

FRAMEWORK

Building capability in NSW health services for people with intellectual disability: the Essentials

Intellectual Disability Health Network



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

- *service redesign and evaluation* – applying redesign methodology to assist healthcare providers and consumers to review and improve the quality, effectiveness and efficiency of services
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www.aci.health.nsw.gov.au

AGENCY FOR CLINICAL INNOVATION

Level 4, Sage Building
67 Albert Avenue
Chatswood NSW 2067

PO Box 699 Chatswood NSW 2057

T +61 2 9464 4666 | F +61 2 9464 4728

E aci-info@health.nsw.gov.au | www.aci.health.nsw.gov.au

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Executive summary

This document comes at a time when Australian society has embraced unprecedented reforms in the inclusion and support of people with an intellectual disability (ID). The National Disability Strategy, the National Disability Insurance Scheme (NDIS) and the NSW Health Disability Inclusion Plan are indicative of this momentum. Such emphasis is particularly welcome given the documented gaps in both health status and access confronting people with an ID.

In this context there is particular recognition of the continuing importance of health services in the multiagency matrix of integrated care for this population, across the whole age spectrum. Appropriate and equitable access to mainstream health services is a key commitment of NSW Health. The system is further supported by a range of specialised hubs of healthcare expertise as points of tertiary referral, advice and escalation.

The Agency for Clinical Innovation (ACI) Intellectual Disability Health Network has undertaken a substantial body of work, in extensive consultation with colleagues across the state, to generate a spectrum of documents and tools termed 'Building capability in NSW Health services for people with intellectual disability: The resource pack'. This, the Essentials, is the key final component of the resource pack, serving as a summary document and conduit to all other components. Together they provide guidance to the local health districts (LHDs) and specialty health networks (SHNs) in seeking to meet their commitment to improve and enhance services to people with an ID.

Sections 1 to 4 of this document describe the challenges of the current status, the case for change and the 10 principles of quality service delivery for people with ID. This is followed by a review of the development of the resource pack and its many links. Section 6, entitled 'Actions and tools: the self-assessment process', delivers the most immediately relevant and useful guidance to colleagues at the coal face. Areas for action are categorised across four enabling domains (workforce, communication, data, system) as well as actions specific to health service delivery domains, incorporating mainstream (mental health, hospitalisation, integration within NSW Health and integration external to NSW Health) and specialised health services. This approach creates a total of nine categories for action, with guidance for prioritisation within each category and tools for self-assessment. Some of these suggested actions specifically relate to improving health outcomes of Aboriginal and Torres Strait Islander peoples with ID.

The consultation process has allowed the prioritisation of actions into a clear hierarchy and implied sequence for implementation. Given the context of existing workloads, this staged and balanced approach seems practical and helpful. Accordingly, the 'key (high priority) actions' are schematically displayed for each category in Section 6. They are followed by a corresponding self-assessment tool and relevant links to resource documents and examples of implementation from LHDs across NSW. The online version, allowing rapid and user-friendly access to items of interest along with relevant links is available on the ACI website. There are also proposals for evaluation and further development of the resource pack and the Essentials documents as part of the implementation stages.



Professor Donald MacLellan

Acting Chief Executive
Agency for Clinical Innovation

Foreword

On the basis of the best available population data to date, there are 328,000 people in Australia (1.86% of the total population) with intellectual disability, either as the primary disabling condition or an associated condition.¹ Compared to the general population, people with ID and their carers have a less favourable experience of the healthcare system with poorer health outcomes, shorter life expectancy and higher mortality rates. For Aboriginal and Torres Strait Islander people who already experience poorer health outcomes, having a disability can further reduce health outcomes.

Building capability in NSW Health services for people with intellectual disability: the Essentials provides guidance to LHDs and SHNs on key aspects of health service provision to meet the healthcare needs of people with ID. It serves as a summary document and conduit to a broader resource pack which contains documents and tools to assist in the implementation of the suggested strategies. The Essentials also provides LHDs and SHNs with a range of self-assessment tools that enable them to map their capabilities and monitor their progress. Its intention is to facilitate and support the work of LHDs and SHNs as they deliver improved patient care to people with disabilities generally, and to people with ID in particular.

The [UN Convention on the Rights of Persons with Disability \(UNCRPD\)](#), the [National Disability Strategy \(NDS\)](#) and the [NSW Health Disability Inclusion Action Plan \(DIAP\) \(2016 – 2019\)](#) as well as other important disability services reform, policies and legislation underpin the rationale for the guidance provided here. The advent of the NDIS will further reinforce the importance and scope of appropriate health services for people with ID. The focus of the Essentials document and the broader resource pack is on the role of services provided by NSW Health and their essential contribution to the overall health and wellbeing of people with ID.

An extensive consultation process with representatives from across LHDs and SHNs, including clinicians, managers, carers and patients and our partners from other government and non-government sectors, has directly shaped the content and the format of this important resource. This consultation process has included Aboriginal and Torres Strait Islander groups within NSW Health and within the disability sector.

The Essentials sits at the front of a resource pack full of useful information, tools, interviews and videos, references and external links. The resources enable the capability of delivering on the triple aims of:

1. Improving the health outcomes of a defined population;
2. Enhancing their healthcare experience; and
3. Reducing cost and waste.

There is particular recognition of the importance of patient (and carer) related health outcomes as well as their experience of healthcare.

Your colleagues on the ACI Intellectual Disability Health Network trust that you will find all these resources both useful and informative.



Emeritus Professor Les White AM

Inaugural Chair

On behalf of the Intellectual Disability Health Network

¹ Wen X 1997. The definition and prevalence of intellectual disability in Australia. AIHW Catalogue no. DIS 2. Canberra: AIHW. *The Service Framework to Improve the Health Care of People with Intellectual Disability (2012)* quotes 0.9% of total population.

Acknowledgements

The Co-Chairs of the ACI Intellectual Disability Health Network thank the Network's executive group members for their contribution in shaping the final outcome of this work.

The ideas and actions for capability building were gathered through an extensive consultative process across LHDs and SHNs and throughout the broader membership of the Network. Consumer and carer partnership has been a key feature of the process.

Many of the tools to support the suggested actions are the direct result of the commitment of the Network's membership to improve the experience of people with ID as they access the services of NSW Health. These tools help to improve health outcomes.

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 the resource pack and the Essentials.

Name	Organisation
Maria Heaton	Parent and ID Health Network Co-Chair
Les White	ID Health Network Co-Chair
Jenny Martin	Hunter New England LHD and ID Health Network Co-Chair
Vivian Bayl	Sydney Children's Hospital Network
Melissa Clements	NSW Department of Education
David Coyne	National Disability Insurance Agency
David Dossetor	Sydney Children's Hospital Network and Co-Chair Models of Care subcommittee
Seeta Durvasula	Centre for Disability Studies (Sydney University); Director ID pilot and Co-Chair Research and Development subcommittee
Michelle Henwood	NSW Family and Community Services, Ageing, Disability and Home Care and Assistant Co-Chair Workforce and Development subcommittee
Louise Farrell	NSW Ministry of Health
Robert Leitner	South East Sydney LHD; Director ID pilot and Co-Chair Models of Care subcommittee
Barbara Lewis	Northern Sydney LHD and Co-Chair Access and Equity subcommittee
Kathryn McKenzie	NSW Ombudsman's Office
Melinda Norton	NSW Family and Community Services
Tony Pooley	National Disability Services
Chris Shipway	NSW Agency for Clinical Innovation
Natalie Silove	Sydney Children's Hospital Network and Director ID pilot
Jim Simpson	NSW Council for Intellectual Disability
Jacqueline Small	Sydney LHD and Co-Chair Access and Equity subcommittee
Tracey Szanto	NSW Agency for Clinical Innovation, Network Manager
Julian Trollor	UNSW Sydney

Glossary

Definition	Description
Carer	According to the NSW Carers (Recognition) Act 2010 , a person is a carer if they are an individual who provides ongoing personal care, support and assistance to any other individual who needs it.
Co-design	A way of bringing patients, families and staff together to share the role of improving health services. It is a method used to capture the emotional content of patients, families and staff healthcare experiences and can serve as the foundation for patient-centred healthcare improvement. ²
Support network	A support network for a person with ID might include family members, service provision staff, a case manager or advocate.
Areas for action – health service delivery	A range of suggested actions to improve the access, health experience and outcomes of people with ID, covering mainstream health services (mental health, hospitalisation, integration of services within NSW Health and with external services) and specialised health services.
Areas for action – enabling domains	Any of the domains of workforce, communication, data and systems are common elements across any organisation. Actions within these areas will support service delivery and contribute to improved health outcomes for people with ID.

² Definition used by ACI PEACE team https://www.aci.health.nsw.gov.au/__data/assets/pdf_file/0005/256703/peace-framework.pdf

Abbreviations

Abbreviation	Description
ABF	Activity-based funding
ACI	NSW Agency for Clinical Innovation
CALD	Culturally and linguistically diverse
CHAP	Comprehensive health assessment plan
COAG	Council of Australian Governments
CNC	Clinical nurse consultant
DIAP	Disability inclusion action plan
ED	Emergency department
GA	General anaesthetic
HETI	Health Education and Training Institute
ID	Intellectual disability
IDMH	Intellectual disability mental health
LHD	Local health district
MH	Mental health
NDIA	National Disability Insurance Agency
NDIS	National Disability Insurance Scheme
The Network	ACI Intellectual Disability Health Network
NGO	Non-government organisation
PC	Primary care
PCeHr	Patient controlled electronic health record
PEACE team	Patient Experience and Consumer Engagement Team
PHN	Primary health network
SHN	Specialty health network
The Essentials	Building capability in NSW Health services for people with intellectual disability: The Essentials
The resource pack	Building capability in NSW Health services for people with intellectual disability: The resource pack
UNCRPD	United Nations Convention on the Rights of Persons with Disability

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Drew's story

Drew is a 26-year-old Aboriginal man who has an intellectual disability and cerebral palsy. He lives with his parents in rural NSW. He has a nasogastric tube in situ that is used for nutritional supplements and medication.

He aspirated nutritional formula while in respite care and was admitted to hospital with pneumonia.

There had been previous discussions with Drew's family about having a gastrostomy tube inserted into his stomach for feeding, but it was later found not to be possible, due to Drew's severe kyphosis. His family were never happy with this proposal as they identified food as one of his few pleasures in life.

Nasogastric tubes are not a preferred long-term mode of feeding because of the risks involved. For Drew, they were often dislodged and management in the rural area where he lives was very difficult. The local hospital is unable to replace the tube so Drew needs to travel to the base hospital for replacement of his nasogastric tube. There is no care coordinator available to advocate for Drew, develop a pathway to care which could bypass the emergency department (ED), or book regular appointments. Insertion requires a radiologist and having the correct tube available. This often means Drew is hospitalised for the weekend, and kept hydrated with an intravenous infusion while he waits for a replacement tube and the radiologist to be available.

The hospital discharge planner identified issues around Drew's ongoing care and unmet needs, and was able to navigate a clear pathway through the health system which incorporated a multidisciplinary approach to care planning. Drew and his family were at the centre of discussions and were supported by the Aboriginal Health Worker. The hospital discharge planner became the key contact for Drew within the health service.

You can read more case studies of effective supports delivered by health services to people with intellectual disability at www.aci.health.nsw.gov.au/resources/intellectual-disability/toolkit/intellectual-disability-toolkit/discharges-from-hospital-intellectual-disability-case-studies

Harry's story of unmet needs

Harry, 45, lives in disability supported accommodation. He has intellectual disability, mental health concerns and needs communication support. Harry has an ingrown and infected toenail which will require a medical procedure. He is afraid of being in hospital with people he does not know, especially as his past visits to hospital were not pleasant experiences.

The staff at Harry's house are not sure about the health system and Harry's health needs. Harry does not have a regular GP but staff, after some effort, were able to get referrals to appropriate health specialists.

Eventually Harry receives a letter to attend a clinic.

The health staff in the clinic are unfamiliar with working with people with ID and their lack of confidence and communication skills unnerves Harry, who becomes anxious and wants to go home. In the confusion of the moment, there is no time for health staff to assess Harry's needs around communication support, mental health and ID support.

There is no opportunity for health staff to explore ways in which Harry's needs could be managed and security staff are called to contain the situation as Harry becomes more frightened and his behaviour escalates. Staff are unsure what to do, do not know where to access support and decide they are not skilled to care for people with ID.

Harry returns to his supported accommodation without being assessed. He refuses to consider attending the next clinic appointment.

The supported accommodation staff are reluctant to be involved with the next clinic appointment after this experience and all their efforts, which did not help in the end.

Harry's toenail becomes septic and he becomes very unwell. Accommodation staff call an ambulance and Harry is admitted to the local hospital's ED. He remembers his previous experience and becomes very anxious again. The staff remember Harry from his recent visit and avoid caring for him as they lack confidence in their skills.

Harry stays in hospital for six weeks while he receives treatment. This is much longer than expected.

Mary's story of success

Mary, 45, lives in disability supported accommodation. She has intellectual disability, mental health concerns and needs communication support. Mary requires a medical procedure to meet her health needs. For Mary, this means using visual aids and social stories. Often an anaesthetic is required to ensure fear and anxiety do not prevent effective assessment and intervention. She is afraid of being in hospital with people she does not know, especially as her past visits to hospital were not pleasant experiences.

