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

- **Service redesign and evaluation** – applying redesign methodology to assist healthcare providers and consumers to review and improve the quality, effectiveness and efficiency of services.

- **Specialist advice on healthcare innovation** – advising on the development, evaluation and adoption of healthcare innovations from optimal use through to disinvestment.

- **Initiatives including Guidelines and Models of Care** – developing a range of evidence-based healthcare improvement initiatives to benefit the NSW health system.

- **Implementation support** – working with ACI Networks, consumers and healthcare providers to assist delivery of healthcare innovations into practice across metropolitan and rural NSW.

- **Knowledge sharing** – partnering with healthcare providers to support collaboration, learning capability and knowledge sharing on healthcare innovation and improvement.

- **Continuous capability building** – working with healthcare providers to build capability in redesign, project management and change management through the Centre for Healthcare Redesign.

ACI Clinical Networks, Taskforces and Institutes provide a unique forum for people to collaborate across clinical specialties and regional and service boundaries to develop successful healthcare innovations.

A priority for the ACI is identifying unwarranted variation in clinical practice and working in partnership with healthcare providers to develop mechanisms to improve clinical practice and patient care.

www.aci.health.nsw.gov.au
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Summary

This report is a summary of work undertaken by the ACI Intellectual Disability Health Network in moving towards a health system that results in better outcomes for people with an intellectual disability (ID).

It sets out the case for change by examining current disparities between health outcomes for those with an ID, and the general population.

It is aimed at the whole of the health sector – and anyone providing a service to a person with an ID.

It has the following drivers:

- People with ID and their carers want to work with health services to improve the health care they receive and their ability to access appropriate health services.
- Clinicians and managers in NSW health services are keen to provide a better quality of service for people with ID, but need expert support and advice to do so.
- There is a need for better data about the health needs of people with ID, and their use of health services.

This Report

- Provides useful resources that can inform local solutions and collaborations to improve access to health services.
- Provides examples of new ways of working together in the health system for the benefit of people with an ID.
- Provides case examples to illustrate ways of working.
- Will contribute to future solutions, designing a better health service for people with ID.

1.1 The Case for Change

The Service Framework to Improve the Health Care of People with ID (2012), states that approximately 0.9% of the Australian population has an ID. In NSW that correlates to around 65,130 people.

Compared to the general population, people with ID have:

- A poorer experience of the healthcare system
- Poorer health outcomes
- Greater health care needs
- Shorter life expectancy and higher mortality rates
- Higher likelihood of accessing hospital services (including Emergency Departments)
- Longer stays in hospital
- Less access to and benefit from public health or preventative health programmes
- Significant numbers of undiagnosed and untreated health conditions.

These health outcomes and challenges occur across jurisdictions, nationally and internationally.
Lack of suitable housing, unemployment, social support programs, poverty and discrimination are also experienced by people with ID, and have an impact on their health.

There have been many positive developments in the health sector aimed at improving access to health services and health outcomes for people with ID.

These both include and result from the 2011 introduction of the NSW Agency for Clinical Innovation, Intellectual Disability Health Network (IDHN), and the 2012 release of the Health Service Framework.

Improved access to health services for people with ID requires services to be adapted, and staff to be trained. Many health staff have had little training or exposure to people with ID.

This report describes several new and emerging models of care operating in NSW, including approaches in which primary health works closely with the person with ID, their carer, support worker, and specialist and mainstream services.

This report also describes current models in which non-government agencies work with health services to improve the hospital experience of people with ID, while also building workforce capacity. This has the longer term benefit of reducing unplanned hospitalisations.

There are many links throughout the document to tools and resources which are useful for health service planning.

Key findings from the 2013-14 survey of NSW Local Health Districts by the IDHN:

- 42% of LHD Disability Action Plans do not include support for people with ID.
- 89% of LHDs do not have a key contact or resource person within their service for people with ID and their families and carers.
- 79% of LHDs have no information specifically designed for people with ID.
- 95% of LHDs have no routine supports and adjustments available for people with ID.
- 73% of LHDs provide no staff training in ID awareness (though feedback indicates a keen interest on the part of staff for training in this area).

“Access to health care is a fundamental right for everyone in Australia. NSW Health provides a range of community and public hospital services. These services are offered in a way that ensures equal access regardless of gender, marital status, disability, culture, religious beliefs, sexual orientation, age or geographic location.”
The Identified Drivers of Change in NSW:

- People with ID and their carers want to work with health services to improve the health care they receive and their ability to access appropriate health services.
- Clinicians and managers in NSW health services are keen to provide a better quality of service for people with ID, but need expert support and advice to do so.
- There is a need for better data about the health needs of people with ID, and their use of health services.

Diagram 1: The Identified Drivers of Change in NSW as identified by the IDHN.
The sectors of the health system to which this report applies.
Figure 2: The sectors of the health service.

The sectors of the health service are inter-related and interdependent, but all have a role in providing services for people with ID.

There are three high level drivers for change that the ID Health Network has identified from the work of its members in producing this report.

For those in the health system
This report will assist in the development of health services for people with ID, in line with:

- NSW Disability Inclusion Planning
- the principles of the NSW Integrated Care initiatives
- a rights based approach that aligns with State and Federal reform
- an integrated approach to health care, involving service provider partnerships, with the individual at the centre
- policy and governance arrangements that promote and sustain change
- appropriate health care as close to home as possible.

For all people and organisations working with people with ID
This report provides useful resources that can inform local solutions and collaborations to improve access to health services.

For those wanting to help design a more inclusive health system
This report will assist in the development of a “blueprint” for delivery of health services to people with an ID.

A design process is taking place in the first half of 2015. This report and its links and resources, together with other documents (a literature review and an economic analysis) will be used as inputs into the process.

Consultations will take place within the sector and with people with ID and their family and carers.

This Context Report and Toolkit, and the subsequent Essentials are available on the Intellectual Disability Resources section of the ACI website.

The summary discussion section of this report raises relevant issues and questions for the consultation process.

Acknowledgements
This report has been produced by the ACI IDHN with the involvement of people with ID and their families and carers. The strength of this report lies in its diversity of approaches and styles in explaining current developments and emphasising different issues.
These high level Guiding Principles for the delivery of health services for people with an ID have been developed by the ID Health Network. They are available in expanded form at [http://www.aci.health.nsw.gov.au/resources/toolkits](http://www.aci.health.nsw.gov.au/resources/toolkits)

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<td>1.</td>
<td>People with ID have the same access to, quality and range of health services as other people.</td>
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<td>Health services support the cultural and social inclusion of people with ID and their carer.</td>
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<td>Health services recognise the additional determinants of poorer health outcomes for people with ID.</td>
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<td>4.</td>
<td>Health services are delivered in a person and family centred way.</td>
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<td>Health services provide early diagnosis and intervention to enable optimal outcomes.</td>
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<td>6.</td>
<td>Health services for people with ID are integrated across primary, secondary and specialised care.</td>
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<td>7.</td>
<td>Health services are delivered by appropriately trained staff.</td>
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<td>8.</td>
<td>Specialised health services and the integration of their expertise within mainstream services can improve health outcomes for people with ID.</td>
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<tr>
<td>9.</td>
<td>Other government and non-government agencies (e.g. schools, supported accommodation services) play an active role in supporting the health outcomes of a person with ID.</td>
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<tr>
<td>10.</td>
<td>Data is collected and used to inform ongoing health service development, policy and models of care.</td>
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We stayed with Tina in a single room in ED while she had tests and waited for a room on a ward. Her behaviour was getting more difficult to manage.

I brought in photos and tried to tell staff that this was not the “normal” Tina.

The staff are not familiar with people with intellectual disability and think Tina’s behaviour must always be like this.

The staff feel Tina’s parents are managing her well – they know her best. They will leave them to it.

‘It was nice we could have a single room on the ward, but no one spoke to us and we did not know what was going on. Tina was getting more difficult to manage.’

It is good Tina has her own room, but she could go home now. She may be more settled at home also.

Tina’s parents want the staff to believe Tina is “not herself”.

Tina’s parents feel out of the loop with plans as they are isolated in a single room with Tina.

The staff tell them about a Carer Support Worker based in the hospital.

Once delirium is diagnosed Tina starts to improves but her parents are exhausted.

Her stay in hospital was 18 days.

Tina (33 yrs) has an intellectual disability. She likes cooking, bowling, art and using her computer. She is cared for fulltime by her parents and keeps to routines.

We (parents) contact her Neurologist. We won’t be able to cope at home.

Prolonged stay as single room not available on ward. Tina has a family member with her at all times.

Tina pulled out her cannula and refused to eat. She is loosing weight. And her behaviour is more difficult to manage.

Tina is diagnosed with delerium. Medication starts and discharge is planned.

Discharge planning multi-disciplinary meeting takes place on day of planned discharge.

No community supports organised. Pressure on ward for beds.

Pain, vomiting, headache and temperature. Numerous tests. Diagnosis of a bowel inflammation.

Case Study 2 – Tina’s Story

This graphic example of how Tina and her family experience health services (above line) and how health service staff understand Tina’s experience (below line) underpin many of the themes of this Context Report.
Section 4
Service Framework to Improve the Health Care of People with Intellectual Disability, 2012

Summary

This chapter gives a summary of the July 2012 Service Framework to Improve the Health Care of People with ID, developed in response to poor health outcomes for people with ID.

The NSW Ministry of Health has piloted three specialist ID health teams and the ID Health Network pursuant to the Service Framework.

This chapter defines ID and sets out the five tiers of the Service Framework.

4.1 Definition of Intellectual Disability

Intellectual disability begins during the developmental period. The diagnosis is based on the severity of deficits in adaptive functioning determined by clinical assessment. Standardised intelligence testing is part of the person’s assessment. Impairments in adaptive functioning can occur in the following areas:

- Conceptual – e.g. language, reading, writing
- Social – e.g. empathy, interpersonal communication skills, social judgement
- Practical – e.g. personal care, self-management, lifestyle.

The severity of ID can be described clinically as mild, moderate, severe or profound.

A person’s functional capacity may be affected by their health and other factors, including:

- The specific characteristics and aetiology of their diagnosis
- Related co-morbidities (physical, mental or behavioural)
- Family and community supports
- Access to health services (including specialist health services)
- Understanding of and ability to act on preventative health advice
- Housing
- Financial situation
- Educational and work opportunities
- Challenging behaviour
- Other health conditions (diagnosed or undiagnosed).

Other conditions common to the general population but also experienced by people with ID (such as gastro-oesophageal reflux, heart conditions, schizophrenia, sight and hearing difficulties) all compound the effects of a person’s ID on their functional capacity.

ID can be confused with other conditions distinguished by the subsequent loss of cognitive and adaptive functions. Acquired Brain Injury can affect a person’s functional capacity and may be caused by accident, abuse, stroke or drugs and alcohol. If this happens during the developmental period they are considered to have an intellectual disability. Over time and with therapy some cognitive and/or physical abilities might be regained.

People diagnosed with autism may also have ID, but it is not necessarily the case.

Dementia is another example where there is a progressive loss of cognitive and adaptive functioning. These diagnoses are quite different from ID but may also affect a person with ID.

Developmental Disability may include physical and/or ID.
4.2 Broad aims of the Service Framework

The broad aims of the Service Framework are to:

- Promote the inclusion of people with ID and their family/carer in health services, alongside the rest of the community
- Enable the provision of specialist ID health services to:
  ▲ improve health outcomes for people with an ID,
  ▲ support the other tiers of in the provision of care.

4.3 Five tiered framework

The Service Framework outlines the five tiers of health services for people with an ID.

- Tier 1 – Strategic health policy and population health
- Tier 2 – Primary health and community health care
- Tier 3 – Acute health care services
- Tier 4 – Specialised health services for people with ID
- Tier 5 – State wide clinical leadership, research, education and training

The Service Framework at Tier 4 supports a multidisciplinary approach with specialist ID teams acting in a consultative role. The specialist teams provide expert advice, build workforce capacity and improve patient outcomes as a result.

The Service Framework at Tier 5 supports the development of a specialist network. The **ID Health Network** sits within Tier 5 (see the section below on the ID Health Network).

A key partner in the development of the ID Health Network was the state disability service (Ageing, Disability and Home Care (ADHC)). With the introduction of the National Disability Insurance Scheme (NDIS) and the increasingly important role of the NGO sector in disability service provision, the Service Framework continues to evolve in its application.

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**Diagram 3: Tiers of Health Service as described in Health Service Framework (2012)**
Summary

This section discussed the fifth tier of the Service Framework – State wide Clinical Leadership, Research, Education and Training. It discusses the broad representation within the IDHN and the central role of carers and consumers.

In 2011 the ID Health Network was set up to support the aims of Tier 5 under the Service Framework. The ID Health Network is being evaluated annually by KPMG (2012-2015).

The ID Health Network has two Co-Chairs, Ms Maria Heaton (Carer) and Prof. Les White (NSW Chief Paediatrician). The ID Health Network has a broad membership across Health, the Disability sector, Education and the NGO sector. Its membership includes people from regional and rural NSW.

It has an Executive Group which guides the direction and work of four subcommittees:

- Access and Equity
- Research and Development
- Models of Care
- Workforce and Capacity.

Agency for Clinical Innovation ID Health Network

Domains of Activity

To Progress and Promote

**Access & Equity**
- Equitable access to appropriate services
- Affordability
- System/Structure

**Models of Care**
- Prevention
- Effectiveness
- Sustainability
- Quality
- Comprehension
- Ongoing support in life journey

**Workforce & Capacity**
- Capacity development & workforce education, training and support

**Research & Development**
- Standards of data collection and analysis
- Collaborative research
- Evaluate health and other outcomes

Shared Elements

- Rural, Remote and Regional
- Consumer and Carer Engagement
- Disadvantaged Groups (Indigenous, CALD, Refugee)
- Social, Emotional, Behavioural Aspects of Care
- Collaboration, Linkages, Integration and Partnerships (Health and Beyond)
- Rights, Advocacy and Promotion in Broader Sectional Context

Diagram 4: IDHN Subcommittee Structure
Each of these subcommittees also has two co-Chairs. Carers are key members of the ID Health Network, including the ID Health Network co-Chair, Maria Heaton, awarded NSW Carer of the Year for 2013. Each of the four subcommittees of the ID Health Network includes carers who have been instrumental in shaping the focus of the work of the subcommittees.

The ID Health Network also consults widely with consumers and carers in workshops and forums, and for feedback and input into specific pieces of work. The NSW Council for Intellectual Disability also represents people with ID on the Network’s Executive.

The Manager of the ID Health Network sits on the Advisory Group for the tier 4 multidisciplinary intellectual disability health team “pilots”. The Clinical Directors of the three intellectual disability health teams are members of the Network Executive. Representatives of these three and other specialist tier 4 health services are members of different ID Health Network subcommittees.

The members of the ID Health Network are regularly consulted by the Ministry of Health regarding policy related to disability inclusion planning and communication about the NDIS for health service staff.

Direct access to clinical expertise is a key feature of the Network.

ACI has supported ID research, resource development and educational opportunities, including at LHD level, with Primary Health Networks, tertiary institutions and NGOs.

The ID Health Network members often present at LHD events and forums, including forums on Hospitalisation, Disability Action Plan development, NGO / LHD partnerships, Grand Rounds, Registrar Training and undergraduate health teaching opportunities. The ID Health Network was a sponsor of the Health Symposium as part of the Special Olympics in Newcastle, in 2013. The ID Health Network has been involved in the Subject Matter Expert (SME) group to develop an e-learning module on Disability with NSW Health Education and Training Institute (HETI) and is currently part of the SME group developing an on-line training resource about Disability and Justice with HETI.

5.1 Representatives

In addition to strong Carer representation, the ID Health Network has and representation from the following key agencies / groups:

**NSW Ministry of Health**

The Ministry of Health is responsible for health policy and for disability inclusion action planning for health in NSW. Within NSW Health, the Strategy and Resources Division leads disability sector reform through the Government Relations and Integrated Care Branches.

The Ministry of Health consults with the membership of the ID Health Network for advice regarding matters before the Minister, and in developing policies, guidelines, strategies and frameworks.

The Ministry of Health currently funds the ID Health Network and the three tier 4 pilot teams (see page 19). The Ministry is also funding an external evaluation of the ID Health Network and the pilots.

The Ministry is also responsible for the negotiations regarding the role of NSW Health in the transition to the NDIS.

The Department of Premier & Cabinet and NSW Treasury lead the transition to the NDIS. NSW Health is a partner. FACS and ADHC lead on some initiatives and NSW Health supports implementation. Members of the ID Health Network are consulted by the Ministry of Health on issues relevant to health and intellectual disability. The ID Health Manager is a member of the Ministry of Health NDIS Working Group.
The Ministry of Health’s Disability Home website is an importable resource for information for interested professionals.

Direction three of the State Health Plan is the delivery of truly integrated care. The aim is to redesign the NSW health system so that people can navigate services more easily through the system, resulting in better outcomes. The Ministry of Health is implementing models of integrated care through the NSW Local Health Districts in partnership with other providers, particularly primary care. People with complex and long term health needs are expected to particularly benefit from a more integrated health system.

NSW Family and Community Services (FACS) Ageing, Disability and Home Care (ADHC)

The Disability Inclusion Act was passed in the NSW Parliament on 14 August 2014 and is the basis for the disability action planning which will occur across the state.

With the launch of the NDIS in NSW in the Hunter area in July 2013, ADHC began the process of the transfer of disability services to the NGO sector. ADHC continues to support people with ID during the transition phase, whether through direct service delivery or through referral to other suitable service providers, including the NGO sector.

The NSW Government is committed to meeting its responsibilities under the agreement with the Commonwealth to implement the NDIS across NSW by 30 June, 2018.

