of the young person about the role of the GP, adult services and the transitioning process with each health service encounter. For Aboriginal young people trust is fostered through a culturally appropriate service such as Aboriginal medical services. For people from culturally and linguistically diverse backgrounds, LHD diversity services and community health services are useful sources of support and advice.
- Use the skills and resources available through tier four ID specialist services and the ACI clinical networks to build workforce capacity.
- Build protocols around roles, communication, expectations, pathways into adult health services and emergency management plans for accessing adult health services during the transition phase.
- Trial this approach using the current transition models (Transition Care Network and Trapeze model) and gather relevant data to drive change.

Communication

Consensus points

- There is no established pathway or procedure for notifying adult health services (local or tertiary) about young people as they enter the transitioning period to enable budgeting, capability building and service planning and design.
- Trust and an ongoing GP relationship are key factors in young people transitioning well.
- As key health professionals in the transitioning young person's life, GPs need to have access to all communication about the young person.
- The GP, with additional and specialist support, is the key driver of referrals, additional support and preventative health measures for the young person with ID and mental illness.

Actions

- Strengthen the focus within adult health services to plan for the transitioning young person through interagency and joint planning involving all stakeholders.
- Embed a reporting link to the LHD NDIS Coordinator, stream leaders and service managers about young people with ID and mental illness to raise awareness and build processes and preparation.
- Strengthen the communication lines between GPs, practice nurses and health services by establishing key contacts. Electronic medical records and My Health Record will support this where GPs have access to appropriate software.

Collaboration

Consensus points

- Mental health services are heavily used by this age group. There is currently no co-ordinated focus on young people with ID.
- Transition for this cohort involves coordinating multiple and diverse teams and is mindful of other agencies which support the person and their carer.
- Handover success relies on having a key clinician with a good knowledge of the young person.
- The particular skills and training amongst adult specialists to support care coordination for people with ID include specialists skilled in a multidisciplinary model. The system's organisation, resource and funding allocation and clinician interest would support this.

Actions

- The adult team or the GP (with specialist adult support) does a health assessment, with support and input from the paediatric team at transition. Handover includes information on the young person's concerns. Opportunities for collaboration could include having the health assessment done in a school clinic environment or a supported accommodation or post-school option environment where carers and those who are most familiar with the young person are more easily included.
- Develop an interagency and collaborative model with key stakeholders such as LHDs, NSW Dept of Education, Aboriginal medical services, PHNs, Family and Community Services, Justice and the National Disability Insurance Agency to support young people with ID and mental illness who require a coordinated systems response to enable them to maintain their health in the community. Although the health may take the lead in the transition response, it will require commitment from other key stakeholders.

- Using the skills and resources available through tier four ID specialist services and the ACI clinical networks, work across agencies to build an adult transition model. This will build workforce capacity and support the multidisciplinary model.
- Refer to the Health of the Nation Outcome Scales for People with Learning Disabilities (HoNOS-LD) to prioritise those young people most at risk and develop pathways, management plans and communication and engagement specific to them.¹⁴

Policy and guidance to system

Consensus points

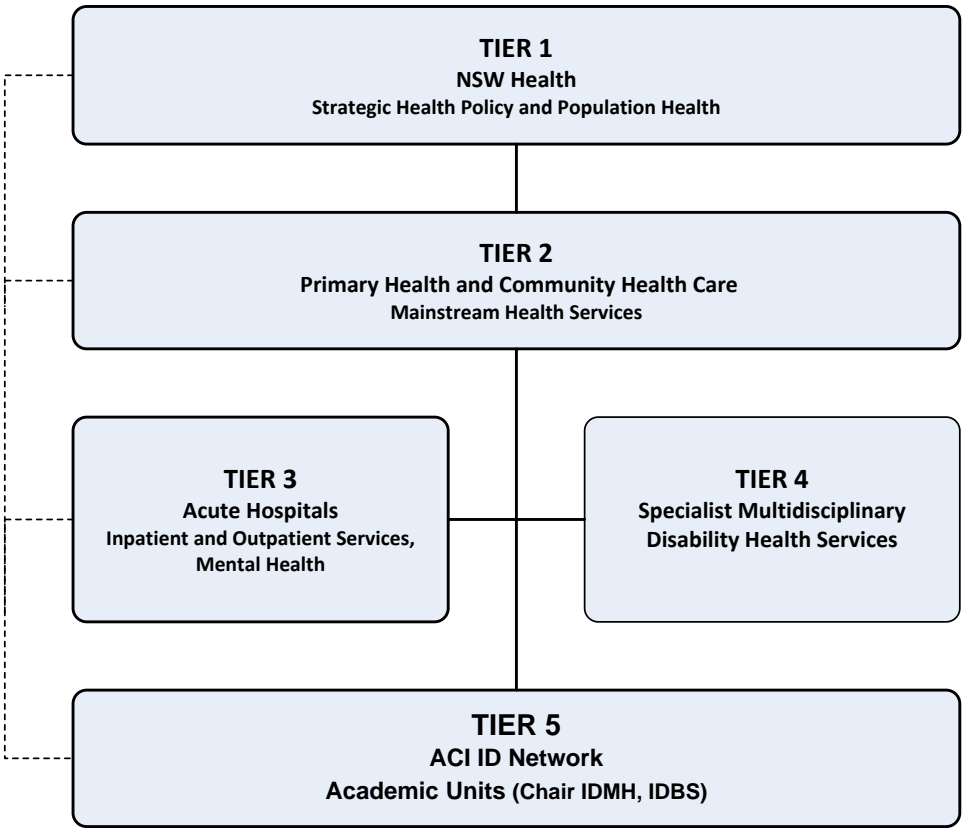
- No NSW Health policy or memorandum of understanding currently exists to support the transition process, including for this vulnerable group at risk of poor health outcomes and over reliance on acute services.

Actions

- Use this consensus statement to influence policy development, guide future service delivery, model implementation and data collection.
- Broadly disseminate the consensus statement to support policy development and service delivery in health and other sectors.

Appendices

Appendix 1: NSW Health Service Framework for People with ID and their carers



Appendix 2: Expert Roundtable attendees

Name	Organisation
Rummana Afreen	Western Sydney Local Health District
Alexis Berry	South East Sydney Local Health District
Lynne Brodie	ACI
David Dossetor	Sydney Children's Hospital Network (Models of Care Co-Chair)
Seeta Durvasula	Northern Sydney Local Health District
Tony Florio	Consultant
Anne Funke	Carer
Pankaj Garg	Sydney Children's Hospital Network
Donna-Lynne Gers	Carer
Maria Heaton	Carer
Jo-Anne Hewitt	The Benevolent Society (apology)
Jane Ho	Trapeze
Tamsin Knight	Family and Community Services
Friedbert Kohler	South West Sydney Local Health District
Robert Leitner	South East Sydney Local Health District (Models of Care Co-Chair)
Kathryn McKenzie	NSW Ombudsman's Office (apology)
Natalie Ong	Sydney Children's Hospital Network
Vincent Ponzio	NSW Ministry of Health Health
Jenny Rayner	NSW Dept of Education
Michelle Shiel	NSW Ambulance
Aline Smith	GP
Jacqueline Small	Sydney Local Health District
Tracey Szanto	ACI
Gail Tomsic	Sydney Children's Hospital Network
Julian Trollor	University of NSW (apology)
Les White	Facilitator and ID Network Co-Chair

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