The team leader at Mary's supported accommodation saw it as her role to make sure she had an understanding of the health system so she could advocate for Mary's health needs. It took months for Mary to understand she needed to see a GP to get referrals to appropriate health specialists for gynaecological and dental reviews.

Mary's regular GP and her accommodation team leader were able to identify a hospital that was able to support Mary and her specific needs. A pre-admission planning case conference was arranged at the hospital and accommodation staff prepared Mary for this using a social story book.

Her team leader brings along the *NSW Health & Ageing and Disability and Home Care (ADHC) joint guideline (2013)*. The health staff are not familiar with the document, but with discussion, everyone decides to use it to work together. The meeting helps everyone to understand Mary's special needs around communication support, mental health and ID support. The staff explore ways in which Mary's needs can be managed while she is an inpatient and put steps in place to do this, such as being there to support her and encourage her to drink after her surgery. Because Mary needs two procedures, the hospital staff suggest that Mary is booked to have both procedures at the same time, while under anaesthetic.

Mary is prepared as an inpatient the day prior to her procedures. Her support staff are given the likely time of medical rounds so they can see medical staff to ask any questions.

Everything went to plan, and Mary did not stay in hospital longer than expected. A comprehensive discharge summary is provided to her support staff and GP who provides routine follow-up care. Group home staff report no adverse impact on Mary's mental health after her hospital stay.

You can read [NSW Health policy Responding to Needs of People with Disability during Hospitalisation](#).

Section 1

How to use the Essentials

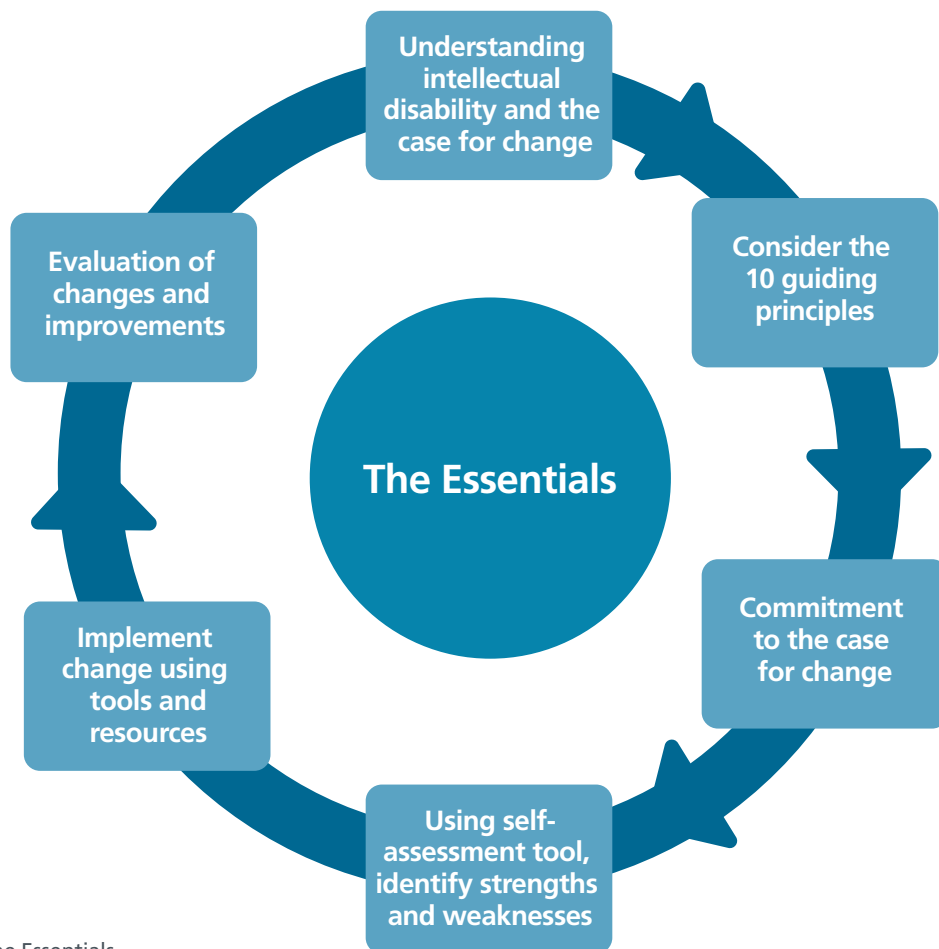


Figure 1. How to use the Essentials

Step 1: Understanding ID

Develop an understanding of ID and the challenges faced by people with ID in accessing and using health services.

If you are not familiar with people with ID and their health challenges we suggest you start with reading [Section 2.1 – Description of intellectual disability](#) and [Section 4 – The case for change](#).

For more information see:

- [Context report and toolkit for health services for people with intellectual disability, 2015](#)
- [Service framework to improve the health care of people with intellectual disability \(2012\)](#).

Step 2: Guiding principles

Understand the 10 guiding principles for the delivery of health services for people with ID developed by the Network.

There are 10 guiding principles in the Essentials. They are based on the [United Nations Convention on the Rights of Persons with Disabilities \(UNCRPD\)](#) and developed through consultation with the Network's membership. These will assist you in thinking about what makes for a quality health service for people with ID. It may be helpful to discuss these principles with your colleagues. A useful starting point for discussion would be to review each of the 10 principles and think about the extent to which they apply in practice in your own LHD or health service. This is likely to show some areas of strength and some of weakness. Your review may indicate areas in which improvements can be made.

The [guiding principles](#) can be found in Section 3 and an [expanded version](#) in Appendix 3.

Step 3: Committing to the case for change

People with ID have poorer health outcomes when compared with the general population.

NSW Health has developed a system-wide [Disability Inclusion Action Plan](#) which describes the steps which NSW Health will take to improve access to mainstream and community health services for people with disability.

A better health service for people with ID in NSW requires commitment to ongoing work and adaptability as major reforms, primarily the [NDIS](#) rollout.

Relevant questions for an LHD to consider.

- Do we have engagement from senior and executive level staff?
- Do we have a senior staff member of the LHD with responsibility for leadership in coordinating disability issues?
- Have we identified local champion/mentors for improved healthcare for people with ID within the LHD?

Step 4: Self-assessment

This step invites you to assess your current service delivery on a range of actions which can support improved health outcomes for people with ID. [11 key actions](#) have been identified (see Section 6), with other suggested actions and guidance available in [Appendix 1](#). A full list of prioritised actions at [6.2](#) and [6.3](#) gives you the opportunity to conduct a self assessment at unit, department, facility or LHD level.

The key actions have been organised into:

- enabling domains (actions which improve workforce, communication, data and systems) and
- health service delivery (mainstream and specialised health services).

Following your self-assessment results, it will be your decision where you place future efforts. You may decide to build on areas of existing strengths, to address areas of deficit or to pursue both. This might be work undertaken by the LHDs or through existing committee structures and included in the relevant strategic and clinical service plans with links to the DIAP and hospital accreditation standards.

For detailed explanation of how the self-assessment process works, see [Section 6](#).

Step 5: Resources and support

The links provided in each section of the self-assessment checklist will take you to a range of resources and documents. These can assist you when considering some of the specific actions.

You can also contact the Manager, Intellectual Disability Health Network, NSW Agency for Clinical Innovation on 02 9464 4632 for further discussion and support around the resources or their implementation.

Tracey.szanto@health.nsw.gov.au

Step 6: Evaluation

Each LHD and SHN and the NSW Ambulance Service has a redesign leader who is a key resource in this process.

Using redesign methodology, ACI aims to support healthcare providers and consumers to review and improve the quality, effectiveness and efficiency of services.

Section 2

Background

“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.”

Your Healthcare Rights and Responsibilities –
A guide for NSW Health staff NSW Health;
Pg. 1; Document Number PD2011_022;
Published: 20-Apr-2011

2.1 Description of intellectual disability

People with ID have a wide range of skills, capabilities, interests, strengths and needs. It is important not to make assumptions about these. Each person with ID is unique and will require an individualised approach to meeting their personal healthcare needs.

Intellectual disability (also known as intellectual developmental disorder) is a condition involving impairment of general intellectual abilities which begins during the developmental period and impacts significantly on a person's adaptive functioning.³ Impairments in adaptive functioning can occur in three areas, including:

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

Assessment is usually based on the severity of deficits in adaptive functioning, which can be determined by clinical and standardised cognitive tools. Formal testing of intellectual abilities will enhance the person's assessment. 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 comorbidities (physical, mental or behavioural)
- family and community supports available
- access to health services (including specialised health services)
- understanding of and ability to act on preventive health advice
- housing
- financial situation
- educational and work opportunities
- challenging behaviour
- other health conditions (diagnosed or undiagnosed).

Health conditions common to the general population but also experienced by people with ID (such as gastro-oesophageal reflux, heart conditions, mental ill-health, presence of autism, sight and hearing difficulties) all compound the impact of a person's ID on their functional capacity.

ID can be confused with other conditions distinguished by subsequent loss of cognitive and adaptive functions. For example, acquired brain injury can affect a person's functional capacity and may be caused by accident, abuse, stroke or drugs and alcohol. If this injury happens during the developmental period and persists, the person is considered to have ID.

³ American Psychiatric Association. *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition*. Washington: American Psychiatric Association; 2013.

Dementia is different from ID in that it is not a developmental disorder and it is usually characterised by progressive deterioration in cognitive function which impact the person's ability to carry out their daily function. Sometimes dementia may also affect people with ID.

There is a link between early onset Alzheimer's disease and Down syndrome.⁴

Developmental Disability is a broad term used to describe a number of physical and cognitive conditions arising in the developmental period.

2.2 The right to self-determination

People with ID have the right to make choices about their lives.

In order to understand and communicate their choices and preferences, people with ID may require support.⁵

Health professionals may also require expert and individualised support to understand the person's needs and choices and their role in the process.

2.3 Complex needs and people with ID

In all age groups, people with ID experience a higher prevalence of health conditions. These can either be associated with their disability (as part of a syndrome) or be direct or indirect consequences of the ID. Such health conditions are often multiple and complex and may include sensory impairment and epilepsy, physical illness or disability as well as mental health and behavioural challenges. Health conditions may also exacerbate functioning deficits in ID. For example a person with ID might have difficulty with muscle coordination for chewing and swallowing. Positioning difficulties as a result of scoliosis may further limit their ability to chew and swallow food, and then may increase their risk of aspiration pneumonia.

Chronic, complex health conditions are increasing across the age spectrum. One cohort comprises those with conditions of childhood which may have been life

limiting in the past. Now these people are surviving well into adulthood with a spectrum of needs and disabilities and this may include ID. For example, people with Down syndrome are now living into older age

Factors that contribute to the complexity of health needs of people with ID include having multiple disabilities, severity of ID, dual diagnosis of ID and mental illness, severe, multiple or deteriorating health conditions, behaviours involving harm to self or others, alcohol and/or drug issues and issues relating to past experience of trauma or neglect. Situational factors can include socioeconomic disadvantage, lack of natural support,⁶ family/carers stress, breakdown in care arrangements, young people leaving care, involvement in the criminal justice system and multiagency involvement in provision of support.

Cognitive and communication impairments mean people with ID often rely on carers or proxies to access healthcare. People with complex support needs may encounter additional challenges to accessing timely and high quality healthcare. This is in part due to the need for health services to provide more accessible services and skilled staff.

A particular challenge for health services is ensuring that all people with ID are catered for by the mainstream health system, including those who have complex needs. This has implications for NSW Health in terms of the coordination of healthcare and the need to develop partnerships with the disability sector to support healthcare delivery and recognise the individual's need to navigate a range of healthcare specialties, along with disability, educational and social services. NSW Health has placed particular emphasis on integrated care, the engagement of primary care providers/networks and partnerships between providers as well as with people with ID and their families.

This emphasis will better support the healthcare needs of people with ID.

⁴ Centre for Developmental Disability Health (CDDH) Victoria. Down syndrome and Alzheimer's disease. Melbourne: CDDH; ISBN 978-1-921570-03-2

⁵ Capacity toolkit from the NSW Attorney General's Department about a person's capacity to make their own decisions

⁶ Natural supports are the help and care that someone receives from relationships that occur in everyday life, from friends, family or the community – NDIS, <https://www.ndis.gov.au/about-us/governance/IAC/iac-advice-independence.html#intro>

2.4 The ACI Intellectual Disability Health Network

The ACI Intellectual Disability Health Network (the Network) was set up in 2011. It has a mandate to work with clinicians, consumers, carers and managers to design and promote better healthcare for people with ID in NSW. The Network is part of the NSW Health 2012 *Service framework to improve the health care of people with an intellectual disability*.

The Network contributes to statewide clinical leadership, research, education and training (see Appendix 4). It has designed a matrix of key activity elements and formed four subcommittees to operationalise the work of the Service Framework (see Figure 2 below).

NSW Health values the contribution of carers and this document includes recognition of this role.