In addition to the NDIS the NSW Government is committed to the redevelopment of large residential centres. This continues to happen alongside the more recent disability reform.

There are current reforms underway of the aged care and homelessness sectors.

NGOs currently deliver sixty percent of services across NSW to people with disability. NGOs provide seventy percent of supported accommodation services in NSW and over eighty percent of other services such as therapy services.

ADHC currently funds specialist disability nursing and allied health positions across NSW, both within ADHC and within NSW Health.

ADHC funds the Chair of Intellectual Disability Mental Health and the Chair of Intellectual Disability and Behaviour Support both at the University of NSW. ADHC also partners with other agencies to build workforce capacity. These are subject to change as the NDIS rolls out and the NGO sector adapts to meet the needs of people with disability.

Currently we are unsure of the impacts that these changes will have on the NGO workforce, whether workers will be employed at similar levels of expertise, and the effect this will have on service users.

As there are numerous state reforms all occurring at once, there is increased impact on supports for people with a disability.

NSW Council for Intellectual Disability

The NSW Council for Intellectual Disability (CID) is a peak body representing the rights and interests of people with ID in NSW. CID represents people through systemic advocacy – constructively engaging with governments to lobby for meaningful change for people with ID. They were instrumental in the development of the Health Service Framework for People with ID, alongside Health and ADHC. They have a particular interest in advocating for people with ID and mental health needs as well as for people with ID in the criminal justice system.
They produce many publications, fact sheets and internet resources for people with ID, including information to assist people with ID with managing their health and interacting with the health system. A representative from CID is a member of the IDHN’s Executive Group and members of CID with ID participate in, and advice on, IDHN activities.

The NSW Ombudsman’s office

In May 2013 the NSW Ombudsman tabled his seventh report on the deaths of people with disability in care. Each of the seven reports identifies a shortened life expectancy of people with disability in comparison to the general population. The reports show how barriers to accessing health care in a timely and appropriate manner adversely affect the health and quality of life of people with disability.

The Ombudsman identifies the need for a person-centred, comprehensive, multidisciplinary and co-ordinated approach to supporting people with disability to manage their health needs. This will assist to:

- Effectively identify and respond to the changing health and other support needs of people with disability
- Enable appropriate transition and continuing support for people with a disability from paediatric to adult health services
- Enable comprehensive assessment and review of people with a disability
- Facilitate access to health services
- Provide health care coordination and support for people with complex needs to minimise resistance to accessing health services and treatment and ensure informed decisions are made
- Provide effective and appropriate support in hospital, and enable coordinated and comprehensive planning for the transfer of care from hospital to home.

The Ombudsman’s reviews also identify that very few of the people with disabilities in care had access to:

- Chronic disease management programs and support (such as Connecting Care),
- Out-of-hospital care (such as Hospital in the Home)
- Preventative health programs and support (particularly those targeted at reducing risks associated with smoking, obesity, poor diet and sedentary behaviour).

The Ombudsman’s Office makes recommendations for improvement and monitors work being done as a result.

More recently, in June 2014 the Ombudsman’s Office convened a roundtable in response to the identified need for a comprehensive, coordinated and multidisciplinary approach to supporting people with disabilities. The roundtable focused on what needs to be put in place to enable people with disability to access appropriate health supports ahead of the full NDIS roll out in June 2018.

Justice Health and Forensic Mental Health Network

Justice Health & Forensic Mental Health Network is a Statutory Health Corporation established under the Health Services Act (NSW) 1997 and is part of NSW Health.

Justice Health & Forensic Mental Health Network provides health care to people in the adult correctional environment, those in courts and police cells, juvenile detainees, and those within the NSW forensic mental health system and in the community.

For some people, entering the justice system is the first time they have had the opportunity to be assessed for cognitive impairment and therefore to know they are eligible to receive support. People with ID are over represented in our criminal justice system.

The ID Health Network hosted a forum with NSW Justice Health and Correctional Services to explore working partnerships between NSW Health, ADHC and Justice Health.
The ID Health Network has representation from Justice Health at subcommittee level.

There are working partnerships between the Juvenile Justice and Criminal Justice system and the work of the specialised intellectual disability health services. ACI and Justice Health are partners in the UNSW led NHMRC Partnerships for Better Health Project: Improving Mental Health Outcomes for People with an Intellectual Disability. The ID Health Network and Justice Health are currently working with NSW Health Education and Training Unit to develop an online training module for health staff.

Justice Health & Forensic Mental Health Network has employed a project manager with expertise in both the disability and justice sectors. The project manager will identify ways in which its services can be more accessible to people with cognitive impairment.

**NSW Ambulance**

The NSW Ambulance Service is developing responses to non-life threatening situations especially with regard to aged care facilities, palliative care and authorised care plans.

They are continuing to develop partnerships to assist appropriate responses for people with ID and mental health co-morbidity. The Ambulance service will make appropriate adaptions so as to provide services for people with a disability that move out of large residential centres. They have recently introduced the Top 5 and the Abbey Pain Scale for people with cognitive Impairment. They continue to work with NGOs, Emergency Departments, Primary Health and groups like Health Direct in order to formalise referral channels to link the person to the appropriate health provider.

The ID Health Network has identified the need for specialist after hours call support for clinicians, care staff and NSW Ambulance to assist with access and care for people with ID. Data could be collected on use of the service.

**NSW Department of Education and Communities**

The Department of Education and Communities supports more than 90,000 students with disability and additional learning needs from Kindergarten to Year 12 (around 12% of students) in more than 2,240 NSW public schools. Around 80 per cent of these students are supported in regular or mainstream schools and classes. Every Student, Every School is a reform initiative to strengthening educational experiences and outcomes for students with disability and/or additional learning or behaviour needs. It has a strong focus on professional learning and support for teachers and support staff.

Students with confirmed disability, including ID, may be enrolled in regular classes with additional support or in specialist support classes. Specialist support classes are located in schools for specific purposes (SSP) and in some regular schools across the state. Where a student is enrolled is informed by their educational needs, their proximity to available services, and the preferences of their parents/carers.

Students with disability and additional learning needs, including students with ID, are provided with personalised learning and support in a range of ways according to their individual education needs. Support may include changes to teaching and learning programs; access to specialist staff who support students and classroom teaching; and additional assistance in the classroom from support staff.

An extensive range of professionals beyond schools, including general and specialist health, mental health and allied health professionals, play a vital role in education outcomes for students with disability.

Continuing implementation of reforms in NSW public schools aim to improve education outcomes for all students. This includes ongoing work to strengthen collaborative approaches to supporting learning and engagement in schooling, particularly in rural and remote areas of the state.
(The NSW School-Link Initiative has been addressing mental health in NSW public schools since 1999. It is a collaboration between the Ministry of Health and DEC with implementation guided by agreed strategic objectives and actions. School-Link focuses on three main areas for children and young people with an intellectual disability)\footnote{NSW School-Link Initiative}.

### The (ACI) Transition Care Network

### Trapeze: a supported leap into adult health

Transitioning from paediatric to adult health care is often a very a stressful time for young people with chronic illnesses and disabilities and their families/carers. For adolescents with ID it often places even more pressure on parents and carers who may need to negotiate multiple new services and healthcare teams.

In NSW there are two transition services working in collaboration to ensure young people with chronic conditions and disabilities are supported during their transition.

ACI provides three Transition Care Coordinators in NSW who are based in adult hospitals and provide a state-wide service. Their role is to ensure continuity of care for young people aged between 14–25 years of age with any chronic conditions/disabilities as they move to the adult health service. They work closely with Trapeze, The Sydney Children’s Hospitals Network.

Trapeze is the specialist adolescent chronic care service for The Sydney Children’s Hospitals Network (The Children’s Hospital at Westmead and Sydney Children’s Hospital, Randwick). The aim of Trapeze is for young people to better manage their conditions as they move over to adult services so they can live their own lives and stay out of hospital. Trapeze facilitates, monitors and coordinates a young person’s care during transition, and strengthens their links with their community and local adult services, especially their GP.

Both transition services are represented on the Executive Group of the ID Health Network through the ACI Transition Co-ordinator.

### Aboriginal Disability Network NSW (ADNNSW)

NSWADN is an expert reference group for the ID Health Network.

NSWADN is an organisation of and for Aboriginal and Torres Strait Islander people with disability living in NSW. The organisation contributes to government policy, processes and makes representations to government on priority issues for Indigenous people with disabilities. Its major aims are:

- Empowerment and promotion of the rights of Aboriginal people with disability
- Creation of a society in which Aboriginal people with disability can fully participate
- Initiation and contribution of and to qualitative research undertaken by appropriate researchers.
Section 6

The National Disability Insurance Scheme (NDIS)

Summary

This section gives a brief and focused summary of the National Disability Insurance Scheme and its tiers of support, as well as discussing possible impacts that the NDIS may have on people with an intellectual disability, under selected topics related to their health and health care.

Following the consultation and report undertaken by the National People with Disabilities and Carer Council in 2008-09, a National Disability Strategy was signed by all Australian governments. The subsequent Productivity Commission Report in July 2012 galvanised a reform movement which led to a series of initiatives, legislative changes and national agreements culminating in the establishment of the National Disability Insurance Scheme (NDIS) led by the National Disability Insurance Agency (NDIA). http://www.ndis.gov.au/

The current NDIS approach to disability reform is a whole of government (Commonwealth and State) approach.

6.1 A Brief Description of the NDIS

The NDIS will fund disability support for people with disability across Australia based on their individual needs and choices. It aims to provide support in a way that enables people to choose how they participate in economic and social life to achieve their goals. Disability support funding is allocated to participants of the scheme, rather than to organisations or service providers. The person with an ID will work with the National Disability Insurance Agency (NDIA), which is the independent Commonwealth statutory agency established to deliver the scheme. The NDIA assists the person with disability to develop a support plan.

The current disability legislative and policy context, in which the NDIS sits, includes:

Internationally:
- The United Nations Convention on the Rights of Persons with Disabilities

Nationally:
- The National Disability Insurance Scheme (NDIS)
- National Health Reform (2008) – leading to developments in Primary Health Networks,
- Activity Based Funding and Personally Controlled Electronic Health Records.

In NSW:
- The Disability Inclusion Act (Aug 2014)
- NSW State Health Plan Towards 2021
- Stronger Together and Stronger Together 2 (2006-2016)

The NDIS will fund personalised supports related to disability support needs (unless those supports are part of another service system’s universal service obligation or covered by “reasonable adjustment”).

The NDIS may have impacts on the way NSW Health delivers and funds health services for people with a disability and the interface between health and disability services, for example, patient referral pathways, clinical input into disability assessment, and information sharing.

NSW Health aims to keep people healthy and out of hospital, and to provide quality clinical services with timely access and effective infrastructure.
NSW Health will continue to be responsible for:

- Diagnosis and clinical treatment of health conditions which aim to improve the health status of the population
- Any time-limited, goal orientated services and therapies where the predominant purpose is treatment directly related to the person’s health status.

There are considerable challenges in maintaining and, where appropriate, repositioning the roles and responsibilities of health services in response to the transition to NDIS. The healthcare, both mainstream and specialist, of people with ID and of children with developmental conditions is a critical component in the quality as well as duration of their lives. These important realities will continue during and after the introduction of the NDIS.

Planning and assessment is delivered separately to support under the NDIS.

The NDIS first stage launch commenced in New South Wales in July 2013 in the Hunter region. It includes the local government areas of Newcastle, Maitland and Lake Macquarie. In September 2015 the NDIS will be rolled out in the Nepean Blue Mountains district. The full scheme will be rolled out across NSW until 2018, although the service system is already changing in preparation.

### 6.2 Tiers of support under NDIS

The NDIS provides three tiers of support:

**NDIS Tier 1** – Targets everyone in Australia by creating and promoting community awareness of disability issues, encouraging social inclusion.

**NDIS Tier 2** – is called Information, Linkages and Capacity Building (ILC). ILC services are services that are available to all people affected by disability (approximately 4 million Australians, and 800,000 people in NSW). These services assist mainstream services to be inclusive of, and responsive to, people with disability. Over time these can reduce demand for individual funding packages.

**NDIS Tier 3** – Provides eligible people with a disability with individual funding packages. The packages are available for the individual to spend on “reasonable and necessary individual supports” – specific supports, aids and equipment from specialised and/or generic service providers and facilities in the community.

The NDIS will also provide early intervention support for children from 0–8 years of age with permanent disability or developmental delay to maximise their development opportunities and minimise the impact of their disability.


There is potential for NSW Health Local Health Districts to provide both tier 2 and tier 3 services, as a registered provider under the NDIS.

### 6.3 NSW Department of Family and Community Services (FACS)

NSW FACS will be progressively withdrawing from direct disability service delivery prior to the full implementation of the NDIS. By 2018 all disability services provided by FACS are planned to be transferred to the non – government sector.

A concurrent reform is the ongoing devolution of NSW government funded large residential centres to enable people with disability to live in the community in supported accommodation. This will have workforce implications as medical and nursing personnel currently employed at large residential centres will no longer be employed there, with flow on effects for service users.
6.4 Possible Impacts of the NDIS on people with an intellectual disability

Some people with ID will need communication support to enrol and then participate fully in the NDIS. The role of an advocate will be especially important for people with ID who lack capacity for decision making about their support needs. People with an ID from large residential centres are especially in need of advocacy and support. The experiences of the long term residents of Stockton, a large residential centre in the Hunter launch site will inform the NDIS roll out.

Planners may also need special support to work with people with an ID.

People with ID may need tailored support to adapt to change. Familiar staff, routines, transport and accommodation may change. For participants of the scheme these changes could cause an increased demand for mental health support that will need to be responsive to the needs of people with ID. The transition to the NDIS in the Hunter launch site will provide lessons.

Carers

NSW Health recognises the unique role of the carer, and will continue to acknowledge the role of the carer and to offer carer support. The voices of carers of people with ID are essential in capturing, understanding, improving their experiences of health services through co-design and co-production of solutions.

Carer Support programs operate in each LHD to improve access to health services for carers and to support them in their caring role.

Confidentiality

Some people with ID have the capacity to make all or some decisions regarding their needs. Others have an appointed guardian, while still others have a “person responsible”. The need for protocols around confidentiality, consent and privacy relating to information exchange as part of the NDIS are important. Government agencies are currently working together with carer providers and consumers and their families in the launch site on these issues.

Integrated Care and Care Co-ordination

For people with intellectual disability care co-ordination plays an important role in ensuring their needs are met in a timely and appropriate manner, including in housing, education, health, wellbeing and employment.

The chronic and complex health needs of some people with ID impacts on their lifestyle and the support they need to live in the community. Care coordinators can assist, and are often an advocate for the person with ID.

Mental Illness

People with ID have high rates of mental illness and challenging behaviour. These can be overlooked, misunderstood or attributed to their ID. Funding packages and individual plans under the NDIS should appropriately reflect this understanding and plan for it.

NGO Sector

During the transition phase to the NDIS, as government disability support services are withdrawn, the NGO sector will face challenges in meeting the needs of people with ID. NGOs currently provide many services to support people with ID, but there may be a lag time between the withdrawal of government disability services and the ability for NGOs to provide the number and the types of services people may now choose to purchase. This may affect the timing of a person’s transition from health to the community when accessing needed support services during recovery from a health event.

In addition it may not be viable for an NGO to provide a service in some areas of NSW.

At an individual level, a lag time between NDIS eligibility assessment, funding and procurement of services may have an impact on people whose functions change in that time. They may remain in hospital longer or be readmitted to manage risk and complications arising from inappropriate or inadequate service supports. Agency partnerships to facilitate transitions and integrated, co-ordinated support to live in the community are crucial. A wide range of stakeholders have a role and responsibility to implement and respond to whole of government decisions.

Competition could mean greater service choice, and may lead to further development of innovative staffing models, such as allied health assistants working between sectors.
New partnerships, policies, protocols and pathways between Local Health Districts and NGOs around the hospitalisation of people with intellectual disability are already developing. The launch site in the Hunter has strong NGO involvement and partnerships with LHDs. Their experiences will help inform the rest of NSW.

In collaboration with NSW Health and other agencies, the Department of Premier and Cabinet is working to provide an interagency approach to manage the disability service restructure in NSW. Part of this is to establish Health’s position and responsibility on the interface between Health and the NDIS. Disability services have been and will need to continue to be, involved in supporting people with ID to live healthy lives in the community. For example this may include diet, exercise, social interaction, medication management and health monitoring services as well as enabling visits to the GP, dentist and enrolment in appropriate chronic disease management programmes. This has important implications for regulation of the NGO sector and for the skills of disability support workers. The NDIS is articulating a Quality and Safeguards Framework to ensure the health of people with ID does not suffer as a result of the changes to the way services are delivered.

**Aboriginal People**

Aboriginal people with ID will benefit from the NDIS if it results in quality NGO services with appropriate cultural capacity. There are current initiatives to increase the capacity of Aboriginal community controlled organisations to assist Aboriginal people with a disability.
This section shows the results of a statewide survey of NSW Local Health Districts supports for people with an ID, conducted by the ID Health Network.

The results showed generally low levels of support, but high levels of motivation to improve. Clinicians interviewed were keen to improve the service they offered for people with ID.

7.1 A Survey of NSW Local Health Districts

In 2013/14 the ID Health Network’s Access and Equity subcommittee interviewed more than 90 key contacts from Local Health Districts. The interview questions with de-identified aggregated State-Wide Data are below:

**Figure 1: Does your LHD Disability Action Plan (DAP) include support for people with intellectual disability?**

- **Yes**
- **No**
- **DAP not yet finalised**
- **Unsure**

42%

**Comment:** 26% of the key clinicians interviewed in the survey across NSW Local Health Districts, were unsure about how their Disability Action Plan supported people with ID. 42% were able to identify that their LHD’s Disability Action Plan did support people with ID. The discussions with clinicians and managers stemming from this question indicated a desire for more information about ID and how to assist people. Since then the ID Health Network has joined with some LHD’s to support the further development of their Disability Inclusion Plans, including resources and tools.
Figure 2: Is there an identified key contact / resource person for people with intellectual disabilities their families / carers, within your service?