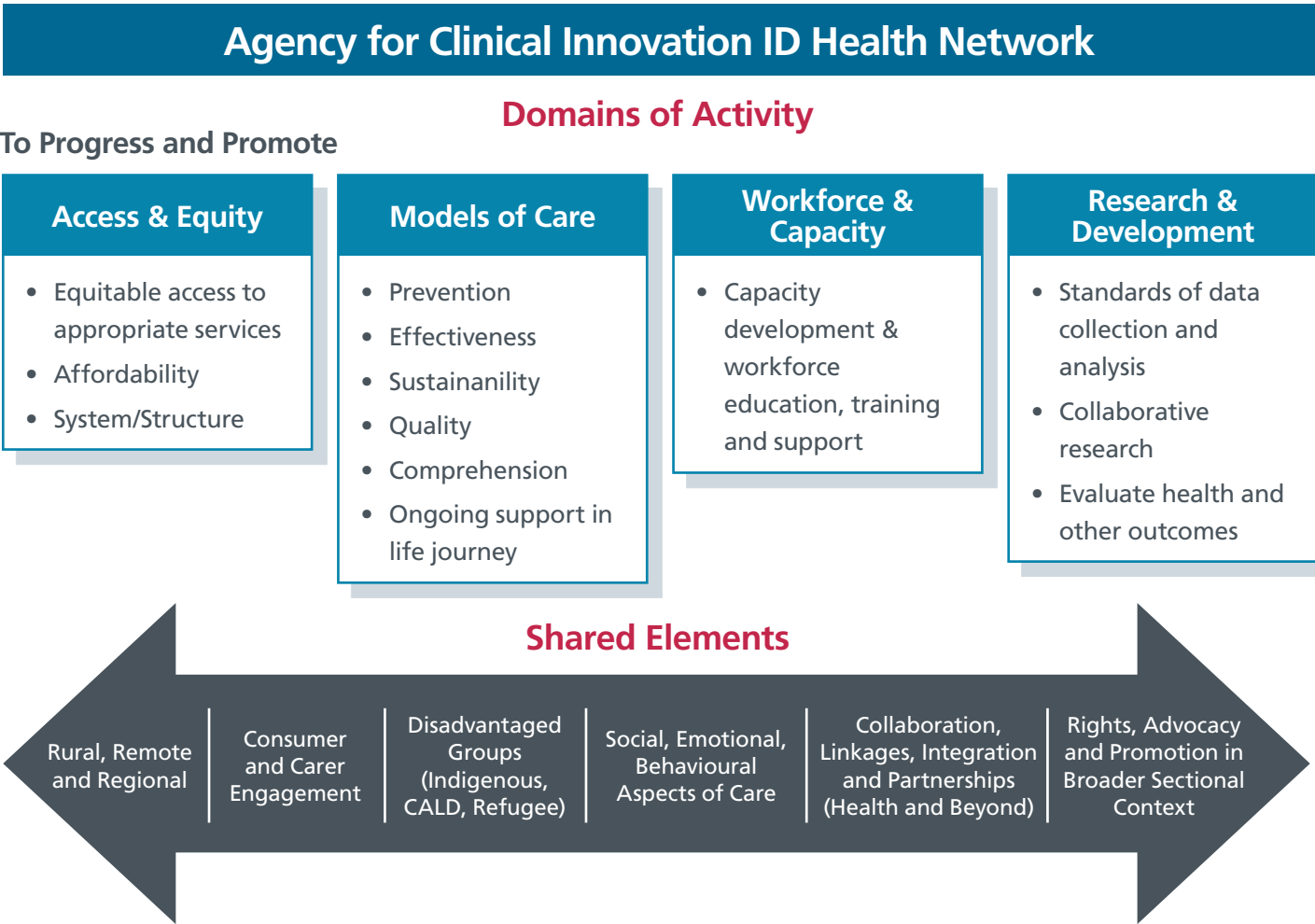


Figure 2. The ACI Intellectual Disability Health Network domains of activity

Section 3

10 guiding principles of quality health services for people with ID

10 guiding principles underpin the delivery of quality health services for people with ID. They provide guidance around both what to do and how to do it.

The principles are based on the [UNCRPD](#) and have been developed through consultation with the Network's membership, consumers and carers and with health and partner organisations/agencies.

See Appendix 3 for an [expanded version](#).

- 1** People with ID have the same access to quality and range of health services as other people
- 2** Health services recognise the poorer health outcomes for people with ID
- 3** Health services provide early diagnosis and intervention to enable optimal outcomes
- 4** Health services support the cultural and social inclusion of people with ID and their carer
- 5** Health services are delivered in a person and family centred way
- 6** Health services for people with ID are co-designed and integrated across primary, mainstream and specialised care
- 7** Health services are delivered by appropriately trained staff
- 8** Specialised health services and the integration of their expertise within mainstream services can improve health outcomes for people with ID
- 9** Collaboration between government and non-government agencies (e.g. schools, supported accommodation services) supports the health outcomes of a person with ID
- 10** Data is required to inform ongoing health service development, policy and models of care

Section 4

The case for change

4.1 Health outcomes for people with ID

People with ID have poorer health outcomes when compared with the general population.

- Life expectancy can be up to 20 years less than the general population.⁷
- Age-specific mortality rates from a range of health problems are higher as they are often undiagnosed or poorly managed.⁸
- People with ID have less access to and gain less benefit from public health or preventive health programs.
- There is less access to primary and secondary prevention.⁹
- There is greater use of hospital emergency departments.
- People with ID experience longer and repeated hospital admissions.¹⁰

People with ID are likely to have one or more health conditions. People with ID across all age groups are more at risk of developing mental illness than the general population. Frequently, mental health conditions are under recognised or inadequately managed.

People with ID may face barriers when accessing the health system because of difficulty in understanding what is going to happen or negative or uninformed staff attitudes about people with disability. This has been graphically documented by the patient journey work undertaken by the ACI Intellectual Disability Health Network.¹¹

The poorer health of people with an ID has direct system costs. For example, people with a disability aged 35 to 64 cost the NSW health system more than other NSW citizens¹² of comparable age. This is because of a higher number of separations¹³ per person and a longer average length of stay.

Delivery of quality services for people with ID in mainstream health settings can be challenging for many reasons, with many challenges based in communication between health professionals and people with ID and lack of knowledge on the part of health workers about how to best meet the needs of people with ID. Working effectively with a person with ID can minimise opposition to physical examinations, tests or procedures and reduce resistance to attending or staying for medical appointments.¹⁴

There are three health barriers faced by people with ID.¹⁵

1. People with ID may not understand something is wrong with their health, and/or not know what to do, and/or not know where to go for help.
2. Carers and disability support staff may not recognise the symptoms, understand the consequences of, or know who to contact about health concerns.
3. Health professionals may lack knowledge and experience in working with people with ID.

⁷ NSW CID & Australian Association of Developmental Disability Medicine Position statement on the health of people with intellectual disability. Sydney: NSW CID; 2014

⁸ Australian Institute of Health and Welfare (AIHW). Health status and risk factors of Australians with disability 2007–08 and 2011–12. Canberra: AIHW; 2016.

⁹ NSW Ombudsman. Report of reviewable deaths in 2012 and 2013 Volume 2: Deaths of people with disability in residential care. Sydney: NSW Ombudsman; 2015.

¹⁰ Trollor J, Srasuebkul P, Xu H, et al Cause of death and potentially avoidable deaths in Australian adults with intellectual disability using retrospective linked data BMJ Open 2017;7:e013489. doi: 10.1136/bmjopen-2016-013489

¹¹ NSW Agency for Clinical Innovation (ACI). Patient journeys. Sydney: ACI; 2015.

¹² NSW Government Department of Family and Community services. Use of emergency and inpatient hospital services by ADHC clients – Final Report. Sydney: NSW Government Department of Family & Community Services; 2012.

¹³ The number of separations (death, discharge, sign out or transfer) is the most commonly used measure of the utilisation of hospital services rather than admissions

¹⁴ NSW Ombudsman. Report of reviewable deaths in 2012 and 2013 Volume 2: Deaths of people with disability in residential care. Sydney: NSW Ombudsman; 2015.

¹⁵ Taggart L, McKendry L. (2009) Developing a mental health promotion booklet for young people with learning disabilities. Learning Disability Practice 2009; 12(10):27-32.

“ I think they avoid dealing with him because they don't have much experience with people with Disabilities.

”

Josie & Geoff
(From Real People Real Lives)

These barriers mean that having ID is likely to result in poorer health. For some, a specific health event may lead to reduced intellectual functioning, exacerbation of anxiety and mental illness or challenging behaviour.

Recent data linkage about hospitalisation in NSW underlines this issue.¹⁰

There is support available to improve the health services we offer and, in turn, the person's experience of health service delivery and ultimately, of health outcomes.

The Essentials provides support to LHDs and SHNs to improve the health outcomes of people with ID in the context of both the requirement for disability inclusion action planning and for the rollout of the NDIS.

Access to quality healthcare is a fundamental human right for everyone and this is recognised in the [UNCRPD](#) and supported by NSW Health policy.

Key findings from a 2013–14 survey of NSW LHDs by the Network showed that:

- 42% of LHD disability action plans did not include support for people with ID
- 89% of LHDs did not have a key contact or resource person within their service for people with ID and their families/carers
- 79% of LHDs had no information specifically designed for people with ID
- 95% of LHD's had no routine supports and adjustments available for people with ID
- 73% of LHD's provided no staff training in ID awareness (though feedback indicates a keen interest on the part of staff for training in this area).

The survey is discussed in the [Context report and toolkit for health services for people with intellectual disability, 2015](#) (Section 7).

4.2 NSW Disability Inclusion Act 2014 – Disability inclusion action planning

The *NSW Disability Inclusion Act 2014* and subsequent regulation aims to recognise the rights of people with disability and ensure that they can access mainstream services and be part of the community. The legislation requires the development of the [NSW Disability Inclusion Plan](#) together with separate disability inclusion action plans by each government department and local council in NSW.

NSW Health has developed a system-wide [DIAP](#). The health DIAP describes the steps which NSW Health will take to improve access to mainstream health services and community health services for people with disability and improve equitable access to employment. The plan contains four key areas for concentrated action to improve inclusion. These are:

- promoting positive attitudes and behaviours
- creating liveable communities
- providing equitable systems and processes
- supporting access to meaningful employment opportunities.

These mirror the key goals of the *NSW Disability Inclusion Plan*.

The system-wide NSW Health DIAP sets the vision and establishes the expectation that LHDs and statutory health organisations will develop and implement their own locally relevant inclusion strategies. It aims to elevate the voices of people with disability in planning and designing health services and facilities to promote improved inclusion, improved systems and processes and inclusive attitudes and behaviours.

The Essentials contains suggestions and strategies to support improved health outcomes for people with ID. It aligns with and supports the NSW Health [DIAP](#).

¹⁰ Trollor J, Srasuebkul P, Xu H, et al Cause of death and potentially avoidable deaths in Australian adults with intellectual disability using retrospective linked data *BMJ Open* 2017;7:e013489. doi: 10.1136/bmjopen-2016-013489

4.3 The National Disability Insurance Scheme

A better health service for people with ID in NSW requires commitment to ongoing work and adaptability as major reforms roll out.

Foremost amongst current reforms is the rollout of the NDIS. As an insurance scheme, the NDIS mandates support for eligible Australians with permanent and significant disability based on their individual needs and preferences.

The NDIS was launched in July 2013 at a number of trial sites across Australia in response to an inquiry by the Productivity Commission and the 2011 agreement by the Council of Australian Governments (COAG) supporting the need for radical reform of disability supports in Australia. The NSW trial site was in the Hunter region. The NDIS is being implemented across NSW between 1 July 2016 and 30 June 2018.

NSW Health is undertaking significant planning in line with the NDIS.

NSW Health welcomes this new era for people with disability. A transition plan will assist LHDs to respond to the reforms in their commitment to deliver health services to people with disability.¹⁶ Key aims of the new way of delivering health services to people with a disability under the transition plan are to:

- provide integrated healthcare to people with disability while supporting their access to the NDIS
- improve preventive care and in the longer term reduce hospitalisations
- address other acute episodes as a result of better, integrated health for people with disability in the community.

Health services are likely to become increasingly central to multidisciplinary care and leadership in the context of transition to NDIS.

The use of the tools and suggestions in the Essentials will strengthen and support efficient and effective transition to the NDIS, for example, in helping to confirm roles. Strong collaborative action with the NDIS will lead to better outcomes all round as a healthy person will have lower disability support needs and a person with good disability support will be healthier.

“ John, 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 for John back to the group home with support.

This results in ongoing consultation and the involvement of the GP, as well as group home manager to prevent future unplanned hospitalisation for John and improved health outcomes.

”

From *Context report and toolkit for health services for people with intellectual disability, 2015*. Sydney: ACI, 2015.

More information on the NDIS can be found at www.ndis.nsw.gov.au, www.ndis.gov.au and [NSW Health's Disability web page](#).

¹⁶ [NDIS Transition Plan](#)

4.4 The importance of mainstream and specialised health services for people with ID

The reform initiatives described in this document and elsewhere in the resource pack recognise the continuing critical contribution of health services to the comprehensive care of people with ID. They acknowledge and emphasise the need to continue to provide a range of mainstream health services across primary, secondary and tertiary settings. Improvements and enhancements to health service utilisation are flagged as integral to the reform process.

Appropriate and equitable access to mainstream health services is a key commitment of NSW Health. Service capability is underpinned by supportive policy, appropriate culture and practice along with training and development opportunities. Mainstream services include those delivered in the community, emergency departments, ambulatory clinics and inpatient settings.