Comment: Only 11% of LHDs identified a key contact for ID.

Figure 3: Does the LHD have information specifically designed for people with intellectual disability, and their families / carers or involved professionals?

Comment: There was limited availability of health care information specifically designed for people with ID (21% of LHDs).

Figure 4: Does the service / hospital disseminate information about the available services for people with intellectual disabilities?

Comment: Fewer than half the LHDs disseminated information about the healthcare services for people with ID.

Figure 5: Are supports / adjustments routinely available for people with intellectual disability in your LHD to facilitate access to health services?

Comment: In only 5% of LHDs are supports or adjustments routinely available for people with ID.

For a more comprehensive discussion on all of these findings, go to link.
Summary

This section is based upon the results of a state wide survey of NSW Local Health Districts’ about workforce education and training about ID. It also discusses other workforce research, surveys and attempts to build the capacity of the workforce to support people with ID. In particular it notes clinicians’ interest in further education and training to work more effectively with people with ID.

8.1 The Current Situation

In 2013/14 the IDHN interviewed more than 90 NSW Local Health Districts’ nominated key contacts. The following workforce question was asked.

Figure 6: Do all staff receive intellectual disability awareness training in orientation or as part of their ongoing internal professional development?

In summary they said:

- There is a keen interest from clinicians and health staff in knowing more about how to work with people with ID and their carers to improve services.
- General awareness training and development of communication skills in working with people with ID is needed for all health professionals.
- Training needs to be evaluated at Local Health District level.
- Clinical staff thought web based training would assist regional and rural staff to access training.
- A clinical competency document for health and other agency staff would be useful to identify skills needed when working with people with an ID. Particular knowledge gaps were:
  - How to effectively work with carers in the health system
  - Better understanding of guardianship and consent issues.
- There is a need for a key contact in health to assist with navigating the health system.

Consumers and their families reinforced the need for attitudinal change and better understanding by health staff about disability link.

Clinicians and managers provided additional comments during the course of the survey.

“I think they (health staff) avoid dealing with him because they don’t have much experience with people with disabilities.”

Josie & Geoff
(Person with ID and Carer)
Curriculum and Training Audits

In 2013/14 feedback was collected during education of community nurses and GP Registrars in metropolitan Sydney. The feedback indicated a lack of confidence and formal training in working with people with ID. The nurses and Registrars suggested some practically orientated training programmes to enhance their skill development would be helpful.

Results from a National Curriculum Audit of undergraduate Nurses’ training in Australia in 2014 revealed most courses don’t have ID content. Those that do have less than 5% of the course content devoted to ID.

8.2 Building Workforce Capacity

The patient experience is underpinned by appropriately trained staff. Medical, allied health, nurse, generic and specialist training in ID is currently insufficient.

There is a need for investment in:

- Broad based strategies to equip the mainstream workforce
- Training specialists in specific core disciplines. (A major challenge is the limited number of positions for mental health fellows in the public sector)
- Exposure during training to primary and community care and working in multi-disciplinary teams.

The role of the general paediatrician is key in co-ordinating care for children and young people with ID. Most health services have no equivalent role in the adult health system, although the General Physician or Rehabilitation Physician operate within some health services and fulfil this role.

There are a small number of Clinical Nurse Consultants / Specialists in ID. Some of these positions are funded by disability services and others by health. They assist in case co-ordination and support for people with disability and staff.

The existing specialised ID health teams (including the three Ministry of Health funded teams discussed later in this report – see Pg 51) play a major role in building the capacity of health services to deliver best practice care for people with ID. The teams act in a consultative way to build capacity within the health system. The teams also support clinicians, General Practitioners and NGOs to work collaboratively.

In 2013 and 2015 the ACI ID Health Network partnered with the Australian College of Nursing to run two day courses on Nursing Patients with ID. There are opportunities to expand this course in the future.

The ID Health Network is currently working with the Children’s Hospital Westmead, two NGOs and ADHC to develop visual aids for use by health professionals in three clinical scenarios, when working with people with ID.

We really need to have someone to be an ‘umbrella’ for all these services. There needs to be one main doctor who arranges for everyone involved to speak together once a year. To sit around a table together and to review what progress has been made, what issues there are and what we now need to do. I insist on a yearly review...

Milka & Jess
(Person with ID and Carer)
Specialist Training Program (STP) and GP Registrar Training Program

The Commonwealth funds salary contributions for supervision, rural placement and the development of educational supports for STP Registrar and GP Registrar positions.

The STP enables medical specialist trainees to rotate through clinical settings specialising in ID (as well as many other settings) to gain specific experience not available in public teaching hospitals. STP Registrar placements in ID take place in specialist multidisciplinary ID health teams.

Some General Practice Registrar Training Program offers senior GP Registrars a term in extended skills such as disability medicine.

8.3 ID Health Network Toolkit / Resources

The ID Health Network has been involved in developing a number of resources to assist in building the capacity of the workforce, as follows:

- Four short videos on ID and Primary Health
- Australian College of Nursing ID Course
- Hospitalisation and specific health issues videos
- Disability Awareness video – HETI
- Schoolkit
- Co-design project
Based on the ID Health Network’s survey of current research activity in NSW in the field of ID, this chapter refers to some of the research and projects which the ACI ID health Network funds to improve health outcomes for people with ID in NSW.

Currently ID is not coded in admission or discharge health records as a co-morbidity. This affects the ability of health services to organise services and pathways between them and evaluate their effectiveness, which would improve outcomes.

9.1 Research and Development work within the ID Health Network

The National Disability Services State of the Disability Sector Report 2014 states that:

"The most comprehensive audit of disability research concluded that the current disability research base is not fit for purpose for the reform agenda. The audit also found there was no critical mass of research on topics of priority to the National Disability Strategy, the National Disability Research and Development Agenda and the NDIS."

The ID Health Network through its Research and Development Subcommittee, surveyed NSW academics, researchers and practitioners working in the field of ID and health.

For the full report and to see the Catalogue of Current Research in NSW in ID go here.

The survey sought to:

- Understand the research landscape in NSW and construct a catalogue of current research
- Highlight possible gaps in research
- Discover barriers and enablers of research
- Canvas opinion on a disability data set (see below).

Of the 109 respondents, 41% of respondents were from the health sector and 40% were clinicians. 40% worked with adolescent / adult clients.
9.2 The importance of data and the need for a universal identifier

The collection, interrogation and reporting of data on health service access, use and outcomes is considered critical to improve the health of people with ID. There is no state or territory in Australia which routinely reports such data, although international examples suggest the merits of doing so.

A first step to data collection is the development and implementation of a health identifier, clearly identifying whether a person has ID. This needs to include children and adults with developmental delay as well as ID. Implementing an identifier is a potentially sensitive issue for people with ID. It needs careful consideration and consultation with people with ID and advocacy groups.

There is a need for both population and individual level data. It should advise health planners and administrators.

Research on health outcomes for people with a disability relies largely on linking data between health and the disability sector. In the latter people with disability are identified when they register for disability services. As not all people with intellectual disability are participants in the disability sector, there is limited state (or national) data on specific health outcomes across all people with ID.

ID is not coded in health records as co-morbidity in admission or discharge data.

The ACI ID survey shows 86% of respondents think a comprehensive NSW ID data set is very important (42%) or essential (44%) for health planning, identification of needs, co-ordination of care, and improving health promotion.

The ID Health Network has a position paper on the need for an ID data set.

A data linkage project between ADHC and NSW Health (2012) to gain insight into the health needs and hospitalisation of ADHC clients (2005/06 – 2009/10) drew on data sets from:

- Disability Services (DS) and Home and Community Care (HACC) National Minimum Data Sets (NMDS); and
- NSW Health Admitted Patient Data Collection and Emergency Department Data Collection.

There is further data linkage work being done by Health and FACS to show the use of health service by FACS clients. Data goes back to 2010.

9.3 ACI Support of ID Research

The ID Health Network is actively involved in or financially supporting the following work:

- The School based Exercise Program for children with ID at risk of obesity (SCHN Westmead Campus)
- The Evaluation of the WentWest Child Development Care Coordination Project
- Understanding Mental Illness in People with ID: An e-Learning Resource for Carers Project (UNSW Australia)
- NHMRC Partnerships for Better Health Project: Improving the Mental Health Outcomes for Persons with ID (3DN, UNSW Australia)
- ID Co-Design Project (Hospitalisation)
- Forums run in partnership with local Health Districts on research and related work in ID, Mental Health and Hospitalisation, amongst other topics
- The development and evaluation of visual aids for clinical procedures involving people with ID.

The Research and Development Subcommittee of the ID Health Network has developed or is involved with:

- A position paper on a minimum data set
- A catalogue on recent ID research in NSW
- A gap analysis of ID research
- Guidelines on ID research
- Guidelines on Inclusive Research and ID
- The University of Newcastle Disability Research Network.
Summary

This chapter discusses what ABF is and how the Activity Based Management funding model aims to support evidence-based Models of Care. ABF developments are an important consideration in the development and sustainability of specialised Model of Care for ID services.

The introduction of ABF will impact on the delivery of health services for people with ID. The ID Health Network and the NSW Ministry of Health ABF Taskforce participated in a forum to discuss the effects of the introduction.

The ABF model funds outputs, rather than throughputs. In the future the ABF will also be used as a management tool (Activity Based Management – ABM).

The ABF model:
- Classifies patients into relevant clinical groups with homogenous costs
- Documents the number of episodes of care for each patient
- Costs a representative number of patient episodes
- Determines a price for the average patient, set by the Independent Hospital Pricing Authority (IHPA) based on data submitted by health jurisdictions across Australia.

The IHPA has categorised four care streams based broadly on different resource use:

(i) emergency department services 
(ii) acute admitted services 
(iii) sub-acute and non-acute care admitted services 
(iv) non-admitted services and outpatient services.

The National Weighted Activity Unit (NWAU) compares costs across and within care streams. The weighting aims to standardise prices so that activities can be monitored and compared.

The key implications of ABF and ABM for ID are:
- Clinical classification must accurately reflect the actual cost of output. When specialist multidisciplinary services cannot be accurately classified due to coding limits an inaccurate price could be allocated to the activity.
- The shift to ABM means a transition from efficiency to value, including measuring patient outcomes. This is problematic for people with ID because of the chronic and complex nature of their health issues, and the requirement for multidisciplinary teams.

The focus of discussions between the ID Health Network and the ABF is:
- A classification for Tier 2 non-admitted patients for people with ID
- A National Weighted Activity Unit (NWAU) adjustment for developmental disability
- A NWAU adjustment for review by multidisciplinary teams (for people with ID)
- A non-admitted cost differential between initial and subsequent consultations for people with ID.

10.1 Resources / Toolkit of the ID Health Network
- A Network position paper on Activity Based Funding.
Section 11
Hospitalisation and Co-Design

Summary

This chapter discusses the third tier of the Service Framework – Acute Health Services. It is based on feedback, interviews and discussions with clinicians, consumers and carers.

The chapter also discusses the Co-Design Hospitalisation project, a partnership between ACI and SESLHD.

11.1 Background

Current research suggests that significant numbers of patients in the general community are receiving treatment in acute care settings, when a different setting would be more appropriate, more cost effective and lead to improved health outcomesiii. People with intellectual disability are in this category.

Tina’s story (see page 7) shows how a presentation to the ED can lead to an 18 day hospital admission for someone with ID. The lengthy admission was caused by communication difficulties, complexity of diagnosis and lack of support for discharge into the community.

Key Findings of the ADHC and Health data linkage project iv

The in-patient hospital utilisation of ADHC clients is significantly higher than the rest of the NSW population, and this difference is greatest for those under 65 years of age.

The increased rate of hospitalisation for ADHC clients is exacerbated by an increased length of stay leading to overrepresentation of ADHC clients in ED and hospital. In terms of bed days: Disability Services clients stay 4.1 times longer than the population.

For HACC clients (aged under 65) the average stay is 8.7 times the population on an age standardised basis.

The Emergency Department (ED) utilisation of ADHC clients is significantly higher than the rest of the NSW population, and as for inpatient hospital utilisation, this difference is greatest for the under 65 year old HACC service users.
11.2 Feedback on acute care

Feedback and analysis from patient interviews, clinician comments and discharge case studies undertaken by the ID Health Network highlight the importance of:

- Clinical pathways and referral pathways for people with ID
- Improved communication with patients and their family / carer
- Better access to mental health services for people with ID
- An identified ID key contact in the health system at an LHD level, accessible by patients, carers, family, GPs and NGOs
- Appropriate community supports to allow for early discharge
- Improved patient record management and flagging of people with ID
- Access to specialist ID health services for people in regional and remote areas of NSW
- Access to specialist ID health services for clinicians at different levels of the health system
- Appropriate ways of working with people with ID and their family / carer
- The need to engage the GP in transitions of care
- Educational support on ID for health staff

Roger was admitted in a dissociative rage to a mental health unit where he remained for many weeks. Multiple attempts to discharge him were unsuccessful.

Eventually, after working with Roger, his mother and the disability case worker, a purpose-built garden unit in an NGO group home was found for Roger. He was transferred with the support of the hospital’s discharge planner and the social worker.

With appropriate management protocols and a person-centred care plan, Roger rapidly settled with minimal medication. He now engages with the community.

A specialist intellectual disability health team:

- Was involved in planning and implementing hospital discharge.
- Available for clinical consultations in person and by phone during the transition
- Built the capacity of clinicians and carers by engaging them in the process. The NGO is engaging with a local GP for Roger’s health needs.
- Engaged the family throughout with the aim of ultimately returning Roger to independent living with family support.

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The Person with ID, the Hospital, Group Home and Specialist Supports
– A Partnership supporting transfer of care.

Roger (17) has intellectual disability, Autism and emotional dysregulation with violent behaviour. Neither his mother nor emergency respite services can manage his behaviour. After a lengthy admission to a Mental Health Unit in a public hospital and with the involvement of Roger’s mother, Roger was able to be transferred to supported accommodation in the community with ongoing support for Roger and staff.

Roger, aged 17 years, with mild intellectual disability and severe autism was admitted to his local hospital mental health unit following months of severe emotional dysregulation, violence, damage to property and an inability to leave his house. His mother was unable to manage. Attempts were made to access emergency respite care but a placement was not found due to Roger’s extreme agitation and violence.

Eventually, after working with Roger, his mother and the disability case worker, a purpose-built garden unit in an NGO group home was found for Roger. He was transferred with the support of the hospital’s discharge planner and the social worker.

With appropriate management protocols and a person-centred care plan, Roger rapidly settled with minimal medication. He now engages with the community.

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- Available for clinical consultations in person and by phone during the transition
- Built the capacity of clinicians and carers by engaging them in the process. The NGO is engaging with a local GP for Roger’s health needs.
- Engaged the family throughout with the aim of ultimately returning Roger to independent living with family support.
• Policies and processes inclusive of people with ID at an LHD level
• Access to behavioural support for people with ID
• Increased use of tele-health
• Support for and acknowledgement of the role of the carer
• Health staff understanding staffing models in supported accommodation.

11.3 Co-design of Health Services to Avoid Unnecessary Hospitalisation

Co-design is the process of designing health services by bringing together all stakeholders and consumers to develop those services. Co-design opens new perspectives and possibilities for innovative service delivery, and leads to significant improvements in health and well-being for people with complex health needs and their carers.

Hospitalisation Co-Design toolkit: Developmental Assessment Services, Kogarah is partnering with the ACI Patient Experience and Consumer Engagement (PEACE) Team to produce a toolkit explaining co-design principles for hospitals. This will optimise the patient journey from community to hospital care and back again. Areas of particular focus include managing challenging behaviours and the role of higher level consultancy services. The key focus is on young people and adults.

The toolkit will look at key stages in the patient journey including:

a) **Intervention** – proactive community care and strategies for interventions to avoid unnecessary hospitalisation

b) **Hospitalisation** – including pre-admission planning and in-hospital care with a focus on patient-centred care, staff training and orientation, management of the environment, co-ordination of diagnostics, and intervention and early discharge planning. Key outcomes include decreased length of stay and minimised distress.

c) **Avoidable re-admissions** – through planned community-based reviews and medical and mental health care, which optimise recovery and prevent relapse.

For more information go to www.aci.health.nsw.gov.au/resources/intellectual-disability

11.4 Patients with Intellectual Disability being Discharged from Hospital to Supported Accommodation

**Background**

A working group of the ID Health Network analysed ten de-identified discharge journeys of patients with ID, from public hospitals into supported accommodation. The analysis identifies the characteristics of effective discharge planning. This will assist the development of policies and procedures for people with ID. The analysis has wider application to health at every level, and for other agencies and service providers who work in partnership with people with ID.

The characteristics of effective discharge planning to supported accommodation were found to be:

- patient–centred planning from pre-admission
- collaboration between agencies and with the GP
- the ability to adjust services for the needs of the person with ID
- **policy to guide practice**
- a key contact for people with ID in the LHD
- individual community health management plans
- a clinical decision making tree
- a pathway to care when accessing health services
- access to after-hours specialist ID clinical support for local decision makers
- appropriate recognition of the carer
- an understanding of supported accommodation and the skills of support staff (For example, many assumed clinical staff were available in supported accommodation)
- clear transfer information, both written and verbal, that is reviewed with the person with ID and their family / carer.
NSW Health and state disability services produced a joint guideline to foster service collaboration, supporting residents of government supported accommodation services.

The ID Health Network working group on discharge of patients with an ID found that:

- NSW Health staff were generally not very familiar with the joint guideline
- Health staff require training in communicating with people with ID and their family / carer
- Supported Accommodation Staff require training in:
  - Gastrostomy feeding
  - Positioning of the person with ID
  - Identifying a health concern and the process for escalation.

These case discussions also show that the disability support worker may not understand the information exchanged within the health team, or be able to prioritise it. There is therefore a need for written information.

Health staff regularly misunderstood the model of care in supported accommodation, and the skills of the support worker. Health staff often assumed support staff had nursing knowledge and that group homes are a clinical environment.

In Mary’s case (Case Study 3) the risk screening at pre-admission and the transfer of care planning was attended by the group home team leader, who was also a Registered Nurse and understood the health system and the clinical issues, leading to better planning.
Case Study 3 – Discharge Journey

The Person with ID, the GP, the Disability Service and the Hospital. A partnership supporting transfer from hospital to supported accommodation.

Mary (65) lives in state disability supported accommodation and is in need of some surgical procedures which she is reluctant to have due to her anxiety. She also has ID, mental health concerns and needs communication support. With the help of her GP and the RN from her group home she attends pre-admission planning case conferences in the hospital. They are in line with the NSW Health and ADHC Joint Guidelines for transfer from hospital for people with a disability. The collaboration between the hospital and the group home result in better health outcomes for Mary.

The tests recommended were invasive and staff found their local hospital was not able to accommodate Mary’s specific needs. They found it difficult to explain to her how she would benefit by attending medical appointments. The Team Leader of the group home is a Registered Nurse with an understanding of the health system and health needs. It took nearly 12 months before she and her team of staff were able to convince Mary to see a GP who then referred her on to appropriate specialists.

The first step was identifying a hospital within the LHD which was better equipped to support Mary. With the help of her GP and the RN from her group home, Mary attends pre-admission planning case conferences in the hospital. The NSW Health & Ageing and Disability and Home Care (ADHC) Joint Guideline (2013) was brought to the meeting by the Team Leader from the group home.

Although health staff were not familiar with the document, and the anaesthetist initially thought the concepts were unsustainable, with discussion, everyone decided to work together using the joint guidelines. The pre-admission meetings ensured that Mary’s special needs around communication support, mental health and ID support were highlighted. The staff from the group home and the hospital explored ways in which Mary’s needs would be managed while she was an inpatient and steps were taken to put processes in place to provide Mary the support she needed.

The hospital they were dealing with thought of ways to make things better for Mary and suggested an innovative model whereby Mary was booked to have both procedures at the same time, while under anaesthetic.

Mary was prepared as an inpatient the day prior to her procedure.

Mary was discharged on the planned day without any complications and received routine follow up care from her GP. There was no report from group home staff of an escalation in mental health problems as a result of the hospital admission and procedures.
11.5 ACI ID Health Network’s Toolkits

/ Resources

The ID Health Network has created templates for use by health service providers, such as letters explaining appointments, hospital visits, and giving feedback to providers.

The subcommittees of the ACI ID Health Network have produced:

- Co–design project
- Patients’ journeys
- Clinicians comments
- Discharge discussions
- Mainstream supports for people with ID (Page 23).
Barriers to good health outcomes for health to people with intellectual disability include:

- Being aware of a health concern and knowing what to do about it. This could apply for the person with ID themselves and/or their carer and support staff.
- Health professionals lacking knowledge and experience in working with people with ID.

People with ID typically have low health literacy, which is associated with poorer health, higher medical expenses, non-adherence to medication and increased hospitalisation. A health care provider may need support to access appropriate information for a person with ID, and to know when a person with ID doesn’t understand the information.

12.1 Background

People with ID benefit from appropriate health promotion in the same areas as their peers, including dental health, mental health, relationships, smoking, nutrition and obesity, sexual health, sun exposure, hygiene and exercise. The information or service needs to be adapted to the particular needs of the person receiving it.

Reviews of deaths of people with disabilities in care, undertaken by the Ombudsman can be found here.

These reports identified that few people with disability had access to:

- Chronic disease management programs and support (such as Connecting Care)
- Other out-of-hospital care (such as Hospital in the Home)
- Preventative health programs and supports (particularly those targeted at reducing risks associated with smoking, obesity, poor diet and sedentary behaviour).
12.2 An Example of Policy Shaping Practice

Partnering with the NGO Disability Sector – a coordinated and collaborative approach

In the Illawarra and Shoalhaven Local Health District (ISLHD) there was evidence of patients with disability having negative hospital experiences, including premature and uncoordinated discharges and extended stays and frequent readmissions. Disability organisations lobbied for better quality and safety of care, and a person centred approach.

Initial attempts were largely unsuccessful as they lacked high level support and formal policy processes to review current systems and procedures. Governance structures that facilitated community partnerships for planning, design, monitoring and evaluation of health programs were lacking.

In 2013 the Australian Commission on Safety and Quality in Health Care introduced standards, including standard 2: “Partnering with Consumers”. Standard 2 requires health services to actively involve consumers in improving patient experiences and health outcomes.

In this same year the ISLHD partnered with disability health services and consumers to develop the 2014-2017 ISLHD Disability Action Plan.

As a result of the partnership and plan:

- A memorandum of understanding between the local health district and NGOs was signed;
- Consumers and NGOs became involved in ISLHD staff training;
- Consumer resources were delivered in an easy to use and understand format;
- Community representation was implemented on ISLHD’s Consumer Participation Council;
- Improved communication processes between ISLHD and the disability sector were implemented;
- There was meaningful engagement with consumers to improve access and delivery of services;
- An ISLHD Clinical Disability Liaison CNC position was created and funded, to provide leadership; advocacy and clinical expertise to staff.

12.3 ID Health Network Resources / Toolkit

- An exercise program in schools for children with ID
- Guidelines and tools for LHDs to develop inclusive services
- Recent NSW Ministry of Health policies and guidelines published specifically addressing the needs of people with ID.
Section 13
Primary Health and Community Health

Summary

This chapter discusses Tier 2 of the Service Framework (2012) – Primary Health and Community Health Care – and looks at different models and partnerships in operation in the community, and their links to other tiers of the health system and to NGOs.

Case studies illustrate ways of working collaboratively.

The importance of the annual health assessment for people with ID is highlighted.

The chapter includes a discussion on the transition of people with an ID to other health services, and from large residential centres into the community.

13.1 Background

Evidence suggests poor access to primary health care for all people is strongly related to higher rates of potentially avoidable hospitalisations.

Common features of successful programs that have reduced avoidable hospitalisation for chronically ill Australians are:

- Early identification of people at risk of hospitalisation
- Care co-ordination and integrated care
- Equity of access to primary health care
- Multidisciplinary approach to care
- Medium to long term disease management.

People with intellectual disability often have:

- High rates of undiagnosed illness, and chronic and complex health needs
- Unique health care needs requiring adapted care delivery
- Illnesses overlooked or attributed to their disability
- Additional barriers to access (transport, carer, literacy, waiting periods)
- Communication difficulties and low health literacy.

Some GPs work closely with NGO and disability service group homes to support the health care needs of people with intellectual disability.

“I did up a chat book a couple of years ago for visits to the GP. We took photos of the surgery, the receptionist, the waiting room, the doctor, all of the people and things he will encounter…”

The receptionist and the paediatrician at the country Hospital are great with him.

Ivita & Reece
(Person with ID and Carer)
13.2 Transition to other health services

Transfer of clinical information about the patient’s hospital admission and discharge instructions relies on good communication between services and between tiers within services. Communication may be complicated when the person has ID and communication aids are not used or are not suitable, or when a support person or advocate is not appropriately involved.

Risks are high during transition of care. A key contact or case co-ordinator within a hospital is useful.

Residents of large residential centres moving into the community

As large residential centres are devolved, some people with ID and chronic and complex health conditions will move into community supported accommodation or group homes. While this creates the opportunity for the formation of new partnerships, there is also a need for careful planning around the needs of the person with ID. The involvement of the GP and primary health providers is critical. Prior to transition the health care needs of residents may have been met internally.

13.3 Intellectual disability health teams

Some Primary Health Networks have a particular interest in the health care needs of people with ID and have formed partnerships with ID health specialists to provide education and after hour services.

Primary Health Network and GP involvement in the ID Health Network, and the creation of the ID health teams, have led to new pathways, partnerships and education opportunities within the health sector.

13.4 NGO service model

The state wide NGO service NSW Developmental Disability Health Unit (DDHU) is run by the Centre for Disability Studies and located at Royal Rehab. It is for people over 16 and conducts comprehensive annual health assessments for people with ID and reports back to a person’s GP with findings and recommendations. The service provides psychology consultations and counselling. The model provides additional specialist support for the GP.

The specialist team relies on the GP for patient history and continuum of care. The clinic co-ordinator and the GP practice nurse are a key point of contact. GPs are often unsure of referral pathways and available of services for people with ID. The local relationships between the Primary Health Network and the specialist team have assisted GPs in this regard.
Mavis (50) has intellectual disability and epilepsy, schizophrenia and osteoporosis. Mavis sees her Neurologist and Psychiatrist for regular reviews.

She has been referred to a Respiratory and Sleep specialist for assessment and treatment of possible sleep apnoea. Her GP has referred her for other preventative health actions (e.g. breast screening, immunisations). The detailed reports and recommendations provide guidance to Mavis’ GP about ongoing health management. They are also useful for Mavis’ case manager to assist with ongoing health care planning.

Mavis is a 50 year old woman with a mild range of intellectual disability and complex health problems. These include epilepsy, schizophrenia, a history of multiple fractures with a diagnosis of osteoporosis.

Mavis lives in a group home and saw her general practitioner for a comprehensive health assessment.

Mavis' seizures are poorly controlled and cause her to fall. She is reviewed regularly by her psychiatrist and neurologist. She had not had an assessment of her bone density for several years.

Over several visits, Mavis’ GP took a thorough medical history from Mavis and her support staff. Mavis was noted to have symptoms of possible sleep apnoea, which had not previously been identified. She was referred to a Respiratory and Sleep specialist. Sleep studies confirmed severe obstructive sleep apnoea for which she was treated.

She was also referred for a bone density examination to monitor for osteoporosis.

Mavis had several visits to her GP for referrals for other assessments and management. Detailed reports with recommendations were provided from the specialists to Mavis’ GP. The GP and the practice nurse spoke with Mavis about the results. Mavis' case manager was also appropriately informed.

The GP referred Mavis to an NGO specialist ID health team for additional advice. The specialist team provided guidance to Mavis’ general practitioner on preventive health, including diet and exercise. Mavis’ case manager also received health care planning suggestions. Mavis’ GP has since enrolled her in a community based integrated care programme for health maintenance. The case manager is working with the programme staff to ensure they engage Mavis appropriately in the service and adapt their services to meet her needs.
Case Study 5 – The person with ID and their GP

Jake and his GP involved with the Specialist Disability Health clinic, Psychiatry and School Clinic.

Jake (13) is referred by his GP to a Paediatrician who seeks support from a Specialist Disability Health clinic for a comprehensive health assessment, after escalating behaviour difficulties which cause hospitalisation for self-harm. He has intellectual disability, Autistic Spectrum Disorder and anxiety and depression. The Specialist Disability Health Clinic refers him for paediatric psychiatry, blood tests, dietician support and reviews his medications. With Jake’s Mum, they organise a school multidisciplinary clinic and establish behaviour strategies.

Jake has a disability caseworker and was using respite services regularly. However, there was considerable family stress.

There were significant concerns regarding Jake’s aggressive and self-harming behaviour. He had little involvement with a paediatrician for a number of years. Jake was referred for a comprehensive health assessment by an NGO run specialist disability clinic.

After collaboration between the clinic and GP:

- An appointment was arranged with a paediatric psychiatrist with expertise in children with intellectual disability within the mainstream NSW health system to address his behaviour issues;
- Jake was referred to the disability service behaviour management team;
- Blood tests were arranged to investigate nutritional difficulties due to a restricted diet and loose bowel motions.

Jake’s medication was reviewed and he started a regular program of respite and school attendance with regular reviews by the psychiatrist.

Strategies were put in place by the clinic at Jake’s school to manage episodes of aggression and self-harm.

13.6 Partnerships with Primary Health Training

The Australian College of Nursing and the ID Health Network ran a two day course on nursing care for patients with ID. An experienced GP presented on how she effectively responds to her patients with ID. Her practice is part of the Commonwealth funded GP Supported Registrar Training Program, which builds the capacity of the workforce to meet the health care needs of people with ID. The ID Health Network videos for GPs and Primary Health workers are here.

Illawarra Disability Health Network

Disability service providers and family representatives within the Illawarra area have formed a Disability Health Network to address hospital issues that impact on people with a disability. During 2013 the local health district engaged with the Illawarra Disability Health Network to identify ways to improve the district’s disability action plan.

More recently, and as a result of the Network’s lobbying, the Illawarra / Shoalhaven LHD developed a clinical nurse liaison role. This role will liaise between health staff, the person with a disability and their carers or support staff. They will facilitate education for staff on disability issues and provide input into policy and procedures. (Refer to page 39, Section 12.2 to see how policy drives practice).
The key elements of success resulting from this partnership are:

- A memorandum of understanding between the local health district and service providers
- The paid involvement of disability support staff in the hospital setting
- Education and training
- Plain English materials
- A collaborative approach towards reviewing current processes and policies.

Other examples of local health partnerships

Local health services are keen to support and partner with NGOs, Primary Health Networks and GP practices to ensure good health outcomes.

- **Special Care Dentistry Department** of Sydney Dental Hospital (SLHD) has assisted NGOs to establish dental care models for people with ID. The team includes dentists, hygienists and dieticians.
- Some people with ID require a general anaesthetic for dental work. The SDHT (Pg 54, Pilot 3) has developed a pathway to hospital that provides a general anaesthetic for dental and other procedures. This model could be adapted locally.
- **Community Owned Primary Health Enterprise (COPHE)** is a small team working to grow community influence in primary health care by owning and running services to meet the needs of their community. COPHE aims to increase access to affordable and appropriate primary health care for poorly served communities or client groups. They support local community groups or non-government organisations to develop services.
- **The Village Medical Practice** in Summer Hill is an example of a GP Practice which has developed processes and pathways to meet the needs of local people with disabilities living in group homes and boarding houses. They have processes for admission and discharge planning with local hospitals that draw on the support of specialist ID health teams, local private medical specialists and allied health professionals as required.

**After hours support**

The **MRID team** in Kogarah is developing a model that will provide after hour support for the health care needs of people with ID in supported accommodation.

The proposed model draws on the established protocols and processes within SESLHD to help reduce unplanned admissions and unnecessary presentations to the Emergency Department. It is based on interagency collaboration between Family and Community Services (ADHC), Primary Health Networks, Health, and people with ID and their family / carer.

The team can be used by on call services to:

- Provide advice to enable disability support workers and health staff to meet the immediate health concerns of the person with an ID
- Provide alternate pathways to care, such as referrals to the clinic or the GP, or appropriate assistance the following day
- Utilise MBS funding
- Strengthen ongoing relationships with Primary Health Networks
- Build the capacity of all partners to provide support during routine office hours that reduces reliance on acute care services after hours.
13.7 Annual Health Assessment

Feedback on primary health models was given by the Primary Health Networks and others at a Primary Health Forum hosted by the ID Health Network. The feedback identified the need for longer appointment times, chronic disease management plans, annual health assessments and the importance of a good historian for people with an ID.

Annual health assessments should include checks to ensure people with ID have access to preventative health measures for example: immunisations and cervical screening. Risks such as obesity, smoking, diet and lack of exercise should be addressed.

Health checks are not well utilised by people with ID. Comprehensive Health Assessment Program numbers are low and annual reviews even lower. Getting more people with an ID to undergo health checks is important. Annual Health Assessments identify health problems and improve health promotion.

The ACI forum discussed the funding model under the Medicare Billing Scheme, and recommended the need for community health programmes (Health One; Connecting Care and Integrated Care) to be more inclusive of people with ID. The personally controlled electronic health record was seen as important for maintaining medical histories.

13.8 People with ID accessing Alcohol and Other Drug (AOD) services

Accessing AOD services tends to be extremely difficult for people with ID. Unless AOD services ensure fair access and treatment that accommodates people with ID, AOD problems are likely to go untreated and the individual is more likely to have involvement with Juvenile Justice and the Corrective Services.

13.9 ID Health Network’s Resources / Toolkit

The ID Health Network, with the expertise and assistance of GPs, produced four short videos for GPs on the pathways to care for people with ID. Those videos include a person with ID and a carer speaking of the importance of having a good GP, and what makes a good GP visit.

The videos also discuss the role of the GP in the person’s journey in and out of hospital and the importance of communication between different parts of the health system.

NSW Council for Intellectual Disability and the Ombudsman’s office have useful ID information and fact sheets for providers and consumers of primary health.

With support from ACI, Wentwest Medicare Local trialled an initiative in Western Sydney for children with developmental delay. In the course of this initiative GPs expressed support for the assistance of syndrome specific information which forms part of the Comprehensive Health Assessment Programme.

The NGO sector has some valuable population health and community health initiatives. For example Family Planning has a focus on sexual health for people with ID and builds health workforce capacity through its presentations, materials and consultations within primary health, acute health and specialist ID health services.

The IDHN has developed some guidelines for GPs about working with people with ID based on the experiences of Network members, including GPs. There are also suggestions for LHDs on how to engage with GPs and reduce unnecessary hospitalisation of people with ID.

I wouldn’t like my son to be in hospital on his own. If a person has a disability they are going to get left in the corner, no matter how good the service is, if they are not making some kind of noise. When my son is in hospital I have not left him alone unless another relative was there. I’m confident that he got the best treatment he could get.