An essential cornerstone of comprehensive, evidence-based and networked clinical services is access to centres of additional expertise and specialisation. Tertiary hubs and related hub-and-spoke arrangements are well described in a range of clinical domains and jurisdictions. The capacity to escalate care through appropriate channels and defined pathways for either advice or referral are key to integrated care and to delivery of 'right care, right place, and right time'. Such channels ensure professional support, continuing clinical education and maintenance of quality across the system. The [literature review](#) of health service models of care for people with ID supports the role of tertiary centres specific to the clinical challenges relating to this population. Local evidence gathered in the development of the resource pack and the Essentials reinforces the need for access to specialised expertise and support.

NSW Health hubs or centres of specialised expertise in support of the healthcare of people with ID have evolved consistent with the above principles and in response to local needs, across a broad spectrum of clinical settings and age categories. These centres vary in their target populations, models of care and clinical focus, according to their history and local circumstances. Examples of particular focus and expertise include aspects of early childhood and developmental delay, complex illness/syndromes involving ID, Aboriginal or CALD populations, transition between paediatric and young adult healthcare, and

mental health comorbidities and challenges for people with ID. These hubs play essential roles in diagnosis and assessment, well exemplified by the early childhood teams, as well as providing leadership in care coordination and continuing guidance. Despite variations in service models, these hubs need to share some or all of the common elements of a specialised health service.

- Multidisciplinary care is delivered by a team of clinicians with particular interest and expertise in the healthcare of people with ID.
- Consumer engagement and support is central and consistent with appropriate inclusion of people with ID.
- Pathways and channels to escalation for either advice or referral are clearly identified and practiced.
- Networked integration into a comprehensive approach to appropriate care is in place.
- Feedback to and support of mainstream health services occurs.
- Research towards and application of best available clinical evidence are pursued.

Since 2011, NSW Health has funded three newly established centres of expertise as pilots to explore and enhance existing models of care. At the same time the ACI Intellectual Disability Health Network was established as a guiding support, network and leadership structure across the services.

As with the historic hubs, the new centres vary in their specific focus of clinical interest as well as in the particular populations they serve. However, each one adhered to the principles above and in their subsequent evaluation documented the important, continuing place for such teams in a comprehensive NSW Health response to the needs of people with ID.

These NSW Health centres of expertise, whether old or new, are distinct from 'specialist services' as defined within the disability agencies. However, it is considered essential that the two domains cooperate and, as such, constitute a key element of interagency collaboration and integrated care. In addition individual clinicians across NSW Health have developed and are providing clinical expertise in accordance with particular health problems of people with ID. These contributions are embraced as part of a systemic approach that supports the work of multidisciplinary health teams.

The centres/teams described in this section provide tertiary expertise and act as hubs of networking in support of mainstream healthcare services and professionals. In concert, these different levels of response provide a comprehensive response to the needs of people with ID.

The documents, resources and tools encompassed in the resource pack and the Essentials provide a comprehensive range of support and guidance to NSW Health mainstream services.

The distribution and service configuration of tertiary centres is recognised to be challenging and in process of further development. It is limited by the number of trained professionals available to the system. LHDs should consider the establishment/maintenance of or access to such centres for patients with ID and for the clinical professionals delivering mainstream services. The particular challenges of access to such expertise in rural settings may be addressed by appropriate partnership arrangements with centres in metropolitan LHDs.

Section 5

Overview – the resource pack and the Essentials

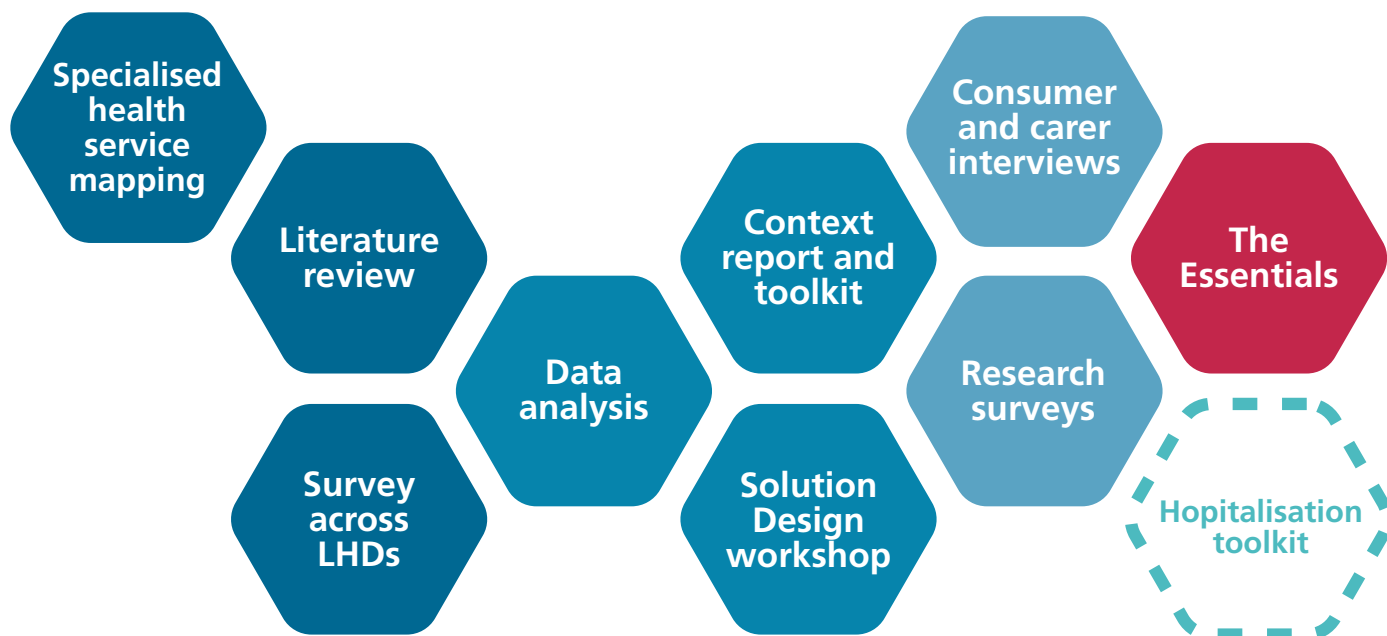


Figure 3. The components of the resource pack

5.1 The resource pack

What is Building capability in NSW Health services for people with intellectual disability: the resource pack?

The resource pack is a suite of documents, resources and background research undertaken or compiled by the Network to guide the provision of health supports to people with an ID. The resource pack components (see Figure 3 above) include:

- specialised Mapping of specialised services within NSW Health for people with ID (2015)
- a [literature review](#) on current models of health service delivery for people with ID (2015)
- the 2013–2014 survey of NSW LHDs disability responsiveness (see Section 7, page 23 of the [Context report and toolkit for health services for people with intellectual disability, 2015](#))
- economic data analysis [report](#), 2015
- Solution Design workshop:
 - [Effective Service Delivery for People with an Intellectual Disability](#)
 - [Summary Analysis of people admitted with Intellectual Disability in the NSW Public Health System](#)
 - [Setting the Scene](#)
 - [MoH update](#)
 - [Partnering with Disability Services to develop a Disability Action Plan](#)
- [Context report and toolkit for health services for people with intellectual disability, 2015](#)
- [Real people, real lives](#) – consumer and carer interviews exploring the patient journey, 2014–2015
- [Research surveys](#)
- the hospitalisation toolkit¹⁷
- the Essentials (this document).

The ACI's [Intellectual Disability Resources](#) provide more information.

¹⁷ See [ACI website](#) - progressively updated as material is developed

5.2 The Essentials

What is Building capability in NSW Health services for people with intellectual disability: the Essentials?

This is the Essentials. It brings together a range of resources and information which can help to improve the health experience and outcomes of people with ID.

It contains a list of principles and consumer reported experience measures which can be used to demonstrate that people with ID are receiving quality healthcare.

A major component is a self-assessment checklist using practical suggestions for actions to help deliver quality health support across NSW.

Where there are resources which support the suggestions for action, these are listed and hyperlinked as appropriate.

The Essentials and the resource pack have been compiled for healthcare staff working in health services in LHDs in NSW. It will be useful for clinicians and managers throughout NSW Health who want to make a difference to their delivery of health supports for people with ID in NSW. LHDs may also find it helpful to draw on these resources in considering local actions to provide more inclusive health services for people with disability in alignment with their DIAP and hospital accreditation (Standard 2 in particular).

The Essentials and the resource pack can also provide guidance for those working in primary health, in government and non-government agencies who have responsibilities around the health needs of people with ID and their interaction with the health system. It will also be of interest to people with ID themselves and their carers.

“ 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.

”

Vita and Reece
(From *Real People Real Lives*)

5.3 Structure of the Essentials

The [Solution Design Workshop](#) undertaken by the ACI Intellectual Disability Health Network categorised the experiences of people with an ID and aligned them with the four enabling domains. These enabling domains are workforce, communication, data and system. Actions undertaken in the enabling domains can improve the overall quality of the healthcare system for people with ID and contribute to a person with ID and their carer and family reporting positive experiences.¹⁸ These experiences align with and reflect the goal that people with ID will receive health services which meet their full range of healthcare needs and expectations (see Figure 4 below).

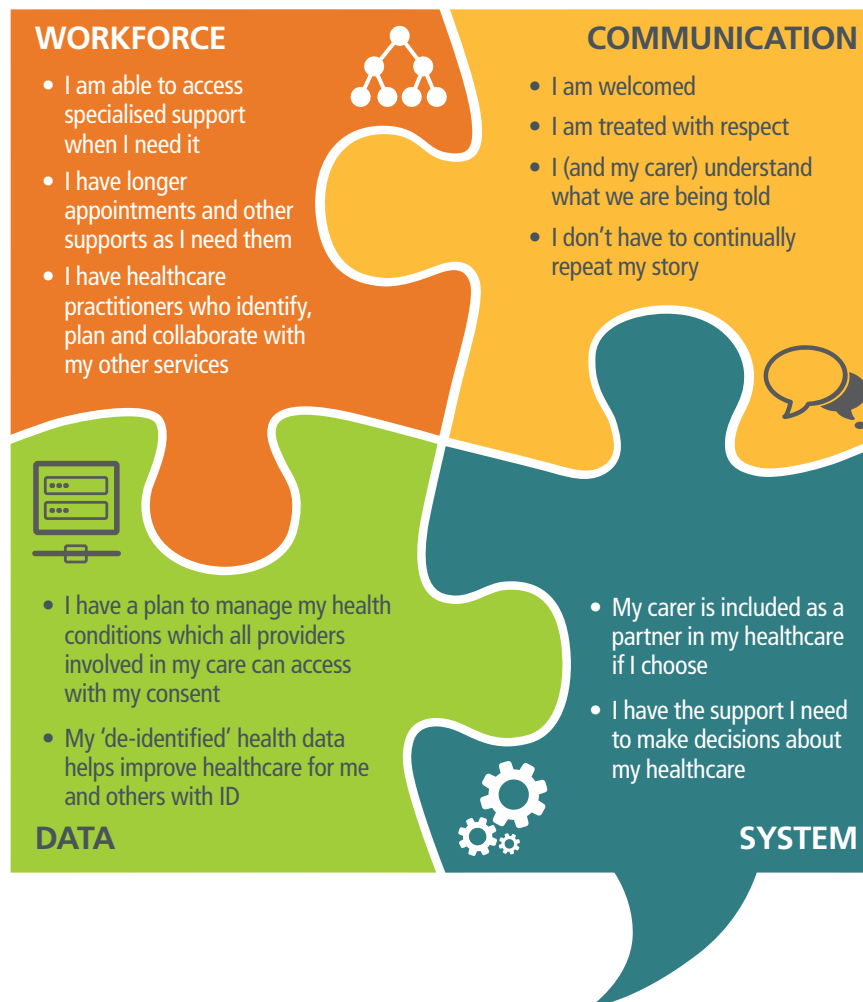


Figure 4. Experiences of people with ID aligned with four enabling domains, characterising a responsive health system

The structure of the Essentials is shown in Figure 5.

The components are:

- purpose
- 10 guiding principles of quality health services for people with intellectual disability
- areas for action including:
 - enabling domains
 - health service delivery domains
- consumer reported experiences.

The health service delivery domains contain both mainstream health services (mental health, hospitalisation and integration of services both within and external to NSW Health) and also specialised health services.

In [Section 6](#) the areas for action under these domains are prioritised and tools to support action are listed. The self-assessment tool is also here.

¹⁸ The Consumer Reported experience is similar to the concept of PREMs (patient reported experience measures) which are a features of integrated care, but without being subject to a formal measurement system. More information about PREMs is available in [Overview: What are PROMs and PREMs?](#)

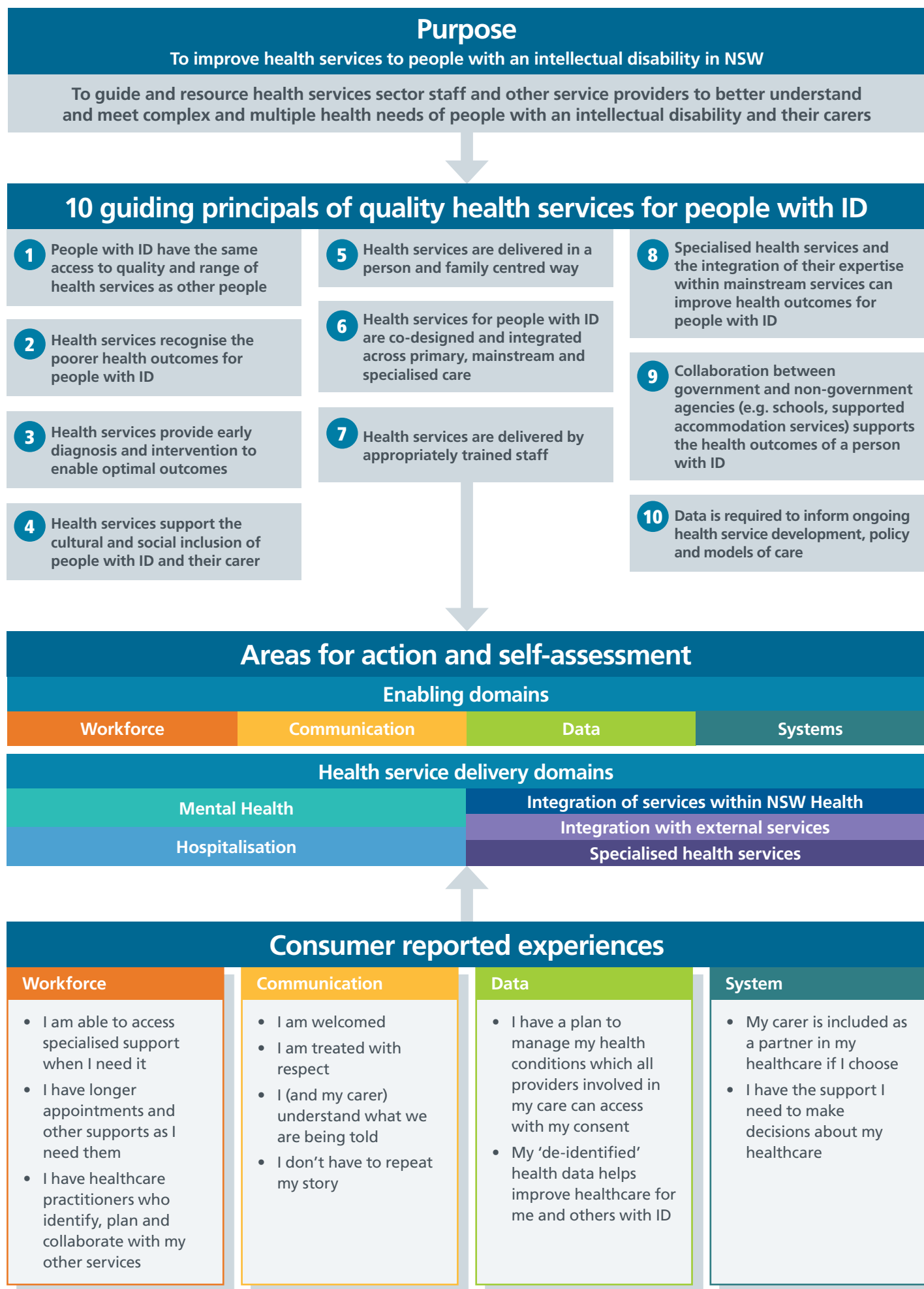


Figure 5. The structure of the Essentials

5.4 George's story – an example of how the Essentials is useful for LHDs

George's story

George has ID and is coming into hospital for a hernia repair.

The LHD process for achieving this outcome includes the following:

- **Guiding principle 5**
Health services are delivered in a person and family centred way
- **Relevant NSW Health policy**
[*Responding to Needs of People with Disability during Hospitalisation*](#)
- **Enabling domain**
[*Workforce*](#) – health staff are supported to make reasonable adjustments as needed
- **Health service delivery**
[*Hospitalisation*](#) – preadmission visits/clinics are offered to people with ID and their support network prior to a planned hospital stay
- **Toolkit to support action**
[*Say less show more; Hospitalisation toolkit*](#)

George's reported experience:
'I was able to go to hospital like everybody else'

“ Deryk (11) is diagnosed with developmental delay. His behaviour has recently escalated and he has been admitted to the ED 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.

”

Vita and Reece
(From [*Real People Real Lives*](#))

Section 6

Areas for action and tools – the self-assessment process

6.1 The self-assessment process explained

STEP 1

ANSWERING YES/NO/UNSURE

The statements requiring a response are illustrated in [Sections 6.3](#). These statements seek a response from the LHD about recommended actions to build capability in health services for people with ID.

The areas for action are categorised into domains.

Don't be deterred by the number of actions. The self-assessment will enable choices about where to focus for change at any point in time.

The domains include:

- enabling domains – workforce, communication, data and system
- mainstream health service delivery domains – mental health, hospitalisation and integration of services both within NSW Health and external to NSW Health
- specialised health services.

[See Figure 7 and Section 6.2](#)

STEP 2


DECIDING WHERE TO MAKE CHANGE

Analyse the types of responses under each domain.

Decide whether you are going to focus on areas of strength or weakness and how these align with your disability inclusion action plan, and other identified areas of need, resources, priorities and strategic planning.

You might decide at this point in time to work on the **key (high priority)** action under each domain or you might decide to begin by concentrating on just one area for action (for example mental health) and identify three actions to implement in that area.

The actions have been prioritised using colour intensity to assist with decision-making:

- | | |
|--|--------|
| 1. Key (high priority)  | dark |
| 2. Second level of importance | medium |
| 3. Third level of importance | light |

STEP 3

USING THE LISTED RESOURCES TO SUPPORT IMPLEMENTATION

Once you have decided where to focus your effort for change, whether it is to build on identified strength or weakness, the recommended supports and resources will be useful.

Some have been developed by the ID Health Network and others by our partners. Some are templates, pathways or tools and some are more general guidance. They are updated on a regular basis as new tools become available, and as the NDIS is rolled out across NSW.

In the process of building capability, you may develop your own tools, supports and resources or adapt those already available to meet local need.

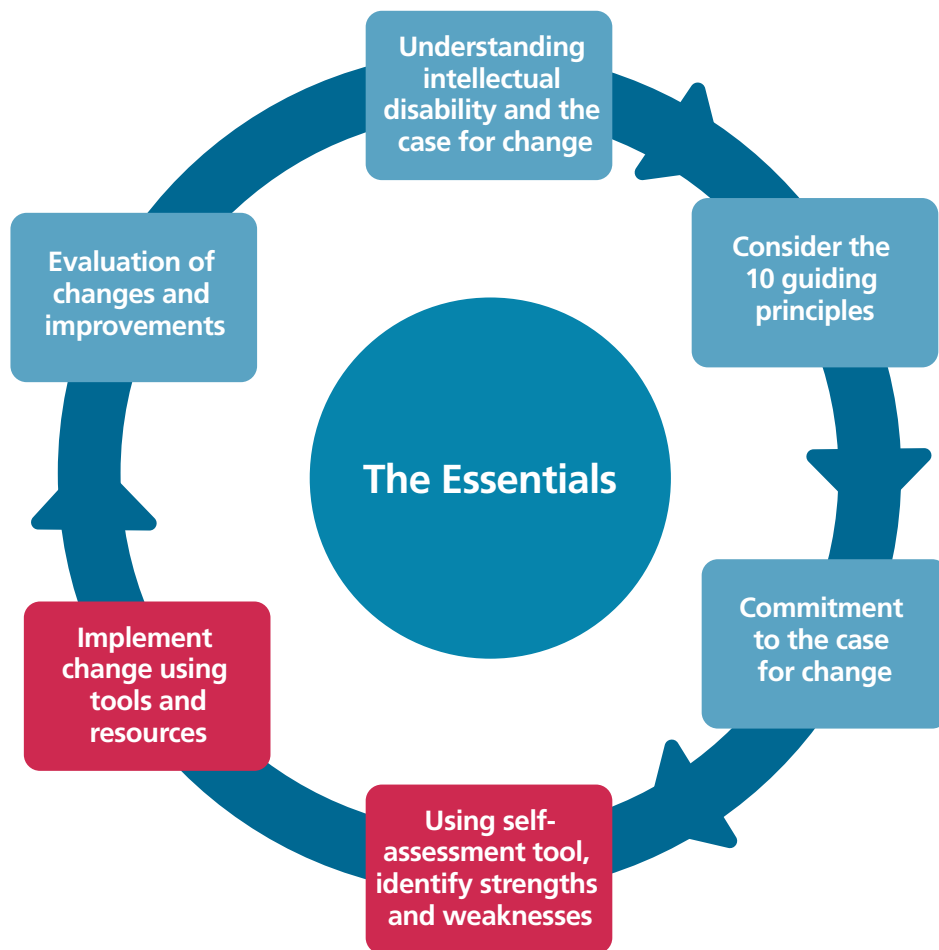



Figure 6. Where the self-assessment process fits in the overall work presented in the Essentials

6.2 Prioritised areas for action

This section shows the identified actions which build capability within health services for people with ID. In the self-assessment tool, the actions have been prioritised using colour intensity to assist with decision-making:

1. Key (high priority) 

2. Second level of importance

3. Third level of importance
- | |
|--------|
| dark |
| medium |
| light |

There are actions under enabling domains: workforce, communication, data and systems.

There are also actions under health service delivery domains: mental health, hospitalisation, integration within NSW Health, external to NSW Health and specialised services.

For instructions on where they fit into the self-assessment process read [Section 6.1 – The self-assessment process explained](#).

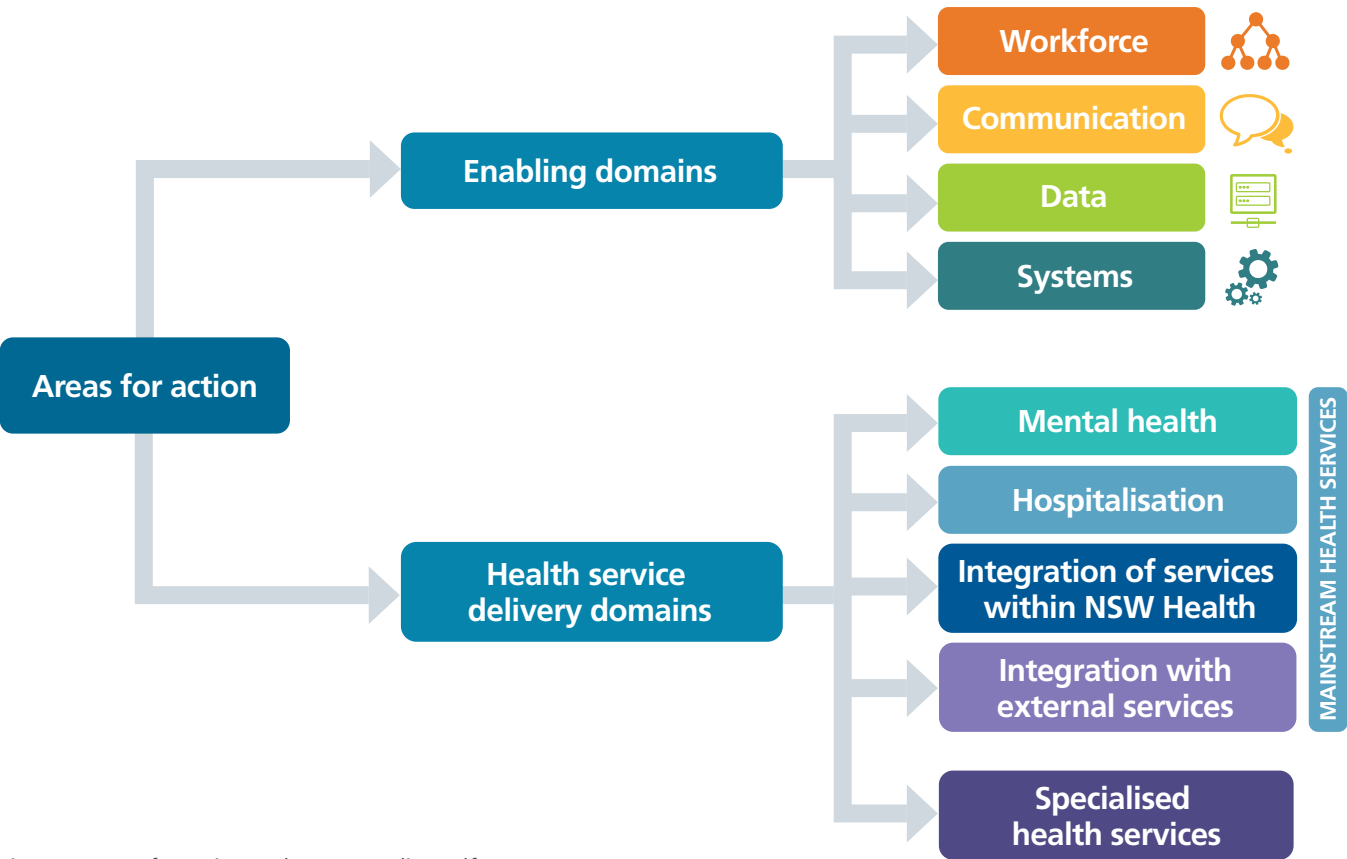


Figure 7. Areas for action and corresponding self-assessment

6.3 The self-assessment tool

6.3.1 Workforce

SELF-ASSESSMENT AGAINST WORKFORCE ACTIONS

Workforce actions are concerned with building the capacity of the health workforce to understand and respond to the health needs of people with intellectual disability. This includes the sharing of expertise and resources between specialist and mainstream services, including primary care. Such sharing is particularly important where multiple and complex conditions are involved.


This section seeks to understand the level of responsiveness and skills of your current workforce with respect to people with ID.