To stay in the country Hospital I had to go to a pre-op meeting. They had a care plan thing where you could write down the five important things for the staff to know about the person. So I wrote about his nervousness and don’t like things happening without knowing about it. They have brought it in for children, people with disabilities and mental health problems.

Ylvia & Reece
(Person with ID and Carer)
Section 14

Mental Health Services for People with Intellectual Disability in NSW

Summary

This chapter discusses the high rate of mental illness experienced by people with ID, and poor access to mental health services. An improved model of care for the mental health of people with ID requires significant development of capacity in mainstream health and mental health, and the funding of subspecialty mental health services.

14.1 Background

People with ID experience high rates of mental illness and poor access to mental health services. People with an ID have the right to timely access to quality generic and specialist mental health services. The development of a comprehensive model of care for people with ID and mental health issues will require significant capacity in both mainstream health and mental health services. Further, the development of uniformly accessible subspecialty ID mental health services would assist mainstream health and mental health services to meet the needs of people with ID and complex mental disorders.

The ACI ID Health Network has been active in developing the capacity of mainstream health services in ID and mental health. Examples include the hosting of two successful forums on ID mental health with the Children’s Hospital Westmead and ADHC. The ACI ID Health Network has also produced a video on the mental health of people with ID.

The provision of timely access to quality mental health services to people with intellectual and developmental disability will require significant training and education for all levels of the health workforce. A broad based approach would include enhancing training and education at both undergraduate and postgraduate levels, by including curriculum content in ID mental health in relevant disciplines such as medicine, nursing psychology/clinical psychology, speech and communication therapy, occupational therapy, and physiotherapy.

Further, specific competencies and training are required for the NSW public mental health workforce. An example of specific training in this area is the IDMH e-Learning suite of resources developed by the UNSW Australia Chair of Intellectual Disability Mental Health (see http://www.idhealtheducation.edu.au/). Further, the development of subspecialty clinicians in ID mental health would be of significant benefit, as a more specialised service could assist in equipping the mainstream health and mental health workforce, and by consultation, could assist with more complex case review.

Significant capacity in ID mental health currently exists within the state based disability sector. This critical expertise is employed by ADHC and includes practice leaders to support professional development, psychologists with specific expertise in behaviour support and mental health, nurses with significant experience and knowledge, and a variety of allied health staff who have specific subspecialty knowledge. This workforce has enabled people with ID and severe mental health problems to be managed and treated in the community. The ADHC funded Client Monitoring and Review System has reviewed several hundred high risk cases each year with multi-agency, multidisciplinary input, including from Specialist ID Psychiatry. The future of this expertise and capacity is uncertain.
Community based and residential respite are appropriate and effective therapeutic environments to manage some people with ID and complex mental health problems. Many families are exhausted or are managing their own health concerns and unable to continue care. Long term hospitalisation for a person with ID is not the best option. Improving the severe and often chronic mental health problems of people with ID is likely to be the most cost effective component of intervention.

A more detailed discussion of how key members of the ID Health Network see models of service delivery are found below:

- **Adults with an Intellectual Disability and Co-occurring Mental Disorders**
- **Building a Model of Care for the Mental Health of Children and Adolescents with Intellectual Disability in NSW.**

### 14.2 Examples of services to support mainstream health service delivery

As the level of complexity of ID and mental health increases, communication becomes more difficult. There is more challenging behaviour and more physical co-morbidities. The importance of access to specific mental health training, clinical and referral pathways and access to specialist IDMH consultative teams for guidance and support becomes increasingly important. The specialist multidisciplinary ID health services which include IDMH consultancy are scarce and in heavy demand.

The ADHC funded UNSW Chairs of Intellectual Disability Mental Health and Intellectual Disability Behaviour Support contribute to supporting mainstream services through research, development of educational resources, and academic leadership. *The Guide: Accessible Mental Health Services for People with an Intellectual Disability: A Guide for Providers* are e-learning modules developed specifically for health/mental health professionals are important examples.

The National Roundtable on Mental Health and Intellectual Disability (May 2013) reinforced the importance of subspecialty in mental Health and ID. The National Mental Health Commission’s review of mental health services speaks of the needs of people with ID.
NSW Health Child and Adolescent Mental Health Services (CAMHS)

Deryk (11) is diagnosed with developmental delay. His behaviour has recently escalated and he has been admitted to the Emergency Department by police and ambulance. With no bed availability for a child his age in need of acute inpatient mental health services, he is managed by local clinicians with remote access to consultations with specialist ID Mental Health Psychiatry and Psychology support.

Deryk is an 11 year old boy with developmental delay and other medical conditions. He was diagnosed by a Diagnostic and Assessment Unit. He also has a mental health disorder. He is in foster care and attends school. His Paediatrician had been monitoring behaviour for several years due to recurrent episodes of violence. Initially he was being managed as an outpatient, but more recently at the emergency department for 6 days with special nursing support. More recently ambulance and police have been involved. He was considered to be too young for a mental health setting and the LHD has no CAMHS (child & adolescent area mental health services) inpatient unit. He was reviewed by a psychiatric registrar.

The only designated Mental Health Unit in NSW eligible to take children under 12 had no beds. He had an urgent Outpatient assessment at a neighbouring hospital with a psychiatrist. He was brought by his family to the consultation from the Emergency Department of the district hospital and taken back there afterwards. The Assertive Outreach Team of the LHD CAMHS was consulted. A few weeks later there was a further multi-agency, multi-disciplinary case conference focusing on improving acute sedation management regime by Emergency services to avoid police involvement. The protocol was based on expert advice.

The urgent response of specialist ID Psychiatry enabled his care to be managed in the paediatric ward in the regional LHD, so his medication could be stabilised before returning home. Behavioural approaches were reintroduced which could not be tried earlier. A few months later additional support from an NGO provided training for his foster family to give them skills and extra support. The foster family were enrolled in further parent training classes and supported skilled behaviour and communication management.

14.3 Resources / Toolkits from the ID Health Network

The ID Health Network has produced some short videos for clinicians and support staff which includes discussions about ID and mental health.

The ID Health Network partnered with Ageing Disability and Home Care (ADHC) and the Developmental Psychiatry Team (SCHN Westmead) to host a forum on Dual Diagnosis: Intellectual Disability and Mental Health.

The presentations on Pathways to Care, sexualised behaviour, cross – cultural work, the school environment, school clinics and parenting programmes are available here.

The Mental Health Commissioner has identified intellectual disability as a key area of focus. The Commission’s presentation at the ID Health Network Forum (2014) can be heard here.

The Network’s “Pathways to Care for children and adolescents with ID, challenging behaviour and / or mental health concerns” is here.
Section 15

Specialist Intellectual Disability Health Services

Summary

This chapter sets out the different types of specialist services and their roles in direct service provision, and is based on a state-wide survey of Specialist intellectual disability health services in NSW.

The chapter looks in detail at the three NSW Ministry of Health funded specialist multi-disciplinary ID health teams.

15.1 Background

Most people with ID will access mainstream health services alongside the rest of the community. These mainstream health services may need some adjustments or enhanced staff skills to provide the patient centred care which health delivers. Support and advice to achieve this is part of the work of the LHD’s Disability Inclusion Planning and might include access to specialist services for consultancy and capacity building.

The Access and Equity Subcommittee of the ID Health Network surveyed each Local Health District across NSW to identify the specialist ID health services available in NSW. A full list of specialist services for people with intellectual disability in NSW by LHD has been made available to the Chief Executive of each NSW local health district. These services are typically delivered in multidisciplinary team models of care and are staffed by health professionals with high level of expertise in health care needs of people with ID.

Some examples of specialist ID health services include the Disability and Rehabilitation Team for Young People at Concord (DARTYP) and the state-wide NSW Developmental Disability Health Unit at Royal Rehab, Ryde.

Diagnostic and Assessment clinics for children with developmental delay are also specialist services. These are scattered across NSW. The Developmental Psychiatry Clinic is a partnership between the Children’s Hospital at Westmead and State-wide Behaviour Intervention Service (ADHC) and is a “quaternary” level health service. The Developmental Disability Clinic at Goulburn and the Neuropsychiatry Clinic at UNSW are other examples.

15.2 Multidisciplinary Diagnostic and Assessment Services in NSW

A number of multidisciplinary diagnostic and assessment services exist in NSW, with the first team being established in the 1960s in the inner western suburbs of Sydney. These teams have predominantly provided comprehensive assessments for children suspected of having a developmental disability, although some teams have also provided specialised health services for older children and, in a small number of teams, continuity of care into adult life.

The governance and composition of these teams varies across the state, often reflecting local and historical priorities at the time they were established. Diagnostic and assessment services provide a skeleton of specialised health services for children, young people and adults with intellectual disability. It has long been recognised that there is inequitable and extremely limited distribution of services. Teams such as Lower North Shore Child Development Service and the Parramatta Early Childhood Assessment Team provide diagnostic services for children less than 6 years of age. Disability Specialist Unit provides specialised services across the lifespan. Other services have been established for specific groups of people, such as Diagnostic Assessment and Rehabilitation Team for Young People, in Concord.
15.3 Specialist dentistry services

The Department of Special Needs Dentistry in Western Sydney Local Health District is an example of a tertiary referral centre for management of patients with special needs including ID and mental health. There is a large range of specialist and multi-disciplinary clinics available on-site as well as outreach clinics. Treatment under local anaesthesia, relative analgesia (nitrous oxide sedation), intra-venous sedation and general anaesthesia is available. The department also provides external assessment at residential aged care facilities in the Western Sydney Local Health District, and an oral health education program for carers and allied health personnel.

The ID Health Network, through its Access and Equity subcommittee, is working with NGOs and public health services to produce visual aids to prepare people to attend health services. One of these visual aids is about going to the dentist. Once the trial of these is completed, they will be widely distributed to NGOs providing supported accommodation.

There is also a need to increase the number of dental services with the capacity to treat people with ID. The Special Disability Health Team ‘pilot’ currently based at Fairfield but funded by the SCHN has an interest in dental care for people with ID. They have developed pathways to care and sedation to assist with care. The Specialist Intellectual Disability Health Team based at Cremorne and funded by NSLHD has also developed close links and referral pathways with special needs dental clinics at Royal North Shore and Hornsby hospitals.

"He (Reece) gets really distressed if he doesn’t know the person, and when they touch him without first explaining what they are going to do and how. Normally people go to the dentist and we know that the dentist will look at our teeth and he’ll want us to open our mouths Reece doesn’t know this.

So if this happens with no warning he’ll be upset. If they say “Reece I’d like to see how many beautiful teeth you have, and this is the instrument I will use to look at them, or this one may make a bit of a noise” so he is prepared for what is going to happen. Then it’s a better experience for everyone."

Ylvida & Reece (Person with ID and Carer)
Background

There are three specialist multidisciplinary ID health teams. Each of these three pilot specialist services is located in the community in a deliberate move to promote their capacity building role. They build capacity across the tiers of the framework, with outreach into regional areas. These three pilot services have received funding until June 2016 and are being evaluated by KPMG. They share many common features, but work with and respond to local needs – for example the ID Health Team at Fairfield works closely with refugee families.

Each is described individually below, however the teams share some common features.

- Enhanced access for people with ID and their family / carer to health services
- Multidisciplinary patient assessments
- Involvement in research activity
- Collaboration with government and NGO disability service providers
- Provision of education and training to enhance the capacity of health services including primary health and mental health services.
- Support for acute hospital services to manage complex health conditions and co-morbidities in people with ID
- Exclusively take referrals for people with ID
- Situated in the community, but in close proximity to a hospital
- Have a medical clinical director and a clinical nurse consultant
- Have interactions across the tiers of the health service
- Regularly meet with each other as part of their own service evaluation and quality improvement
- Operate according to local need and expertise
- Provide education and training to enhance the capacity of generic health, primary health and mental health services
- Improve the capacity of acute hospital services to manage complex health conditions and co-morbidities in people with ID
- Enhance access for people with ID and their family / carer to health services to improve their wellbeing and quality of life
- Report regularly to the Ministry of Health and participate in a three year evaluation by KPMG
- Are representatives on different subcommittees of the ID Health Network and the Clinical Directors of each team are member of the ID Health Network.

PILOT 1: Northern Sydney Intellectual Disability Health Team – Northern Sydney Local Health District

Characteristics

Northern Sydney Intellectual Disability Health Team (NSIDHT) is a multidisciplinary health service for school aged children, adolescents and adults with intellectual disability and complex health needs who live in the Northern Sydney Local Health District (NSLHD). NSIDHT is funded through the NSLHD and run by the Centre for Disability Studies (CDS) – a research and education organisation that is affiliated with the University of Sydney.

The Advisory Committee for NSIDHT acts as a forum for advice and direction for the implementation and monitoring of the service in line with its objectives and funding requirements. Its membership includes representatives from the LHD, the Medicare Local, Department of Rehabilitation Medicine at Royal North Shore Hospital, Child development Services, a parent, NSW Council for Intellectual Disability, Area Mental Health, state government disability services, ACI ID Health Network, Special Care Dentistry and NSW Dept. of Education and Communities. Clinics are primarily held at the Cremorne Community Health Centre, but also in schools.
**Service Objectives**

- To provide specialist, multidisciplinary health consultations to school aged children, adolescents and adults with intellectual disability and complex health needs
- To develop linkages and partnerships with local health, disability and education services to improve access to and coordination of these services for people with ID living in NSLHD
- To provide support, education and information to clinicians in the mainstream health sector to enhance the capacity of generic health services to better meet the needs of people with ID
- To provide health related information, resources and education sessions to people with ID, families and support staff
- To conduct Transition clinics to assist clients move from paediatric to adult health services.

**Current Work**

NSIDHT clinics have been operating since January 2013. Clinics in schools commenced in November 2013. Transition clinics involving paediatric and adult teams, together with a Transition Coordinator commenced in 2014. These clinics have been successful in ensuring a smooth transition to adult health services for adolescents and their families.

Ethics approval was received from Northern Sydney LHD to conduct internal (formative) evaluation of routinely collected, de-identified data. This includes client satisfaction measures, demographic data, and Quality of Life measures.

Data analysis for 2013 – 14 showed that clients with complex health needs are being seen at the service. Typically clients with ID also have epilepsy, vision or hearing impairments, psychiatric conditions (e.g. depression, schizophrenia, anxiety), and behaviours of concern (challenging behaviours).

Preventive health care was suboptimal in the clients seen. Over two thirds of those seen had not had dental reviews, over a third had not had vision assessments, and over 40% had not had hearing assessments according to standard recommendations. Over a third of clients were not up to date with their immunisations.

These gaps were detected at NSIDHT through comprehensive health assessments. Clients were either referred for the necessary assessments, or recommendations were made to the general practitioner for appropriate intervention, such as updating immunisations.

An important indicator of health outcomes of the assessments at NSIDHT was the detection and management of previously undiagnosed health conditions and/or health risk factors. These were followed up with referral and/or recommendations for treatment. Timely and appropriate treatment of these conditions is likely to improve the health of the individual, reduce complications and reduce likelihood of future hospital admissions.

**Mental Health and Challenging Behaviour**

Mental health conditions and behaviours of concern were extremely common in those seen at NSIDHT, but there are very few psychology services that cater to the specific needs of children and adults with ID and communication difficulties. The paediatric and adult psychologists and adult psychiatrist at NSIDHT have experience and expertise in this area. They provide assessment, treatment, counselling and therapeutic strategies to the client, family and support staff.

**The Clinical Nurse Consultant**

Health care coordination by the Clinical Nurse Consultant (CNC) is another important role of NSIDHT. Complex health needs can be overwhelming for many families and as a result, recommendations may not be followed up. The CNC with NSIDHT has assisted families in linking with health services and following up on referrals.

**Partnerships**

As well as clinical consultations and recommendations for management, NSIDHT has formed links with health and disability professionals to build capacity in the mainstream system.

Detailed reports with recommendations are sent to general practitioners, families and service providers. The reports provide guidance to general practitioners for ongoing health management of their patients. Telephone and email advice is also given to general practitioners and other health providers.
Links have also been established with Medicare Locals, Partners in Recovery, local special needs dental services, NGO and ADHC disability services. Education sessions with GPs are being planned. Links with the University of Sydney have seen a successful field placement of a Master of Social Work student.

Research
Easy English health information is routinely provided to clinic patients specific to their health needs.

Through research grant funding, the NSIDHT clinical psychologist has conducted a pilot randomised controlled trial of group Cognitive Behaviour Therapy (CBT) for adults with intellectual disability and mild anxiety. This was shown to be effective and there are plans to expand the group sessions. A trial of a parent support group with CBT to reduce parental stress has also been completed with encouraging results. It is anticipated that further group sessions will be conducted.

PILOT 2: Metro-Regional Intellectual Disability Network: a state-wide collaborative multidisciplinary care model - South Eastern Sydney Local Health District

Characteristics
The goal of the Metro-Regional Intellectual Disability Network (MRID) project is to pilot an innovative health service model improve access to coordinated specialist health services for children, adolescents and adults with ID. The MRID network project was funded by the NSW Government's Ministry of Health through South East Sydney Local Health District. It aims to ensure specialist health services meets the changing needs of consumers, carers, and local government, non-government, health, disability, mental health, and education services. A hub-and-spoke service model was combined with telemedicine support. A partnership approach was adopted. Ongoing evaluation is conducted.

Key features include:
- A multidisciplinary team of paediatric, medical, psychiatric, specialist nursing and allied health staff providing access to a range of specialised health services
- A co-design model engaging local stakeholders from government and non-government sectors to provide readily accessed, client-centred, holistic, coordinated care complemented by family and carer support
- A carer representative as part of the project team to ensure consumer engagement in all service design, delivery and ongoing evaluation.
- Capacity building of local services through provision of educational resources, specialist support and networking
- Implementation of a flexible clinic structure, including clinics in various locations such as schools and group homes and the use of Telehealth to provide assessments and consultations at the right place and time for the client
- The co-development of a “Referral Guide” for disability service providers to request specialist clinical support
- Development of data linkage systems to support coordinated care.