WORKFORCE		SELECT ONE	NEXT STEPS
 1	There is a local champion(s)/mentor(s)/key contact for improved healthcare for people with ID within the LHD	YES NO / UNSURE	Specific supports and resources here
 2	A senior staff member of the LHD has responsibility for leadership in coordinating disability issues	YES NO / UNSURE	Specific supports and resources here
3	Staff training is undertaken across sectors: LHD, primary care and non-government agencies, mainstream and specialist	YES NO / UNSURE	If no or unsure, please see additional reading and resources in Appendix 1 and Appendix 2
4	Joint consultations are undertaken with clinicians experienced in intellectual disability health	YES NO / UNSURE	
5	Student placements have been established with specialist teams for nursing and allied health	YES NO / UNSURE	
6	Commonwealth funded Specialist Training Program (STP) positions in ID in the LHD are supported and promoted	YES NO / UNSURE	
7	Health staff are supported to make reasonable adjustments as needed e.g. longer appointment times, minimisation of waiting times	YES NO / UNSURE	
8	Staff training includes patient stories and presentations by people with ID/carers	YES NO / UNSURE	
9	Staff are given opportunities to learn from staff experienced in providing support to people with ID	YES NO / UNSURE	
10	There is a Mental Health ID subspecialty team within the LHD	YES NO / UNSURE	
11	Psychologists and other allied health staff in the LHD are appropriately skilled to meet the needs of people with ID	YES NO / UNSURE	
12	Disability Awareness and Training is included in the LHD's orientation and education programs	YES NO / UNSURE	
		YES / 12	
		NO / UNSURE / 12	

6.3.2 Communication

SELF-ASSESSMENT AGAINST COMMUNICATION ACTIONS



These actions are concerned with ensuring that those involved in support of the person can facilitate the provision of the most appropriate supports to meet the individual's health care needs.

COMMUNICATION		SELECT ONE	NEXT STEPS
 1	All staff (including clerical and clinical staff) are provided with disability awareness training including a values and attitudes component	YES NO / UNSURE	Specific supports and resources here
2	There are LHD website links to carer support/ information – including fact sheets on being in hospital (Carers NSW)	YES NO / UNSURE	If no or unsure, please see additional reading and resources in Appendix 1 and Appendix 2
3	When a person with ID is supported by a “person responsible” for health-related issues/decisions, the latter person is identified and consulted	YES NO / UNSURE	
4	Easy English resources are available to staff e.g. Easy Read medical appointments letter, service feedback form	YES NO / UNSURE	
5	An individual's communication needs are identified prior to an interaction e.g. the involvement of a speech therapist, interpreter	YES NO / UNSURE	
6	There is accessible information for people with ID on how to provide feedback, compliments and complaints	YES NO / UNSURE	
7	Health professionals and people with ID have visual aids which can be used for a range of common procedures	YES NO / UNSURE	
8	The “teach back” method is used to confirm that people with ID and carers understand what has been explained to them	YES NO / UNSURE	
9	Feedback is collected from people with ID and their carer about quality of care received as part of LHD monitoring and evaluation process	YES NO / UNSURE	
10	People with ID are routinely included in any decision-making about them e.g. carer involvement, end-of-life planning, palliative care	YES NO / UNSURE	
11	Staff have learnt a range of commonly used signs and know about common communication aids	YES NO / UNSURE	
12	There is a Family Advisory Council e.g. modelled on Hunter New England LHD	YES NO / UNSURE	
		YES / 12	
		NO / UNSURE / 12	

6.3.3 Data

SELF-ASSESSMENT AGAINST DATA ACTIONS

These actions allow information to be shared, with consent, with all parts of the system as needed to deliver integrated care to people with ID. They also support research, evaluation and data collection to underpin evidence-based service improvements and identification of gaps in healthcare supports.

DATA	SELECT ONE	NEXT STEPS
 1 People with ID are identified in LHD records, including whether they are participants in the NDIS	YES NO / UNSURE	Specific supports and resources here
 2 Policies and procedures are reviewed for their impact on inclusiveness of people with ID	YES NO / UNSURE	Specific supports and resources here
3 An individual's healthcare plan is incorporated into their NDIS plan or individual disability support plan	YES NO / UNSURE	If no or unsure, please see additional reading and resources in Appendix 1 and Appendix 2
4 People with ID are encouraged to keep a copy of their healthcare plan as part of their MyHealth record	YES NO / UNSURE	
5 Carer information is captured in the electronic MyHealth record as needed	YES NO / UNSURE	
6 There is a LHD plan and monitoring of data to track LHD health outcomes for people with ID	YES NO / UNSURE	
7 Local initiatives/specific tools are supplied to ACI to include on the ACI website to benefit other LHDs and service providers	YES NO / UNSURE	
8 Local clinical data accurately reflects activity under the activity based funding model	YES NO / UNSURE	
9 Easy read material is available about sharing information/data	YES NO / UNSURE	
10 People with ID are routinely asked if they have an 'All about me' or 'Passport' profile or 'healthcare plan' which can be accessed by staff	YES NO / UNSURE	
11 Community initiatives that prevent unnecessary hospitalisation of people with ID are documented and reported against	YES NO / UNSURE	
YES / 11		
NO / UNSURE / 11		

6.3.4 System

SELF-ASSESSMENT AGAINST SYSTEM ACTIONS


These actions are concerned with system-wide elements which can support healthcare planning and implementation. Key principles include person-centred care, integrated care; access to care delivered close to the person's home, and maximising existing service networks and systems for the benefit of people with ID.

SYSTEM		SELECT ONE	NEXT STEPS
 1	People with ID and their carers are involved in healthcare planning and setting health goals in respect of their own healthcare	YES NO / UNSURE	Specific supports and resources here
2	Tools to capture the top five essential pieces of information about the individual and their support needs (sometimes called The Top 5 tool) are used routinely and incorporated into health data systems	YES NO / UNSURE	If no or unsure, please see additional reading and resources in Appendix 1 and Appendix 2
3	The LHD integrated care strategy includes provision for the health needs of people with ID, including those from a CALD background	YES NO / UNSURE	
4	Strategies have been put in place for transitioning from paediatric to adult services – e.g. Trapeze/Transition Network model for people with ID	YES NO / UNSURE	
5	Links have been developed between hospital, mental health, dental, Justice and Forensic Mental Health and community based services, including aged care services	YES NO / UNSURE	
6	Links have been developed between hospital, mental health, dental, Justice and Forensic Mental Health and community based services, including disability service providers (including for children in OOH)	YES NO / UNSURE	
7	Links have been developed between hospital, mental health, dental, Justice and Forensic Mental Health and community based services, including Aboriginal Medical Services for people with ID	YES NO / UNSURE	
8	There are links with the carer program in the LHD around ID	YES NO / UNSURE	
9	People with ID and their carers are included at each stage of health service development (i.e. co-design methodology)	YES NO / UNSURE	
10	Clinicians have training in communication and the principles/goals of patient-centred healthcare for people with ID	YES NO / UNSURE	
11	Education is available about supported decision-making strategies	YES NO / UNSURE	
		YES / 11	
		NO / UNSURE / 11	

6.3.5 Mental health

SELF-ASSESSMENT AGAINST MAINSTREAM HEALTH SERVICES – MENTAL HEALTH ACTIONS

Health supports for people with ID who also have mental illness are complex. This impacts both the services and supports required to directly manage the person's mental illness and extends to the management of their physical health issues. These actions address this complexity.


MENTAL HEALTH		SELECT ONE	NEXT STEPS
 1	There is a specific LHD strategy and plan for IDMH which includes the involvement of Justice Health and Ambulance Services	YES NO / UNSURE	Specific supports and resources here
2	Local capacity in IDMH has been mapped, encompassing the PHN, general practice, private specialist (psychiatrist or psychologist), hospital and specialised health services levels	YES NO / UNSURE	If no or unsure, please see additional reading and resources in Appendix 1 and Appendix 2
3	The LHD has easy read brochures and pathways on MH services in the LHD	YES NO / UNSURE	
4	MH services are clear about their current and future role in assessing and treating challenging behaviors in light of current disability reform	YES NO / UNSURE	
5	LHD staff are familiar with 'The Guide: Accessible Mental Health Services for People with an ID: a guide for providers'	YES NO / UNSURE	
6	The ACI ID Network's video 'ID and mental health' is available to staff	YES NO / UNSURE	
7	ED and ambulance services staff have been given training in IDMH to support people presenting to ED	YES NO / UNSURE	
8	There is an established IDMH interagency across all settings of care	YES NO / UNSURE	
9	Comprehensive training resources in IDMH e.g. core IDMH e-learning at HETI online, and expanded range of modules at IDMH e-learning are promoted to LHD staff generally	YES NO / UNSURE	
		YES / 9	
		NO / UNSURE / 9	

6.3.6 Hospitalisation

SELF-ASSESSMENT AGAINST MAINSTREAM HEALTH SERVICES – HOSPITALISATION ACTIONS

The NSW Health policy directive *Responding to Needs of People with Disability during Hospitalisation* includes guidelines on discharge planning, the role of carers, the use of local protocols between hospitals and disability service providers, patient consent and the use of various communication tools.


These actions address LHD responses to each of these issues.

HOSPITALISATION		SELECT ONE	NEXT STEPS
 1	The LHD has its own policies and procedures for the implementation of the hospitalisation policy directive	YES NO / UNSURE	Specific supports and resources here
2	Any individual with ID and complex needs who presents to hospital is given a comprehensive and holistic review	YES NO / UNSURE	If no or unsure, please see additional reading and resources in Appendix 1 and Appendix 2
3	Preadmission visits/clinics are offered to people with ID and their support network prior to a planned hospital stay	YES NO / UNSURE	
4	The joint guideline is used to support health and disability accommodation support services as they work with the person with ID before, during and after transfer of care from hospital	YES NO / UNSURE	
5	Tools to capture the top five essential pieces of information about the individual and their support needs (sometimes called The Top 5 tool) are used routinely and incorporated into health data systems	YES NO / UNSURE	
6	'Care by carer units' have been established	YES NO / UNSURE	
7	Discharge/transfer of care planning takes place for all people with ID who have been in hospital	YES NO / UNSURE	
8	The disability liaison role/champion for the LHD is routinely involved in oversight of episodes of acute care for people with ID	YES NO / UNSURE	
9	Upcoming investigations for people with ID are managed so each interaction can be used opportunistically e.g. general anaesthetic also used for dental care and blood tests	YES NO / UNSURE	
10	The hospitalisation co-design toolkit is used to optimise the patient journey from community to hospital care and return	YES NO / UNSURE	
		YES / 10	
		NO / UNSURE / 10	

6.3.7 Integration within NSW Health

SELF-ASSESSMENT AGAINST MAINSTREAM HEALTH SERVICES – INTEGRATION WITHIN NSW HEALTH ACTIONS


These actions address the extent to which connections have been built across the five tiers of the health system for people with ID as described in the *Service framework to improve the health care of people with intellectual disability*.

INTEGRATION WITHIN NSW HEALTH		SELECT ONE	NEXT STEPS
 1	People with ID who have chronic disease are supported to access chronic disease management programs, out-of-hospital programs and preventive health programs	YES NO / UNSURE	Specific supports and resources here
2	A designated health staff member in the LHD has specific responsibility for support coordination for people with ID and networking with similar roles in other LHDs	YES NO / UNSURE	If no or unsure, please see additional reading and resources in Appendix 1 and Appendix 2
3	Linkages have been made with Trapeze (adolescent chronic care service for Sydney Children's Hospital Network) and ACI transition coordinators to support transition readiness for people with ID from for paediatric to adult services	YES NO / UNSURE	
4	Partnerships with primary care providers and Aboriginal Medical Services in the LHD have been established to provide coordinated support to people with ID	YES NO / UNSURE	
		YES / 4	
		NO / UNSURE / 4	

6.3.8 Integration with external services

SELF-ASSESSMENT AGAINST MAINSTREAM HEALTH SERVICES – INTEGRATION WITH EXTERNAL SERVICES ACTIONS

An important health service principle speaks to the value of partnership with other government and non-government agencies in supporting the health outcomes of people with ID. Such partnerships can enhance access to care, establish pathways of care and follow-up and are addressed in these actions.

INTEGRATION WITH EXTERNAL SERVICES		SELECT ONE	NEXT STEPS
 1	Local service mapping and liaison has been undertaken in the LHD to identify all NGO disability services and ability linkers and NDIA outlets	YES NO / UNSURE	Specific supports and resources here
2	Partnerships have been established with PHNs to offer training and capacity building for GPs and practice nurses in understanding the health needs of people with ID	YES NO / UNSURE	If no or unsure, please see additional reading and resources in Appendix 1 and Appendix 2
3	There are local preventive health program messages specifically tailored for and targeted to people with ID which recognise cultural differences	YES NO / UNSURE	
4	Comprehensive health assessment e.g. through Australian Government Department of Health Medicare Health Assessments and tools such as the CHAP tool in primary care are offered to people with ID	YES NO / UNSURE	
5	The LHD plays a role in encouraging the establishment of a community hub model for people with ID and complex needs e.g. healthcare home/patient-centered medical home	YES NO / UNSURE	
6	There are local preventive health program messages specifically designed for Indigenous people who also have ID	YES NO / UNSURE	
7	Integrated care/support plans are routinely developed between NGO/primary care/acute health services	YES NO / UNSURE	
8	People with ID and complex health issues are enrolled in healthcare homes, where available	YES NO / UNSURE	
		YES / 8	
		NO / UNSURE / 8	

6.3.9 Specialised health services

SELF-ASSESSMENT AGAINST SPECIALISED HEALTH SERVICES ACTIONS

Specialised multidisciplinary ID health teams currently exist in different areas of NSW with different models of service delivery. They are a backbone strategy in provision of quality health services for people with an ID. They do this both through direct service provision and consultancy and education to mainstream health providers.