The provision of Specialist Training Positions in Paediatrics, Psychiatry, Rehabilitation and General Medicine enhances the capacity of mainstream services and the workforce.

Partnerships
Partnerships were developed with NGO disability service providers, NSW government disability services, local schools and Health in ten localities across NSW. As of 30 June 2014, fourteen different sites had been developed to host a range of comprehensive psychiatry, medical and school clinics, and 688 clients had been registered of all ages. The resulting MRID model successfully changed the focus in participating services from ongoing management by specialists, with severe constraints due to limited resources, to a consultative model emphasizing support and education of more generalist services. Increased access to expertise and clinical partnerships have increased the number of alternative pathways to care resulting in a reduced number of unplanned presentations and admissions to hospital.
Current Work and research

Educational activities include the ongoing provision of education forums and the development of interactive web-based resources. MRID.net has produced, or is the process of completing, four toolkits.

a. **SchoolKit®** – based on a few decades of partnership between the staff, students and families of Cairnsfoot School, their individual service providers (e.g. case manager) and Kogarah Diagnostic and Assessment Centre). This toolkit offers a range of tools, resources, models of care, theory and tips to the various stakeholders who may be interested in learning more about this integrated model of care. The website is highly engaging with cartoon scenarios, “real life” stories, video footage and a range of practical tools such as fact sheets.

b. **Co-Design Toolkit** – the uniquely successful partnership of 20 years between the Angelman Syndrome Association and DAS was groundbreaking for its time, involving health professionals and families in innovative service delivery. The process was underpinned by a model that is now recognised as Co-Design. The tools, processes and resources in the Co-Design toolkit have emerged from the MRID.net experience of applying and implementing this model to deliver health care services in a range of contexts.

c. **Hospitalisation Co-Design Toolkit** – See page 32, Section 11.

d. **Regional & Remote** – NGO Partnership Co-design: A toolkit relevant to all three toolkits listed above. It will build on the MRID.net experience of a city-based specialty tertiary service partnering with rural and remote stakeholders in the Illawarra Shoalhaven Local Health District and beyond. This toolkit will be integrated and cross-referenced with the other toolkits

The research activities have focused on the development of the model of care. The MRID team received the top award for best abstract at the 2nd World Congress on Integrated Care in Sydney, November 2014 for its innovative, integrated and co-designed model of care for people with intellectual disability and their carers.

PILOT 3: Specialist Disability Health Team - Sydney Children’s Hospital Network

**Characteristics**

The Specialist Disability Health Team (SDHT) is a service of the Sydney Children’s Hospital Network, with clinical governance and operational management through the Child Development Unit of the Children’s Hospital at Westmead. The service is located in Fairfield, within the boundaries of the Sydney South West Local Health District (LHD). Referrals are accepted for children residing in the Bankstown, Fairfield and Liverpool Local Government Areas (LGAs). They have a culturally and linguistically diverse population and a high proportion of people speaking a language other than English at home – Bankstown LGA (60%), Fairfield LGA (55%) and Liverpool LGA (75%) (compared to the State average of 27.5%). The region accepts a high proportion of new arrivals and refugees.

The population within region is anticipated to dramatically increase by 20% over the next five years. By 2021, the South West Sydney LHD will be the most populous LHD in NSW. Many families have complex social and health needs, which are often linked to disability. The high rate of profound disability (4.4%) in the South West Sydney LHD is directly associated with poorer health outcomes and higher demands for health care services.

The SDHT has a broad mandate to provide specialist health care delivery, develop clinical pathways, service networks and resources, undertake research, and build capacity with mainstream health care services. The Team provides comprehensive health assessments for school aged children with an ID up to the age of 18 years. Clinical services are provided through multidisciplinary clinics located at Fairfield, school clinics and home visits. A range of specialist clinics are provided by the team to address target health conditions and meet the individual needs of the children and their family.

Through interdisciplinary and interagency collaborations, the SDHT aims to coordinate care for the children and their families/carers. In providing a community-based specialist service, the team is building links between primary, secondary and tertiary care providers, establishing a more integrated service model.
The core clinical team consists of a Developmental Paediatrician, Clinical Nurse Consultant, Social Worker, Exercise Physiologist, and Dietician (all part-time appointments). The team are supported by a Project Manager and Administrative Assistant (also part-time).

Funded partnerships extend the range of specialist services and include a Consultant Child and Adolescent Psychiatrist, Adult Transition Physician, and an Adolescent Gynaecology Clinical Nurse Consultant. Access is available to a Fellow in Child Psychiatry and a Registrar in Community Paediatrics provided by the Developmental Psychiatry Service at CHW and the Department of Community Paediatrics, respectively. These integrated clinical training arrangements are in recognition of the educational value of placements within the SDHT for Community Paediatric and Child Psychiatry training. It is anticipated that these arrangements will lead to the formalisation of high quality training positions in paediatric ID health, which is currently an under-recognised area of specialty training.

Current Work

Clinical services

The team runs twice-weekly multidisciplinary paediatric clinics in Fairfield and monthly schools clinics, where comprehensive health assessments are completed. SDHT clinics are provided by the core clinical team comprised of the Developmental Paediatrician, Clinical Nurse Consultant, Social Worker, Exercise Physiologist and Dietician. School clinics involve members of SDHT team working in consultation with the school staff, including the principal, teachers, school counsellor, clinical psychologist ADHC lead clinician, and the child or young person and their family. Specialist mental health clinics are held monthly, and a specialised weight management service is in development, which includes nutrition and dietary management and a school-based exercise intervention program. Home visits and joint consultations with specialist clinical teams at CHW are arranged, as required.

In addition the team provides consultation to local health care providers (Paediatricians, GPs and Community Health teams) and assists them to make reasonable adjustments to clinical pathways. In doing so, the team is building the capacity of mainstream health services, while also developing partnerships with other government and non-government service providers.

Transitioning to Adult Health Services

Specialist Transition Clinics are held quarterly, which include members of the SDHT clinical team and a Consultant Rehabilitation Physician. With the involvement of the ACI Transition Co-ordinator, clients are transitioned to adult mainstream and specialist health services. There are significant challenges in finding specialist ID services for young people to transition to as they reach 18 years of age in the local area. DARTYP at Concord (LINK) and CDS at Ryde (a state wide adult service) (LINK) are both appropriate referral pathways.

Clinical pathways and guidelines

Clinical pathways have been developed for the project focus areas including:

- Obesity and weight management
- Mental health and behaviour management
- Gynaecology and menstrual management
- Dental and oral health
- Transition to adult care.

In addition, Clinical pathways are being developed to address a number of associated clinical issues, including:

- Sleep assessment
- Gastroenterology investigations
- Sexual and reproductive health
- Paediatric and Adult Rehabilitation services.

Clinical guidelines are being developed to improve clinical management:

- Sedation Guidelines for management of children ID who present behavioural challenges during health care encounters.

Education and resources development

- Formal and informal education sessions have been developed and delivered to health care staff and parents through professional forums and case conferences and through parent morning tea meetings.
- Resources have been developed, including –
  - SDHT service brochures, which are also been translated into a range of community languages
  - A service directory and health information for parents, addressing the five focus areas
• Work has also been undertaken on the development of new ‘Fact Sheets’ on disability related topics that are not already available.

Service networks and workforce capacity building:
• Collaboration and partnerships have been developed with local and tertiary hospitals, state disability services, NGOs and the Department of Education and Communities.
• To establish this specialist service required intensive service development and reliance on the effective development of health, disability and education networks and partnerships.

Research
The SDHT research projects aim to inform the development of care pathways, build capacity within mainstream health care services, improve access to health care services and improve the health care experience for the carer and person with ID.

Current projects are focussed on:
• Exercise Intervention – development of an exercise programme for school students with an Intellectual Disability, including feasibility testing and evaluation
• “Paving the way for Paeds with Needs” Project, has three components:
  ▲ A survey of clinical staff in relation to orientation to working with children with ID and training needs
  ▲ The development of a Personal Disability Profiles to inform clinicians of individual clients needs and facilitate communication in clinical encounters
  ▲ The development and evaluation of ‘Social Stories’ for preparation of children with ID for medical appointments, procedures and hospital admission.
• Piloting of a paediatric comprehensive health assessment tool for health screening of children with ID.
Summary

This chapter discusses the role of the nurse as a central contact point and a conduit through the complexity of the health system for people with an ID.

16.1 Background

The role of the nurse was common to all specialist ID health teams when they were proposed. Each of the three Ministry of Health funded ID Health Teams employ a Clinical Nurse Consultant.

Reviews of the disability liaison nurse role in New Zealand and UK has shown that people with ID, their carers and staff found the role assisted communication and promoted an integrated approach to care.

The clinical nurse consultant (CNC) is a key contact for the person with ID and their family and carer. They assist them to move through the consultation process, from arranging appointments and follow ups, to identification of particular health and support needs in the community. The CNC in ID currently exists in other areas of health as well, for example as part of other specialist health teams. The people who are referred to the teams typically have complex and chronic health care needs. The CNC is often involved in consultation with health staff from the community, primary health, disability support staff and the hospital to support and inform them about patient care and adjustments to the delivery of health services. The nurse can be involved in data collection, research, journal writing, patient management, treatment, medication advice, and forum presentation.

The nurse has a broad view of the person with ID and their required social supports and lifestyle which enables them to put the delivery of health services in context.

In interviews with clinicians about health services for people with ID, clinicians identified the need for a key contact person to assist patients and health professionals navigate the complex health system. In interviews with people ID and their families people with an ID identified the need for case management to assist them navigate the system and advocate for them. Both these functions are part of the role of the nurse in these multidisciplinary teams.
The Evans family – Multidisciplinary Support from the GP and the ID Specialist Team

Two adolescent sisters with ID and multiple health concerns require assessment, and are referred by their GP for psychological support, and Comprehensive Health Assessment. Referrals, recommendations and multi-agency involvement are supported by the ID Health Team’s Clinical Nurse Consultant.

Douglas, the girls’ step-father, is the sole carer. He has difficulty understanding and coordinating their varied and complex needs.

Ruby has mild range intellectual disability and profound congenital vision impairment. She was referred for assessment by her teacher, whose main concern was with Ruby’s difficulty in regulating her emotions, with episodes of anger, crying, hitting herself and others. Ruby was also involved with a government disability case manager who attended the health assessment at the specialist health clinic. A crisis developed and the Child and Adolescent Mental Health Service (CAMHS) was unable to respond quickly in this situation.

Other options for mental health intervention were investigated by the CNC, but were unsuitable due to lack of appropriate skills of the health professionals, or due to fees that were unaffordable for the family. Therefore, an appointment with the clinic’s specialist psychologist was made. The psychologist established rapport with Ruby and has been teaching her techniques to manage her anxiety. Douglas was also given strategies to improve communication with his step-daughters. There have been discussions with CAMHS regarding future collaboration with the specialist health team.

Jade has a moderate range of intellectual disability and a moderate degree of congenital vision impairment. Jade also had a comprehensive health assessment at the clinic. As well as hearing, dental and ophthalmology reviews, arrangements were made for Jade to see the dietitian at the clinic with regards to weight and cholesterol management. The dietitian has worked with Jade and Douglas to implement a healthy diet for the whole family.

The CNC has assisted Jade in charting her irregular menstrual periods and this issue is to be followed up.

A summary report was given to Douglas to give to the GP at the next (booked) appointment, for follow-up. The clinic offered to support the GP should he require it in his ongoing role with the girls’ health.

Following Ruby’s comprehensive health assessment, referrals were also made for hearing and special needs dental assessments. The appointments for these were arranged by the Clinical Nurse Consultant (CNC), a member of the specialist team.

The CNC at the specialist health clinic liaised with the Evans family and assisted them to co-ordinate other agencies with whom the family was involved (GP, school, intensive family support and their government disability case manager) to address the multiple needs of the family as a whole, as well as the girls’ individual health needs.

A summary report was given to Douglas to give to the GP at the next (booked) appointment, for follow-up. The clinic offered to support the GP should he require it in his ongoing role with the girls’ health.
The current opportunities to work with people with ID and their families in the process of co-designing health services which improve their experience of care and deliver better outcomes is important for the providers of services as well as the consumers. As people with disability, including ID, have increasing opportunities to enable them to live in the community and make choices about how they live their lives, the health system is responding to enable them to access quality health services alongside the community in which they live.

This context report and the toolkit to which it links, describes projects, initiatives and partnerships across LHDs delivering inclusive health services for people with ID and their families.

It sits alongside the Network’s literature review of Models of Health service Delivery for People with ID and the ACI Economic Analysis of health service used by people with ID.

After reading this Context Report and linking to the Toolkits:

- Give feedback on this document here
- Consider your local situation in light of the “Shaping an Inclusive Health Service for People with ID” (page 74, Appendix 5)
- Re-read the case studies (page 60, Appendix 1) to see who your key partners might be to progress this work
- Review your Disability Inclusion Action Planning and the role of the person with ID (or their Carer) in the process
- Attend the ID Health Network’s Annual Forums and become a member of the Network to make a difference
- Stay tuned for the on-line release of the Blueprint which will develop from your input and response to this Context Report and Toolkit (see Introduction – page 5).

Should you like to discuss this work, or your involvement with the ACI Intellectual Disability Health Network, please contact:

Tracey Szanto
Manager, Intellectual Disability Network
NSW Agency for Clinical Innovation
Tel 02 9464 4632
Mob 0408 365 528
Tracey.szanto@health.nsw.gov.au
Level 4 Sage Building, 67 Albert Avenue
Chatswood NSW 2057
PO Box 699, Chatswood NSW 2057
www.aci.health.nsw.gov.au
Twitter: @Tracey_Szanto
# Case Study Summaries

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<td>Tina</td>
<td>A diagrammatic experience of hospitalisation for Tina and her family and health staff.</td>
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<td>2</td>
<td>Roger</td>
<td>The Person with ID, the Hospital, Group Home and Specialist Supports – A Partnership supporting transfer of care Roger (17) has intellectual disability, Autism and emotional dysregulation with violent behaviour. Neither his mother nor emergency respite services can manage his behaviour. After a lengthy admission to a Mental Health Unit in a public hospital and with the involvement of Roger’s mother, Roger was able to be transferred to supported accommodation in the community with ongoing support for Roger and staff.</td>
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<td>Mary</td>
<td>The Person with ID, the Hospital, the Disability Service and the Group Home. A partnership supporting transfer from hospital to supported accommodation. Mary (65) lives in state disability supported accommodation and is in need of some surgical procedures which she is reluctant to have due to her anxiety. She also has ID, other mental health concerns and needs communication support. With the help of her GP and the RN from her Group Home she attends pre-admission planning case conferences in the hospital. They are in line with the NSW Health and ADHC Joint Guidelines for transfer from hospital for people with a disability. The collaboration between the hospital and the Group Home result in better health outcomes for Mary.</td>
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<td>Mavis</td>
<td>The Person with ID and Primary Health Partnerships Mavis (50) has intellectual disability and epilepsy, schizophrenia and osteoporosis. Mavis sees her Neurologist and Psychiatrist for regular reviews. She has been referred to a Respiratory and Sleep specialist for assessment and treatment of possible sleep apnoea. Her GP has referred her for other preventative health actions (e.g. breast screening, immunisations). The detailed reports and recommendations provide guidance to Mavis’ GP about ongoing health management. They are also useful for Mavis’ case manager to assist with ongoing health care planning.</td>
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<td>Jake</td>
<td>Jake and his GP involved with the Specialist Disability Health clinic, Psychiatry and School Clinic Jake (13) is referred by his GP to a Paediatrician who seeks support from a Specialist Disability Health clinic for a comprehensive health assessment, after escalating behaviour difficulties which cause hospitalisation for self-harm. He has intellectual disability, Autistic Spectrum Disorder and anxiety and depression. The Specialist Disability Health Clinic refers him for paediatric psychiatry, blood tests, dietician support and reviews his medications. With Jake’s Mum, they organise a school multidisciplinary clinic and establish behaviour strategies.</td>
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<td>Deryk</td>
<td>NSW Health Child and Adolescent Mental Health Services (CAMHS) Deryk (11) is diagnosed with developmental delay. His behaviour has recently escalated and he has been admitted to the Emergency Department by police and ambulance. With no bed availability for a child his age in need of acute inpatient mental health services, he is managed by local clinicians with remote access to consultations with specialist ID Mental Health Psychiatry and Psychology support.</td>
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<td>The Evans Family</td>
<td>Multidisciplinary support from the GP an the ID Specialist Team Two adolescent sisters with ID and multiple health concerns require assessment, and are referred by their GP for psychological support, and Comprehensive Health Assessment. Referrals, recommendations and multi-agency involvement are supported by the ID Health Team’s Clinical Nurse Consultant.</td>
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| **8** | **Laura** | Transition from Paediatric to Adult Health Services using Interpreters  
Laura (17) is ready for transitioning from paediatric to adult health services. She has ID, Cerebral Palsy, swallowing difficulties and other health problems. Her family needs an interpreter for appointments and ongoing management instructions. In the past they have not understood the written instructions and not agreed with the management of her conditions. Laura’s paediatrician requests the support of the Specialist Disability Team. The Team organises transition clinics and social work support through the multidisciplinary team. |
| **9** | **Neil** | Tele-health for regional mental health support  
Neil (16) lives in a regional area of NSW and has ID, Cerebral Palsy, epilepsy, behavioural disturbances and mental health conditions. He is in foster care and is supported by a local community and regional mental health team. A multidisciplinary mental health clinic meets via teleconference. It includes Neil, his foster parents, disability, education and other agency staff. They develop his health plan. |
| **10** | **School Clinic** | Multidisciplinary School Clinic  
A multidisciplinary school clinic includes a Specialist Health Team, education and disability representatives, and the parents and carers of a child at a special school. The child has ID, seizures and behaviour concerns. The school clinic establishes that the school, parents and carers are not giving consistent and coordinated dosages of medication. A meeting results in agreed medications and behaviour management strategies and the child has fewer seizures and better school attendance as a result. |
| **11** | **Hospitalisation** | Hospitalisation  
An adult with ID from a group home presents to the Emergency Department. The admitting hospital consults with the Specialist ID Health Team in another LHD regarding patient assessment, management strategies and planning assistance for transfer of care back to the group home with support. This results in ongoing consultation and the involvement of the GP who visits the group home, as well as group home manager to prevent future unplanned hospitalisation and improved health outcomes. |
| **12** | **Wayne** | Comprehensive Health Assessment – GP, Psychiatrist and Specialist Disability Team  
Wayne (29) has ID, behaviour concerns and other medical and health issues. His parents care for Wayne at home. They are new to NSW. His GP refers him to the Specialist Disability Team for a Comprehensive Health Assessment. They make referrals for a dental visit, hearing assessment, weight management and case management. Wayne is allocated a case manager and sees the Psychologist from the Specialist Disability Team for review. |
| **13** | **Dallas** | Psychiatric and Psychological support to attend medical appointments  
Dallas (23) has ID and mental health concerns. His GP sourced resources for the Primary Health Network to assist him. He initially refers him to a specialist about his long term chronic health condition but his extreme anxiety prevents him from attending. He is then referred to a psychiatrist with skills in working with people with ID. The recommended ongoing psychological support in the community over time enables Dallas to manage his anxiety so he can attend appointments. His parents also get support with communication. |
| **14** | **Beth** | GP referral to Neurologist, hospital admission and Psychiatry support  
Beth (30) has ID, mental health diagnoses and is non-verbal. She lives in a group home and has aggressive behaviour, which has escalated. Her GP reviews her and refers her to her Neurologist. She is unable to be reviewed by her Psychiatrist until the next rural clinic. She presents to the ED and is admitted to hospital for 12 days. She is also seen by the speech Pathologist and Dietician and referred for a dental review. |
Summary

This section contains seven examples of patient centred integrated health care. The patient benefits from the tiers of the health services working together. The improved health outcomes and service efficiencies depend on a partnership model of care, reasonable adjustments and access to specialist consultative services in intellectual disability. They provide examples of how patient centred care works with intellectual disability and how the different tiers of health services work in partnership to improve health outcomes for people with ID.

Case Study 8

Transition Clinics from Paediatric to Adult Health Services using Interpreters.

Laura (17) is ready for transitioning from paediatric to adult health services. She has ID, Cerebral Palsy, swallowing difficulties and other health problems. Her family needs an interpreter for appointments and ongoing management instructions. In the past they have not understood the written instructions and not agreed with the management of her conditions. Laura’s paediatrician requests the support of the Transition Co-ordinator.

Cultural and linguistic differences have an impact on a family’s engagement and compliance with recommendations, as is highlighted in the following case study. The multidisciplinary, interagency model of care demonstrates how the health team operates.

Laura is a 17 year old girl with intellectual disability and Cerebral Palsy. Her family do not speak English confidently and require the use of an interpreter. She was referred to the Transition Co-ordinator as her paediatrician was unsure of appropriate transition services for Laura and her family as she moves from paediatric to adult health services and requires different supports in the community.
Laura requires the use of a wheelchair for long distance mobility. In addition, she has a delayed swallow and requires a soft diet. Her mother was unsure whether a swallowing assessment had been completed by a speech pathologist. Laura had previously been seen by a disability sector dietician however the report which was sent to the mother was in English, and therefore she could not understand the content of the report or follow its recommendations. The mother was provided with verbal instructions, however she found these difficult to implement. No follow up was arranged, which meant that these issues were not identified or addressed.

A health assessment was performed and it was found that her weight was appropriately tracking. She was referred to the local health dietician for more culturally sensitive options, and to have her swallowing assessed. A multi-disciplinary team meeting was arranged with Laura and her family. It included a transition coordinator and an adult rehabilitation physician from her LHD. No GP was engaged or involved at this stage, although the Transition Co-ordinator was working with Laura and her family to establish a relationship with a GP. The paediatrician attended for part of the meeting by teleconference.

The local Paediatrician agreed to organise blood tests and a bone x-ray. The transition coordinator investigated appropriate day programs to increase her community participation opportunities. The family requested support to apply for a Medicare card and eligibility for a disability pension.

A comprehensive report was provided to the family with explanations through an interpreter. A planned transition to an adult physician at the end of the current review this year, was to be co-ordinated by the Transition Co-ordinator.

The local paediatrician was unable to transition Laura to adult services due to lack of local specialised services for adults. The specialist team was able to provide a means to transition her through developing partnerships with an adult physician in a state wide service with the help of a transition coordinator (Trapeze). This was done to support local services including adult physicians and a potential GP.

Due to language difficulties and cultural issues, her mother was unable to fully grasp the planned interventions which were recommended. The health complications and consequences were explained to her through an interpreter so that she was able to see the rationale and participate in management plan. It was suggested that an interpreter be used in all communication with her and disability/health services.

Laura’s mother had transport difficulties getting to appointments. The LHD Carer Support Worker was working with community transport and disability services to enable her to bring Laura with her to appointments in a wheelchair accessible vehicle.

Partnership with the local paediatrician had enabled investigations to be performed at a local level. A local GP was still being sought.
Case Study 9

Tele-health for Regional Mental Health Support

Neil (16) lives in a regional area of NSW and has ID, Cerebral Palsy, epilepsy, behavioural disturbances and mental health conditions. He is in foster care and is supported by a local community and regional mental health team. A multi-disciplinary mental health clinic meets via teleconference and includes Neil, his foster parents, disability, education and other agency staff. They develop his health plan.

A psychiatry clinic was arranged for Neil who lives in a regional area to assess rapidly escalating behaviours and review of medications. Neil (16) who has moderate/severe intellectual disability was experiencing increasing erratic and violent behaviour. In addition to acute anxiety and explosive behavioural responses to changes in routine, he has other health conditions. Neil’s behaviour at school is of major concern to staff and students. The foster carers are under significant pressure at home.

Out-reach psychiatric services were not available in a timely manner and access was further complicated by Neil’s age, 16 years, where he falls between the gap between paediatric and adult services. Arrangements were made with the local community mental health service, and with the assistance of the regional mental health team to enable a multidisciplinary team (Psychiatrist, Paediatric Registrar, and Social Worker), to conduct a clinic via video conference.

Regional participants’ representatives from Department of Education and Communities, state disability services, Community Services, foster carers and Neil. Mental Health workers awaited the family on arrival, to support the client’s attendance. The clinic identified a number of underlying, unmet chronic health conditions requiring assessment by the local GP, and Paediatrician.

A comprehensive health plan was developed and recommendations made regarding ongoing management for Neil in the community. These were referred back to Neil’s local GP and paediatrician. The region’s Transition Co-ordinator was contacted to support and guide Neil in his transition from paediatric to adult health services.

Case Study 10

Multidisciplinary School Clinic includes a Specialist Health Team, education and disability representatives, and the parents and carers of a child at school.

Tom has ID, seizures and behaviour concerns. The school clinic establishes that the school, parents and carers are not giving consistent and coordinated dosages of medication. The meeting is able to establish consistency in medications and behaviour management strategies and Tom has fewer seizures and better school attendance as a result.

The school clinic used a multidisciplinary team approach with education representatives, Specialist health Team, state disability services and carers (shared parenting and custody).

Carers were in conflict and blaming each other over the level of provision of care. After discussion involving all parties, it became evident that each carer was administering different levels of medications and at different times with some epilepsy medications being omitted, and the school was also administering medications (on the advice and information provided by parents / carers). As a result, Tom was experiencing increased seizures resulting in absences from school.

A plan was developed in writing for all parties to adhere to consistent administration of medications at designated times as well as a review of medications for escalating behaviour. The GP was informed of the clinic outcomes.

The end result was a consistent approach by all parties to addressing Tom behaviour and medications, and a reduction in school absenteeism due to decreased seizure activity.

For more information on school clinics, please click here.
Case Study 11

**Hospitalisation**

An adult with ID from a group home presents to the Emergency Department. The admitting hospital consults with the Specialist ID Health Team in another LHD about patient assessment, management strategies and assistance with planning for transfer of care back to the group home with support. This results in ongoing consultation and the involvement of the GP who visits the group home, as well as group home manager to prevent future unplanned hospitalisation and improved health outcomes.

A patient with ID and Angelman syndrome who lived in a group home was admitted to hospital following several presentations to ED with swallowing difficulties.

Consultation was prompted by the awareness of the specialist ID health team’s hospitalisation initiatives in another LHD. Hospital staff felt that the use of management strategies such as physical restraints was detrimental to the client’s well-being and sought advice from the specialist team for access to behaviour management expertise. The disability service providing accommodation also requested added support for the client’s family and their staff.

The hospital’s adult Physician, Psychiatrist and Social Worker had several teleconferences with the specialist team personnel to advice on assessment, management and planning for transfer.

Follow up appointments were booked and ongoing support offered to the service provider and the client’s family by the hospital. The GP received an update on management strategies. The Specialist ID health team offered further professional support as needed.
**Case Study 12**

**Comprehensive Health Assessment – Specialist Disability Team, GP, Psychiatrist and links to Health and Disability services**

Wayne (29) has ID, behaviour concerns and other medical and mental health issues. His parents have poor understanding of services and processes and therefore have not accessed any disability services since moving into the area. They care for Wayne at home. His GP refers him to the Specialist Disability Health Team for an assessment. They make referrals for a dental visit, hearing assessment, weight management and case management. Wayne is allocated a case manager. He sees the Psychologist from the Specialist Disability Team for review.

Wayne is a 29 year old man with a moderate degree of intellectual disability, diagnosis of ADHD, mental health problem and reported behaviour disorder. Wayne lives with his parents and extended family.

Wayne and his family recently moved to the area. Wayne has a GP, but had no contact with disability or other health services. Wayne was referred for an assessment.

Wayne was seen initially at the specialist disability clinic for a comprehensive health assessment, including his behaviour. Wayne seemed well, but was overweight and had not had recent reviews for hearing, vision and dental assessments. Referrals and appointments were made for hearing, vision and dental assessments, with follow up by Wayne’s general practitioner. Wayne saw the psychologist with the Specialist Disability Health Team, who worked with Wayne and his parents on strategies to de-escalate the behaviours of concern.

During the clinic it was noted that Wayne did not have access to disability services or social outlets outside the family.

A referral was made for case management and his case manager worked closely with the specialist health team staff and the family to identify their needs.
Psychiatric and Psychological Support to Attend Medical Appointments

Dallas (23) has ID and mental health concerns. His GP sourced resources for the Primary Health Network to assist him. He initially refers him to a specialist about his long term chronic health condition but his extreme anxiety prevents him from attending. He is then referred to a psychiatrist with skills in working with people with ID. The recommended ongoing psychological support in the community over time enables Dallas to manage his anxiety so he can attend appointments. His parents also get support with communication.

Dallas is a 23 year old man with a mild range of intellectual disability and anxiety. He lives with his adoptive parents. Dallas has extreme anxiety and kleptomania. He previously attended a Transition to Work Program.

Dallas’ GP had attended an educational session conducted by the Primary Health Network in his area about ID and the local pathways and assessment tools. This proved helpful in enabling him to conduct Michael’s comprehensive health assessment in stages. He noted that Dallas was in good general health. However, investigations ordered by the GP showed a chronic health condition and referral were made to a specialist. However, Dallas had refused to go.

The GP referred Dallas to a Psychiatrist skilled in working with people with ID and concurrently received psychological support in the community over several months to gain his trust and to help him manage his anxiety. The psychologist also counselled Dallas’ parents about communicating effectively with him. They were directed to on line education for parents and invited to a parent support group run out of the local town hall by other parents.

Dallas’ story illustrated the value of a psychologist with expertise in counselling people with intellectual disability. Within the context of a multidisciplinary team, the psychologist, psychiatrist and GP were able to jointly address Dallas’ physical and mental health needs and assist Michael’s foster parents.
Case Study 14

GP Referral to Neurologist, Hospital Admission and Psychiatry Support

Beth (30) has ID, mental health diagnoses and is nonverbal. She lives in a group home and has aggressive behaviour, which has escalated. Her GP reviews her and refers her to her Neurologist. She is unable to be reviewed by her Psychiatrist until the next rural clinic. She presents to the ED and is admitted to hospital for 12 days. She is also seen by the speech Pathologist and Dietician and referred for a dental review.

Beth is a 30 year old woman diagnosed with Angelman syndrome, severe intellectual disability, epilepsy, depression/bipolar disorder and she is also non-verbal. She lives in a group home in rural NSW. The group home contacted the GP about Beth’s escalating aggressive behaviour. The GP ordered pathology and other testing to see if there were any underlying infections or causes of pain. He advised her to see her Neurologist. The Neurologist is based in a nearby (larger) regional area and was contacted by phone. He suggested further testing, asked the group home to monitor her seizures and behaviour closely and send him reports over a three week period, including a sleep diary, while they waited for an appointment. He also recommended she see the state disability psychology team for behaviour management and her Psychiatrist. He also asked that staff book Beth in to see the Dentist.

Over the following month Beth displayed increased aggressive behaviour toward staff and other residents, who were quite fearful of her. Her Psychiatrist normally conducts regional reviews in Beth’s country town every 6 months and is not due for another few months. Beth had not seen him for 2 years.

No Psychiatrist or psychological support could be found locally and Beth was not able to travel long distances. After a particularly challenging event, Beth was taken to the ED of her local hospital when she was an inpatient for 12 days.

The Psychiatrist was contacted by the local hospital. On assessment it was noted that the group home where she resides has experienced significant turnover of staff, and limited access to psychological behavioural support. A behavioural intervention strategy had been devised by a former house manager deemed “good with challenging behaviour” as the NGO managing the home has been unable to recruit a clinical psychologist. This strategy, on review was clearly inadequate as it was based on Beth’s pre-existing food driven behaviours. The rewards (chocolate frogs) being implemented were clearly impacting on Beth’s weight problem as well as reinforcing her preoccupation with food. Beth had not been reviewed by a nutritionist and restricted community access was inhibiting exercise.

Given Beth’s psychiatric condition she was booked to see the Psychiatrist on his next visit. Beth’s situation was volatile, and left unsupported, was at risk of placement breakdown, deterioration of health condition and possible recurring hospital presentations.

During Beth’s admission Beth was booked for a number of reviews including dietetics (weight), speech (communication), ongoing neurology (epilepsy), dental and psychiatry (medication review). Further bloods were also requested and follow up arranged via the GP.

Beth’s medications were adjusted based on her blood results. She was booked to have a general anaesthetic to enable her dental cavities to be filled. She was waiting on other testing and reviews and was transferred back to the group home.
## Intellectual Disability Health Network Resources / Toolkits

<table>
<thead>
<tr>
<th>Title</th>
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<tr>
<td><strong>Research</strong></td>
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<td><strong>Policy</strong></td>
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<td>in the Development and Review of Policies, Procedures and Models of</td>
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<td>Care</td>
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<td>delivery</td>
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<td><strong>Education</strong></td>
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<td></td>
<td><a href="http://www.schoollink.chw.edu.au">www.schoollink.chw.edu.au</a></td>
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<tr>
<td>(Health Education and Training Institute)</td>
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<td><strong>Primary Health</strong></td>
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<th><strong>Patient / Carer</strong></th>
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<td>School Transition Toolkit – Schoolkit (MRID / ACI)</td>
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<tr>
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### Other Links Within Context Report

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<td>NSW Health Education and Training Institute</td>
<td><a href="http://www.heti.nsw.gov.au">http://www.heti.nsw.gov.au</a></td>
</tr>
<tr>
<td>KPMG Analysis</td>
<td></td>
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<tr>
<td>A Model of Care for Adults with an Intellectual Disability and Co-occurring Mental Disorders (Trollor)</td>
<td><a href="http://3dn.unsw.edu.au/sites/default/files/ddn/resources/MOC%20for%20ACI_3DN%20June%202014.pdf">http://3dn.unsw.edu.au/sites/default/files/ddn/resources/MOC%20for%20ACI_3DN%20June%202014.pdf</a></td>
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<td>Building a Model of Care for the Mental Health of Children and Adolescents with Intellectual Disability in NSW (Dossetor)</td>
<td><a href="http://static1.1.sqspcdn.com/static/f/551166/26068021/1427110495397/Volume+6+Issue+1+final+low+res.pdf?token=3eST7e5CBkpoO%2BdgMrCvDHCVkJkGA%3D">http://static1.1.sqspcdn.com/static/f/551166/26068021/1427110495397/Volume+6+Issue+1+final+low+res.pdf?token=3eST7e5CBkpoO%2BdgMrCvDHCVkJkGA%3D</a></td>
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<tr>
<td>Understanding mental illness in people with intellectual disability: an elearning resource for carers project (UNSW 3DN)</td>
<td><a href="http://3dn.unsw.edu.au/our-projects">http://3dn.unsw.edu.au/our-projects</a></td>
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<tr>
<td>National Health &amp; Medical Research Council Partnerships for Better Health Project, Improving Mental Health Outcomes for People with an Intellectual Disability</td>
<td><a href="http://3dn.unsw.edu.au/our-projects">http://3dn.unsw.edu.au/our-projects</a></td>
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<td>The Village Medical Practice</td>
<td><a href="http://www.villagemedicalpractice.com.au">www.villagemedicalpractice.com.au</a></td>
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<tr>
<td>Resource/Resource Area</td>
<td>Website/Link</td>
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<tr>
<td>Community Owned Private Health Enterprise</td>
<td><a href="http://www.cophe.com/about-cophe/">http://www.cophe.com/about-cophe/</a></td>
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<tr>
<td>ADHC and Health data linkage project</td>
<td><a href="http://www.adhc.nsw.gov.au/about_us/research/completed_research">http://www.adhc.nsw.gov.au/about_us/research/completed_research</a></td>
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## Appendix 4