SPECIALISED HEALTH SERVICES		SELECT ONE	NEXT STEPS
 1	Linkages have been established between the LHD and specialised disability health teams. There is consultation regarding developing protocols about hospital admissions, discharges and ED admissions for people with ID	YES NO / UNSURE	Specific supports and resources here
2	Pathways to access consultative specialist skills and resources specifically addressing the complex health needs of the young person with ID transitioning to adult services are available to build the capacity of local health services	YES NO / UNSURE	If no or unsure, please see additional reading and resources in Appendix 1 and Appendix 2
3	There are opportunities for medical, nursing and allied health staff to gain experience in and exposure to people with ID	YES NO / UNSURE	
4	A specialised ID health or ID mental health service health team has reviewed the health needs of individuals with ID and complex needs and provided guidance to the LHD for ongoing management. Consultation is the preferred service model for the majority of clients, only those with highly complex needs have ongoing access to specialist teams	YES NO / UNSURE	
5	Mental health, aged care health, paediatric, drug and alcohol, general hospital and health promotion services are included in the development of specific LHD linkages with ID health teams	YES NO / UNSURE	
6	Pathways to access consultative specialist skills and resources specifically addressing the complex health needs of the refugee and CALD population with ID are available to build the capacity of local health services	YES NO / UNSURE	
7	Pathways to access consultative specialist skills and resources specifically addressing the complex health needs of rural and remote patients with ID are available	YES NO / UNSURE	
8	Pathways to access consultative specialist skills and resources specifically addressing the complex health needs of the older person with ID are available to build the capacity of local health services	YES NO / UNSURE	
9	There are relationships with primary healthcare providers to support them in looking after complex clients with ID	YES NO / UNSURE	

10	Pathways to access consultative specialist skills and resources specifically addressing the complex health needs of Aboriginal people with ID are available to build the capacity of local health services	YES NO / UNSURE	If no or unsure, please see additional reading and resources in Appendix 1 and Appendix 2
11	There is a cohort of nursing, allied health and other health personnel to provide some specialised capacity in the mainstream health service to support practice in ID during ED or inpatient stays	YES NO / UNSURE	
		YES / 11	
		NO / UNSURE / 11	

6.4 Supports and resources for all key (high priority) actions

WORKFORCE		SUPPORTS AND RESOURCES
1	There is a local champion(s)/mentor(s)/key contact for improved healthcare for people with ID within the LHD.	<p>Context report and toolkit for health services for people with intellectual disability, 2015 – Section 16 page 57 speaks about the role of the specialised nurse and illustrates this with a case study</p> <p>Daniel's story – A video in which a carer and medical professional speak about improving access through local champions</p> <p>Discharge case studies – A summary of findings including how a key contact was important</p> <p>Clinical developmental coordination – shows the importance of a key coordinator role</p> <p>Nurses' role in caring for people with a comorbidity of mental illness and ID: a literature review</p> <p>ACI ID training videos where health staff discuss their roles</p>
2	A senior staff member of the LHD has responsibility for leadership in coordinating disability issues.	<p>Fact sheets for NSW Health staff about the NDIS</p> <p>LHD Clinical Services Plan – an example</p> <p>LHD Disability Inclusion Action Plan – an example from a LHD</p> <p>NSW Health Disability Inclusion Action Plan (2016-2019)</p> <p>LHD NDIS Transition Manager – an example of a position description</p> <p>Responding to Needs of People with Disability during Hospitalisation</p>
COMMUNICATION		SUPPORTS AND RESOURCES
3	All staff (including clerical and clinical staff) are provided with disability awareness training including a values and attitudes component.	<p>Health Education and Training Institute (HETI) online training on disability</p> <p>UNSW ID Mental Health e-learning website</p> <p>ACI ID training videos where doctors, nurses and consumers discuss their own insights</p>
DATA		SUPPORTS AND RESOURCES
4	People with ID are identified in LHD records, including whether they are participants in the NDIS.	<p>NSW Health NDIS information sheets</p> <p>Position statement on the importance of a NSW intellectual disability data set</p>
5	Policies and procedures are reviewed for their impact on inclusiveness of people with ID.	<p>Checklist for including people with disability – Checklist for planning, developing, implementing and evaluating inclusive policies, programs, procedures and strategies</p> <p>Real people, real lives – Stories about people with ID accessing NSW health services</p> <p>Guidelines on research inclusive of people with intellectual disability</p> <p>Working with people with ID in healthcare settings – a fact sheet from the Centre for Developmental Disability Health Victoria</p> <p>Capacity toolkit from the NSW Attorney General's Department about a person's capacity to make their own decisions</p> <p>Rights and responsibilities information for people with ID – developed by Illawarra Shoalhaven LHD</p> <p>Making mental health policy inclusive of people with intellectual disability intellectual disability: A summary for service providers (UNSW)</p>

SYSTEM		SUPPORTS AND RESOURCES
6	People with ID and their carers are involved in health care planning and setting health goals in respect of their own health care.	<p>Improving the experience of hospitalisation for people with intellectual disability (Daniel's Story) – a video discussing what matters most from the viewpoint of a parent</p> <p>Accessing care for a patient with intellectual disability – a video in which Robert discusses what matters most to him as a person with ID</p> <p>Orientation to caring for a patient with intellectual disability – a video for health staff</p> <p>Patient experience and consumer engagement (PEACE) – Resources about using the co-design methodology in service design</p> <p>Compliments and complaints – an accessible resource developed by Illawarra Shoalhaven LHD</p> <p>Being a healthy woman – a resource for women with ID about reproductive and sexual health</p> <p>Easy read health appointment letter – an example of an adapted appointment letter</p> <p>Top 5 – Toolkit – a resource to assist LHDs meet the needs of people receiving health services</p>
MENTAL HEALTH		SUPPORTS AND RESOURCES
7	There is a specific LHD strategy and plan for MH/ID which includes the involvement of Justice Health and Ambulance Services.	<p>A model of care for adults with an intellectual disability (ID) and co-occurring mental disorders (UNSW)</p> <p>Intellectual disability mental health core competency framework: A manual for mental health professionals (UNSW)</p> <p>The guide: Accessible mental health services for people with an intellectual disability: A guide for providers (UNSW)</p> <p>Memorandum of understanding and guidelines between Ageing, Disability and Home Care, Department of Human Services NSW and NSW Health in the provision of services to people with an intellectual disability and a mental illness</p> <p>Provision of services to people with an intellectual disability & mental illness – MOU & guidelines</p>
HOSPITALISATION		SUPPORTS AND RESOURCES
8	The LHD has its own policies and procedures for the implementation of the hospitalisation policy directive.	<p>NSW Health & Ageing and Disability and Home Care (ADHC) joint guideline</p> <p>Responding to needs of people with disability during hospitalisation</p> <p>NSW Health disability inclusion action plan 2016-2019</p> <p>NSW ACI ID Health Network Hospitalisation toolkit</p> <p>The Admission2Discharge Together Folder for People with a Disability A2D</p>

INTEGRATION WITHIN NSW HEALTH		SUPPORTS AND RESOURCES
9	People with ID who have chronic disease are supported to access chronic disease management programs, out-of-hospital programs and preventative health programs.	<p>Say less show more visuals – Resources for training and using visuals in clinical encounters</p> <p>Medicare health assessments resource kit – Fact sheets and proformas</p> <p>Dying to talk – research on speaking with people with ID about end-of-life planning</p> <p>Positive cardiometabolic health for people with intellectual disabilities: An early intervention framework</p> <p>Feasibility of a group-based school exercise intervention for children with intellectual disabilities – Journal of Science and Medicine in Sport</p> <p>Easy read health fact sheets</p> <p>NSW Ombudsman Expert Forum - Rights Project for People with Disability resources</p> <p>Preventing deaths of people with disabilities in care – Information for staff of disability services – from the NSW Ombudsman</p>
INTEGRATION WITH EXTERNAL SERVICES		SUPPORTS AND RESOURCES
10	Local service mapping and liaison has been undertaken in the LHD to identify all NGO disability services and Ability Linkers and NDIA outlets.	<p>Mapping of specialised health services for people with ID in NSW (now available with password on request from LHD or Tracey.szanto@health.nsw.gov.au)</p> <p>Co-design toolkit – a resource to support designing health services in collaboration with service users and providers</p> <p>Schoolkit – a resource to support school clinics for children and young people with ID</p> <p>Guidelines on the pathways to care for children and adolescents with intellectual disability and challenging behaviour and/or mental health problems</p> <p>Primary health networks – contact details, resources and activities according to area</p> <p>NDIS legislation – information and assistance</p>
SPECIALISED SERVICES		SUPPORTS AND RESOURCES
11	Linkages have been established between the LHD and specialised disability health teams. There is consultation regarding developing protocols about hospital admissions, discharges and ED admissions for people with ID.	<p>Partnering with disability services to develop a disability action plan – a presentation by Illawarra Shoahaven LHD</p> <p>Assessing health needs of children with intellectual disabilities: A formative evaluation of a pilot service – from Research and Practice in Intellectual and Developmental Disabilities</p> <p>Diagnostic assessment services – a listing</p> <p>Admission to discharge co-design toolkit (SESLHD)</p> <p>Guidelines on sedation and/or analgesia for diagnostic and interventional medical, dental or surgical procedures – guidance for when the patient has ID</p> <p>Passport to Health – a resource for use in health service encounters for people with ID</p> <p>Evaluation report on the developmental psychiatry clinic – from the Centre for Developmental Studies</p>

Section 7

Appendices

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Appendix 1 – Summary of intellectual disability health network resources/toolkits

The *Context Report and Toolkit for Health Services for People with Intellectual Disability, 2015* referred to in this document can be found on the [Intellectual Disability Network report feedback page](#) of the ACI website.

RESEARCH	
Research survey analysis	What is and isn't happening in ID research in NSW, including comments on a minimum data set
ACI – Intellectual Disability Network Research and Development Sub-Committee discussion paper: Guidelines for research	Guidelines on research procedures in ID, including in the ACI context
WentWest child development care coordination project evaluation	A 12-month pilot project to build local capacity to identify children with developmental delay and support access to services
Guidelines on research inclusive of people with intellectual disability	Good research design reflects the diversity of potential participants and accommodates a variety of approaches
Position statement on the importance of a NSW intellectual disability data set – Draft	Based on results of the Network's research survey, recommendations of the need for a minimum data set are proposed
POLICY	
NSW Health policies with particular reference to intellectual disability - Draft	This document identifies and summarises NSW Health policies, guidelines and frameworks with particular reference to disability for LHDs
Including people with disability: checklist for planning, developing, implementing and evaluating inclusive policies, programs, procedures and strategies (Word doc)	Seven step checklist useful for mainstream and specialised organisations and service providers
Guiding principles in supporting people with ID in health service delivery	Ten underlying principles in short form , expanded form and Easy English (link TBA)
EDUCATION	
Improving the experience of hospitalisation for people with intellectual disability (Daniel's Story)	Improving the experience of hospitalisation – a mother and a medical specialist share their wisdom and experience
Disability awareness online training resource – Partnership with HETI	Let's talk disability and Cognitive disability and the criminal justice system – interactive modules produced in partnership with HETI
ID and hospitalisation – Intellectual Disability training videos (ACI)	Hearing about hospitalisation from Lif O'Connor (CNC), a carer and a person with ID
ID and mental health – Intellectual Disability training videos (ACI)	Dr Bruce Chenoweth (Developmental Psychiatrist)
ID and respiratory health – Intellectual Disability training videos (ACI)	Dr Andrew Ng (Respiratory and Sleep Physician)
PRIMARY HEALTH	
Intellectual disability training videos (ACI)	GPs speak about diagnosis of health concerns when their patient has an ID and the pathway to care from the GP and back again.
Report on primary health and ID (from Primary health forum) (Audio file)	Video recording of the ID Health Network's Forum where the challenges and opportunities around primary health are discussed.