### Glossary of Terms and Abbreviations

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
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<tbody>
<tr>
<td>ABF</td>
<td>Activity Based Funding</td>
</tr>
<tr>
<td>ACI</td>
<td>Agency for Clinical Innovation</td>
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<tr>
<td>ADHC</td>
<td>Ageing Disability and Home Care</td>
</tr>
<tr>
<td>ASD</td>
<td>Autism Spectrum Disorder</td>
</tr>
<tr>
<td>ASDS</td>
<td>Autism Spectrum Disorder (Sensory)</td>
</tr>
<tr>
<td>CALD</td>
<td>Culturally and Linguistically Diverse</td>
</tr>
<tr>
<td>CAMHS</td>
<td>NSW Health Child and Adolescent Mental Health Services</td>
</tr>
<tr>
<td>CBT</td>
<td>Cognitive Behaviour Therapy</td>
</tr>
<tr>
<td>CDMP</td>
<td>Chronic Disease Management Program</td>
</tr>
<tr>
<td>CDS</td>
<td>Centre for Disability Studies</td>
</tr>
<tr>
<td>CNC</td>
<td>Clinical Nurse Consultant</td>
</tr>
<tr>
<td>CP</td>
<td>Cerebral Palsy</td>
</tr>
<tr>
<td>CPAP</td>
<td>Continuous Positive Airway Pressure</td>
</tr>
<tr>
<td>DARTYP</td>
<td>Disability Assessment and Rehabilitation Team for Young People with Multiple Disabilities</td>
</tr>
<tr>
<td>DAS</td>
<td>Diagnostic and Assessment Service</td>
</tr>
<tr>
<td>DEC</td>
<td>Department of Education and Communities</td>
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<tr>
<td>DDHU</td>
<td>Developmental Disability Health Unit, Ryde</td>
</tr>
<tr>
<td>ED</td>
<td>Emergency Department</td>
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<tr>
<td>EMR</td>
<td>Electronic Health Record</td>
</tr>
<tr>
<td>EN</td>
<td>Enrolled Nurse</td>
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<tr>
<td>FACS</td>
<td>Family and Community Services</td>
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<tr>
<td>GP</td>
<td>General Practitioner</td>
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<tr>
<td>HETI</td>
<td>Health Education and Training Institute</td>
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<tr>
<td>HITH</td>
<td>Hospital in the Home</td>
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<tr>
<td>ID</td>
<td>Intellectual Disability</td>
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<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
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<tbody>
<tr>
<td>IDHN</td>
<td>Intellectual Disability Health Network</td>
</tr>
<tr>
<td>IHPA</td>
<td>Independent Hospital Pricing Authority</td>
</tr>
<tr>
<td>ILC</td>
<td>Information, Linkages and Capacity Building</td>
</tr>
<tr>
<td>LHD</td>
<td>Local Health District / Local health Network</td>
</tr>
<tr>
<td>MBS</td>
<td>Medicare Benefits Schedule</td>
</tr>
<tr>
<td>MH</td>
<td>Mental Health</td>
</tr>
<tr>
<td>ML/PHN</td>
<td>Medicare Local/ Primary Health Network</td>
</tr>
<tr>
<td>MRID.net</td>
<td>Metro-regional Intellectual Disability Network</td>
</tr>
<tr>
<td>NDIA</td>
<td>National Disability Insurance Agency</td>
</tr>
<tr>
<td>NDIS</td>
<td>National Disability Insurance Scheme</td>
</tr>
<tr>
<td>NGO</td>
<td>Non-Government Organisation</td>
</tr>
<tr>
<td>NSIDHT</td>
<td>Northern Sydney Intellectual Disability Health Team</td>
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<tr>
<td>NSW</td>
<td>New South Wales</td>
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<tr>
<td>NSWADN</td>
<td>NSW Aboriginal Disability Network</td>
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<tr>
<td>NSWCID</td>
<td>NSW Council for Intellectual Disability</td>
</tr>
<tr>
<td>PCeHR</td>
<td>Personally Controlled Electronic Health Record</td>
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<tr>
<td>PEACE</td>
<td>ACI Patient Engagement and Consumer Experience</td>
</tr>
<tr>
<td>RN</td>
<td>Registered Nurse</td>
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<tr>
<td>SCHN</td>
<td>Sydney Children’s Hospital Network</td>
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<tr>
<td>SDHT</td>
<td>Specialist Disability Health Team</td>
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<tr>
<td>SESLHD</td>
<td>South East Sydney LHD</td>
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<tr>
<td>SME</td>
<td>Subject Matter Expert</td>
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<tr>
<td>STP</td>
<td>Specialist Training Program</td>
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<tr>
<td>UNSW</td>
<td>University of New South Wales</td>
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### 1. The Need for Person-Centred Care

<table>
<thead>
<tr>
<th>Key Issues</th>
<th>How can we:</th>
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</thead>
</table>
| Ensuring that health services for people with intellectual disability are person-centred is critical to achieving the best possible health outcomes. People with intellectual disability may not understand when they have a health problem or how to get help. This can be compounded by communication difficulties and lack of understanding of intellectual disability on the part of health professionals. | - Co-Design and operate health services to ensure that they are fully person-centred and address the spectrum of needs and concerns of people with intellectual disability?  
- Focus on building ongoing relationships between people with intellectual disability and their main health care providers, based on mutual trust and respect?  
- Ensure people with ID and their carer have clear expectations and understanding about their health care, and are involved in decision-making?  
- Acknowledge the role of the carer in upholding the interests of the person with intellectual disability and engage appropriately with them?  
- Provide opportunities for consumer feedback that are readily accessible by people with intellectual disability and their carers?  
- Develop culturally sensitive ways of working with people with ID disability and their carers? |
### 2. Integrated care / transitions between health services

<table>
<thead>
<tr>
<th>Key Issues</th>
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<tbody>
<tr>
<td>For people with ID and multiple social and health needs, care coordination is important.</td>
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<tr>
<td>Coordination is important between health and other service providers (e.g. disability,</td>
</tr>
<tr>
<td>accommodation) and between different levels and kinds of support within the health system</td>
</tr>
<tr>
<td>(e.g. primary care, acute care, mental health, justice health).</td>
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<tr>
<td>NSW Ministry of Health initiatives such as Integrated Care, Chronic Care and Hospital in the Home</td>
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<tr>
<td>acknowledge the interconnectivity of services to support people with complex health issues.</td>
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<table>
<thead>
<tr>
<th>Key Questions</th>
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<tr>
<td>What can be done to:</td>
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<tr>
<td>• Achieve effective integrated care for people with intellectual disability and to facilitate</td>
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<tr>
<td>smooth transitions between different health services?</td>
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<tr>
<td>• Ensure that NDIS individual support packages reflect the full range of health needs of people</td>
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<tr>
<td>with intellectual disability, including preventive care, management of chronic disease,</td>
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<tr>
<td>behaviour support and mental health?</td>
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<tr>
<td>• Ensure comprehensive and accurate medical histories and reliable communication of health</td>
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<tr>
<td>information between service providers?</td>
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<tr>
<td>• Ensure discharge planning from acute health care takes account of the particular needs and</td>
</tr>
<tr>
<td>circumstances of the person with intellectual disability?</td>
</tr>
<tr>
<td>• Strengthen relationships between different service providers and within the health system?</td>
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<tr>
<td>• Establish referral pathways for young people transitioning to adult services?</td>
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### 3. Workforce Education and Training

<table>
<thead>
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<th>Key Issues</th>
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<tbody>
<tr>
<td>Building the capacity of the health workforce to understand the needs of people with ID and</td>
</tr>
<tr>
<td>respond appropriately is important. Training on ID issues needs to be available for health</td>
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<tr>
<td>professionals at all levels, as well as access to specialist advice as required.</td>
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<table>
<thead>
<tr>
<th>Key Questions</th>
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<tbody>
<tr>
<td>• How can we strengthen the capacity of the health workforce for people with ID?</td>
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<tr>
<td>• What is the role of:</td>
</tr>
<tr>
<td>• Health Education and Training Institute (HETI)?</td>
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<tr>
<td>• Specialist ID health services and positions?</td>
</tr>
<tr>
<td>• ID as a cross cutting theme to be addressed in health workforce training?</td>
</tr>
<tr>
<td>• LHD based managers and educators in developing local workforce capacity?</td>
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</tbody>
</table>
### 4. Effective Partnerships

**Key Issues**

Effective partnerships within health and between health and other services enable existing expertise and resources to have maximum effect. They also ensure continuity of care and support for people with ID.

**Key Questions**

- What are the elements of effective partnerships, and how can they be fostered?
- What partnerships might reflect the range of health needs and priorities of people with ID?
- What is the role of training and support for key staff?
- What innovative ways exist to sustain partnerships, e.g. the use of technology to support communication and collaboration?
- What incentives could assist LHDs and primary care to work together to deliver integrated health services for people with ID?
- How can people with ID and their carers be actively involved creating partnerships?

### 5. Relevant Health Services / Sectors

#### 5.1 Primary Care

**Key Issues**

Good primary care is critical for ensuring preventative health, early diagnosis and treatment, effective management of chronic disease and coordination and integration of a range of health care and related services.

**Key Questions**

- What can be done to improve access to primary care for people with ID in a way that is person-centred?
- How can coordination and integration between public health services and primary care services be enhanced?
- How do we ensure:
  - The prioritising annual health assessments and chronic disease management plans?
  - There is a good historian for a person with ID?
  - Community health programs, such as Connecting Care, Integrated Care, Health One, Hospital in the Home are inclusive of and responsive to people with ID?
  - Preventative health care and health promotion programs are inclusive of people with ID?
  - Accurate and reliable communication between acute and primary care, especially at transfer of care?
### 5.2 Acute / Hospital Care

**Key Issues**
People with intellectual disability often have avoidable acute care admissions and poor experiences of hospitalisation.

**Key Questions**
- How can we prevent unnecessary acute care presentations?
- How can acute care be more responsive to the needs of people with ID and their carers to avoid unnecessary admission, improve their experience of health services, improve health outcomes, decrease length of stay and avoid unnecessary readmission?
- How can the following improve care for people with ID in acute settings:
  - An identified intellectual disability contact person within LHDs, accessible to consumers, GPs and NGOs?
  - Access to specialist ID health services, mental health services and behaviour support?
  - Patient record management, including flagging of people with ID?
  - Clinical pathways and referral pathways?
  - Communication with patients and their families/carers during an in-patient admission?
  - Recognition of the carer in their support role during hospitalisation?
  - Tele-health?
  - Community support?
  - Timely and appropriate discharge?
  - NSW Ambulance Services.

### 5.3 Specialist Intellectual Disability Health Services

**Key Issues**
Specialist intellectual disability services provide essential expertise in, management, coordination and support of the health needs of people with ID.

**Key Questions**
- What can be done to maximise the benefit of these services for mainstream health services and for people with ID?
- What are the best models for providing these services?
- What is the role and service relationship with specialists in various clinical fields who participate in the care of people with ID and who have particular skills and expertise?
- How can these services be aligned to support clinicians and people with ID in outer metropolitan, regional and rural communities?
- How can these specialist teams work collaboratively to identify, implement and monitor evidence based clinical practices and service models; develop common outcome measures and evaluate these?
### 5.4 Mental Health

**Key Issues**
People with ID experience high rates of mental illness and poor access to mental health services. Mental illness may go undiagnosed because it is masked by the underlying ID, and is a significant barrier to improved participation and quality of life for people with ID.

**Key Questions**
- How can the mental health needs of people with ID be better identified by mainstream health services?
- How do we meet the demand for specialist ID mental health services?
- How do we improve effective referral pathways to and from specialist ID mental health services?
- How do we develop appropriate mental health and ID skills in the disability sector?

### 5.5 Dental Health

**Key Issues**
Accessing dental care can be very challenging for people with ID. Unless there are dental services that understand and are responsive to the particular needs and concerns of people with ID, their dental care is likely to be sub-optimal.

**Key Questions**
- What should dental care providers do in order to provide a service that is suitable for people with ID, and how can access to appropriate specialist dental services for people with ID be improved?
- Is there a role for:
  - Developing networks/linkages to enable general dental care providers to tap into the expertise of special needs dental services?
  - Training dental care providers in issues around the appropriate provision of dental services to people with ID?
  - Developing resources for people with ID to improve their understanding of what is involved in a visit to the dentist?
  - Identifying and/or developing resources on maintaining good oral health for people with ID, families and services.
### 5.6 Population health, research and data collection

<table>
<thead>
<tr>
<th><strong>Key Issues</strong></th>
<th>The health needs of people with ID must be addressed system-wide to ensure a holistic, integrated approach to their health care needs. There is a need for quality research and data to inform services development.</th>
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</thead>
</table>
| **Key Questions** | • What are the priorities for research, data collection and population health initiatives to support the needs of people with ID?  
• What is the role of the following?  
  ▲ Developing a NSW intellectual disability data set in line with other priority populations?  
  ▲ Coding intellectual disability as co-morbidity in health records for admission and discharge data?  
  ▲ Activity Based Funding, and what funding adjustments might be appropriate for these services?  
  ▲ Requiring funding contracts of all pillars of the NSW health system to be linked to performance indicators against their disability inclusion plans?  
  ▲ Supporting initiatives to address the underlying cause of chronic disease in people with intellectual disability, e.g. smoking, obesity, poor diet, dental hygiene?  
  ▲ Involvement of people with ID and their families in identifying research priorities. |
Acknowledgements

This report is the combined effort of the members of the ID Health Network.

The Network has an Executive Group and four subcommittees. It also has carers actively involved at subcommittee level. The members of the Executive Group are listed below and represent the Network and its subcommittees all of whom helped shape this context report and toolkit.

<table>
<thead>
<tr>
<th>Name</th>
<th>Organisation</th>
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<tbody>
<tr>
<td>Maria Heaton</td>
<td>Parent and ID Health Network Co-Chair</td>
</tr>
<tr>
<td>Les White</td>
<td>NSW Chief Paediatrician and ID Health Network Co-Chair</td>
</tr>
<tr>
<td>Vivian Bayl</td>
<td>Sydney Children’s Hospital Network</td>
</tr>
<tr>
<td>Melissa Clements</td>
<td>NSW Department of Education and Communities</td>
</tr>
<tr>
<td>David Coyne</td>
<td>NSW Family and Community Services, Ageing, Disability and Home Care</td>
</tr>
<tr>
<td>David Dossetor</td>
<td>Sydney Children’s Hospital Network and Co-Chair Models of Care subcommittee</td>
</tr>
<tr>
<td>Seeta Durvasula</td>
<td>Centre for Disability Studies (Sydney University); Director ID pilot and Co-Chair Research and Development subcommittee</td>
</tr>
<tr>
<td>Michelle Henwood</td>
<td>NSW Family and Community Services, Ageing, Disability and Home Care and Assistant Co-Chair Workforce and Development subcommittee</td>
</tr>
<tr>
<td>Liz Junck</td>
<td>NSW Ministry of Health</td>
</tr>
<tr>
<td>Robert Leitner</td>
<td>South East Sydney LHD; Director ID pilot and Co-Chair Models of Care subcommittee</td>
</tr>
<tr>
<td>Barbara Lewis</td>
<td>Northern Sydney LHD and Co-Chair Access and Equity subcommittee</td>
</tr>
<tr>
<td>Kathryn McKenzie</td>
<td>NSW Ombudsman’s Office</td>
</tr>
<tr>
<td>Melinda Norton</td>
<td>NSW Family and Community Services, Ageing, Disability and Home Care</td>
</tr>
<tr>
<td>Sarah Ryan</td>
<td>NSW Agency for Clinical Innovation</td>
</tr>
<tr>
<td>Chris Shipway</td>
<td>NSW Agency for Clinical Innovation</td>
</tr>
<tr>
<td>Natalie Silove</td>
<td>Sydney Children’s Hospital Network and Director ID pilot</td>
</tr>
<tr>
<td>Jim Simpson</td>
<td>NSW Council for Intellectual Disability</td>
</tr>
<tr>
<td>Jacqueline Small</td>
<td>Sydney Children’s Hospital Network and Co-Chair Access and Equity subcommittee</td>
</tr>
<tr>
<td>Tracey Szanto</td>
<td>NSW Agency for Clinical Innovation, Network Manager</td>
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<tr>
<td>Julian Trollor</td>
<td>University of NSW</td>
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</table>
Footnotes

i Individual LHD results are only available for each LHD on request

ii Dr Bee Hong Lo, a member of the Workforce and Capacity subcommittee
   – This feedback was presented at subcommittee meeting and in personal correspondence
   (used with permission), 2015.

iii *The Australian Health Care System: The Potential for Efficiency Gains* is available on the NHHRC

iv Use of Emergency and Inpatient Hospital Services by ADHC clients – Final report (PDF);
   PwC Use of Emergency and Inpatient Hospital Services of ADHC Clients – Final Report, Aging, Disability
   and Home Care, Dept. of Families and Community Services NSW 2012; *Anna Dayton and Anna Cohen,*
   *Pricewaterhouse Coopers (December 2012).*