ACCESSING HEALTH SERVICES	
Catalogue of supports for mainstream health services in NSW for people with ID	Sections 7 and 8 discuss the results of a statewide survey of NSW LHDs and their supports for people with ID in mainstream health services
Issues raised by clinicians during consultation on mapping of health services for people with intellectual disability in NSW (2014) – Draft	As clinicians across NSW LHDs were surveyed about specialised services and mainstream supports for people with ID in NSW, they shared their wisdom, insights and recommendations
Discharges from hospital – case studies of people with intellectual disability	Ways to avoid unplanned re-admission in order to improve the quality of life of the patient and the financial impacts on the health system are explored through case studies
Intellectual disability training videos (ACI)	Hearing from clinicians, primary health and people with ID about providing quality care
Hospitalisation Toolkit	This toolkit is currently under development. As resources and evaluations are available they are added here
Accessing NSW health services for people with intellectual disability	Some broad guidance for people on communicating and understanding how to get care and how to make sure they are satisfied with the care they get
Say less, show more – Visuals or health service visits and training	A series of simple photo stories (visuals) that illustrate what will happen during a physical, dental examination or blood test
Template for easy read appointment letter and easy read health service feedback form (Word doc)	Some templates for local adaptation by service providers
PATIENT / CARER	
Intellectual disability co-design hospitalisation project (MRID/ACI)	PowerPoint presentation which summarises the progress and outcomes of the co-design project
Accessing care for a patient with intellectual disability	Personal insights in video format about encounters with health services
Patient journeys	Summaries of in-depth interviews with mothers, fathers, siblings and people with ID about their journey through the NSW health system and some of the amazing professionals they encountered
Real people, real lives	Conversations with people with ID and their carers about their experiences of the NSW health system categorised by theme
SCHOOL-BASED	
Feasibility of a group-based school exercise intervention for children with intellectual disabilities (SCHN – Specialist Disability Health Team)	Evaluation of a group-based school exercise intervention for children with intellectual disabilities conducted in south west Sydney
MRID Schoolkit (MRID/ACI)	Tools to help set up and maintain school-based clinics to support children and adolescents with complex needs
Presentation on school-based clinics to support children and adolescents with complex needs	PowerPoint presentation on a model and toolkit of multiagency collaborative care for students with a disability

SPECIALISED SERVICES	
Activity based funding PowerPoints and summary 2014	PowerPoint presentation from the ABF Taskforce in NSW Health (2014) for the ID Health Network
ID Health Network ABF position statement	The particular features of specialised ID health services and their multidisciplinary approach to complex care of importance to ABF considerations LINK TBA
Mapping of NSW Specialised ID Health Services (2015) - password protected; seek LHD permission	A listing of specialised ID health services, across the life span in NSW according to LHD in 2015
Diagnostic assessment services	A listing of diagnostic and assessments centres in NSW and their contact details (from CHW website - 2011)
The importance of mainstream and specialised health services for people with ID	A short paper of interest to health services in NSW from the ID Health Network members about the important relationship between specialised ID health services and mainstream health services LINK TBA
CLINICAL PATHWAYS AND MODELS	
A model of care for adults with an intellectual disability (ID) and co-occurring mental disorders	A briefing paper for the ACI Intellectual Disability Network
Caring for people with gastrostomy tubes and devices	A clinician's guide for caring for people with gastrostomy tubes and devices from pre-insertion to ongoing care and removal
Key principles for transition of young people from paediatric to adult health care	Transition principles for health professionals working with young people as they underpin the practices required for successful transition.
Current models of health service delivery for people with intellectual disability – Literature review	Models of health service delivery for people with ID are examined.
Guidelines on the pathways to care for children and adolescents with intellectual disability and challenging behaviour and/or mental health problems	For children and adolescents with ID and challenging behaviour and/or mental health problems
Sedation guidelines for people with ID	LINK TBA

Appendix 2 – Linkages to other useful information

AGENCIES/ORGANISATIONS	
Agency for Clinical Innovation	The ACI works with clinicians, consumers and managers to design and promote better healthcare for NSW
NSW Health	NSW Government health website with links to health information and guidance
First Peoples Disability Network	FPDN is governed by Aboriginal and Torres Strait Islander people living with disability
NSW Council for Intellectual Disability	The NSW CID works with and for people with ID and has available useful health information sheets
NSW Ombudsman	The NSW Ombudsman supports people with disability, including in health-related matters
NSW Health Education and Training Institute	HETI aims to improve the health of NSW and the working lives of NSW Health staff through education and training
Department of Developmental Disability Neuropsychiatry, UNSW	3DN is part of the School of Psychiatry, UNSW Medicine and focuses on the health and mental health of people with ID
Intellectual Disability Behaviour Support Program – UNSW Faculty of Arts and Social Sciences	The program aims to increase knowledge and workforce capacity in the delivery of services to people with cognitive disabilities with complex support needs
Independent Hospital Pricing Authority	IHPA implements the national ABF for Australian public hospitals
LEGISLATION/POLICY	
United Nations Convention on the rights of persons with disabilities	The UNCRPD outlines the rights of people with disabilities – see Article 25 for health matters
Disability Inclusion Act 2014 – overview of the Act	A summary of the Act
The National Disability Insurance Scheme Act (2013)	A scheme to fund individualised support for eligible people with disability
National Disability Strategy (2010–2020)	The national approach to supporting people with disability to maximise their potential and participate Australian society
National Disability Insurance Scheme	The implementation of the Scheme
My Health Record system and Healthcare Identifiers	A digital health record for a patient containing a summary of their health information
NSW Health Disability Inclusion Action Plan 2016–2019	NSW Health system's plan for access to services and employment for people regardless of disability
NSW State health plan: Towards 2021	A strategic framework bringing together NSW Health's existing plans
Stronger together: A new direction for disability services in NSW 2006–2016	A 10-year plan involving major reforms and service expansions
NSW Carers (Recognition) Act 2010	The Act defines who a carer is and establishes the NSW Carers Charter
NDS NSW Implementation plan	The NSW plan to implement the NDS in NSW
Care coordination: Planning from admission to transfer of care in NSW public hospitals	Five steps in coordinating patient care to improve the patient experience and flow
Memorandum of understanding between ADHC & NSW Health in the provision of services to people with an intellectual disability and mental illness	The MOU outlines the principles for collaboration and the guidelines outline the procedures.

<u>NSW Health & Ageing and Disability and Home Care (ADHC) joint guideline</u>	Awareness raising about staff roles and responsibilities for people with disability before, during and after transfer of care from hospital
<u>Responding to needs of people with disability during hospitalisation</u>	A framework for the provision of care for people with disability during hospitalisation
<u>Children and young people's continuing care national framework</u> - UK	Guidance for clinical commissioning groups when assessing the needs of children and young people whose complex needs cannot be met by universal or specialist health services (UK)
<u>Challenging behaviour and learning disabilities overview</u> – NICE	Challenging behaviour and learning disabilities overview
TRAINING	
<u>The guide: Accessible mental health services for people with an intellectual disability: A guide for providers</u>	National framework for mental health service providers working with people with ID
<u>Intellectual disability mental health core competency framework: A manual for mental health professionals</u>	The skill set required by mental health professionals working with people with ID
<u>Into practice: Tips for doctors</u>	This General Medical Council (UK) website aims to help doctors provide better care for people with ID. A practical resource for developing the ID workforce from the UK.
<u>Meet Jessica Workshop Resources</u> – School-Link at the Children's Hospital, Westmead	NSW CHW resource promoting an awareness of the needs of children and adolescents with ID
<u>Intellectual disability: mental health e-learning</u> (UNSW 3DN)	Free e-learning about ID for professionals, carers and consumers
REPORTS/STANDARDS/Frameworks	
<u>Service framework to improve the health care of people with intellectual disability</u>	NSW Health framework describing a tiered model of care to reduce health inequalities for people with ID
<u>Cause of death and potentially avoidable deaths in Australian adults with intellectual disability using retrospective linked data</u>	A 2017 report by Julian Trollor, Preeyaporn Srasuebku, Han Xu, Sophie Howlett
<u>Evaluation report on the Developmental Psychiatry Clinic</u>	The Developmental Psychiatry Clinic is a partnership between the Children's Hospital Westmead and Statewide Behaviour Intervention Service (ADHC)
<u>Intellectual disability resources</u>	The Royal College of Psychiatrists produces a range of materials for mental health professionals and the public
<u>Health status and risk factors of Australians with disability 2007–08 and 2011–12</u>	Health-related factors affect the health status of Australians with disability
<u>Intellectual disability health content within medical curriculum: an audit of what our future doctors are taught</u>	Undergraduate opportunities as a way of building future workforce capability
<u>Improving healthcare provided to people with intellectual disability: The role of mainstream and specialist services</u>	Position statement by the NSW ACI ID Health Network
<u>Transition between inpatient hospital settings and community or care home settings for adults with social care needs</u>	Recommendations for health and social care practitioners in meeting the needs of people with ID
<u>Some steps up the mountain: Audit report on action from the National roundtable on the mental health of people with intellectual disability</u>	Audit report on action from the National Roundtable on the Mental Health of People with ID

<i>Report of reviewable deaths in 2012 and 2013 volume 2: Deaths of people with disability in residential care</i>	Recommendations from the NSW Ombudsman include the support for people in residential care to maximise their health outcomes.
<i>Creating Inclusive NSW hospitals</i>	Addressing the need for health services to meet the needs of people with disability
<i>Psychotropic drug prescribing for people with intellectual disability, mental health problems and/or behaviours that challenge: practice guidelines</i>	The Royal College of Psychiatrists proposes standards for improving clinical practice
<i>Use of emergency and inpatient hospital services by ADHC clients – Final report</i>	The hospitalisation trends and the changing health and support needs of ADHC clients
<i>WA Disability Health Framework 2015–2025: Improving the health care of people with disability</i>	To support health services when developing policy and designing services for better health outcomes for people with disability

SPECIFIC SPECIALISED ID HEALTH SERVICES IN NSW

For a full list see [Mapping of NSW Specialised ID Health Services](#) (2015) – Password Protected; seek LHD permission

Diagnostic assessment services	A list of diagnostic and assessment services currently available in NSW
The Developmental Psychiatry Clinic	A multidisciplinary clinic for young people with ID and emotional/behavioural problems
Disability Assessment and Rehabilitation Team for Young People (DARTYP) Concord	A specialist team working with people with multiple lifelong disabilities
Schoolkit	A multidisciplinary health service for people with ID, across the age ranges
Northern Sydney Intellectual Disability Health Team	NSIDHT is a multidisciplinary health service for school aged children, adolescents and adults diagnosed with ID and complex health needs
NSW Developmental Disability Health Unit	DDHU is a statewide health clinic for adolescents and adults with a developmental disability
Specialist Dental Centre	A service for children and adults in Western Sydney LHD
Child development services at The Children's Hospital at Westmead	A multidisciplinary health service for children and adolescents diagnosed with ID and complex health needs
Metro Regional Intellectual Disability (MRID) Kogarah	Based at St George Hospital a specialist service for people of all ages with intellectual disability
Allowah Presbyterian Children's Hospital	Supporting children with intellectual disability and medical needs
Sydney Dental Hospital	Special care dentistry for children and adults

ADDITIONAL RESOURCES/LINKS

The NSW Ministry of Health's Disability website	NSW Health information of interest to people with disability and staff; links to information and resources
The Admission2Discharge Together Folder for People with a Disability A2D	Created to facilitate timely transfer of relevant and current information to enable hospital staff to meet the needs of people with ID and thereby improve their hospital journeys and health outcomes
Support for carers in NSW	Carer Support Services have been established in all LHDs in NSW
End of life program – Clinical Excellence Commission	A program and resources about improving end-of-life communication and care
Key topics – The Cerebra Centre for Neurodevelopmental Disorders	General background information on rare genetic syndrome associated with ID
CHW School Link	Supporting the mental health of children and young people with ID

Comprehensive Health Assessment Tool (CHAP)	A useful questionnaire for a GP to use in consultation with a person with ID using prompts and guidelines relating to health issues
Comprehensive health assessments for adults with intellectual disability living in the community	Health benefits and medical costs
Conversations with parents at the time of diagnosis	A resource for early intervention staff
Easy Read health information	Useful for many different health conditions
Disability – Family Planning NSW	Resources to promote and protect the reproductive and sexual health and rights of people with disability
Rights and responsibilities – Illawarra Shoalhaven LHD	Information and videos in accessible format
Yarning about disability - ISSUU	Caris Jalla's book exploring Indigenous perspectives on disability
National Health & Medical Research Council Partnerships for better health project, improving mental health outcomes for people with an intellectual disability	Focused on improve access to, and quality of mental health services for people with ID, including using data linkage
Multimorbidity: clinical assessment and management – NICE guideline	Improving care and quality of life for adults with multiple long-term conditions by reducing treatment burden and by promoting shared decision-making
Learning disabilities: challenging behaviour, quality standard – NICE	This covers the care of children, young people and adults with ID and challenging behaviour
Health fact sheets – CID	Easy Read information on health concerns and interactions for people with ID
Appoint an enduring guardian	Advice on health and lifestyle decisions for people with reduced capacity
NSW Ombudsman expert forum – rights project for people with disability resources	A list of resources focused on people with complex needs and marginalised groups
Attorney frequently asked questions	The most common questions relating to making a Power of Attorney from the NSW Trustee and Guardian
Oral care for people with disability – a resource for disability support workers	For carers and disability support staff to provide oral healthcare for people with disability
Partnering with Patients program	A model about the relationships clinicians build with patients, family and carers as partners in healthcare delivery
Psychotropic medication	A list of useful resources in accessible format about psychotropic medications
Rural carers of people with disabilities: making choices to move or to stay	Understanding the decision – making process for carers of children with disability about location
End-of-life for people with intellectual disability	Presentation slides on the end-of-life for people with ID Forum
The teach-back method	A communication method for staff and others to use to ensure the patient understands what they need to know
The Transition Care Network – ACI	Supporting the transition from paediatric to adult health services for young people with chronic health problems and disabilities
Transition for children with intellectual disabilities	A UK website about ID and health
Trapeze: a supported leap into adult health	For health services and young people in NSW who are transitioning into adult health services – a service and resources
Making reasonable adjustments to epilepsy services for people with learning disabilities	Accessible information for service providers and resources on health conditions (UK)

Appendix 3 – 10 principles of quality health services for people with intellectual disability (expanded version)

The 10 principles underpin the delivery of quality health services for people with ID. They provide guidance around both what to do and how to do it. Easy read version [available here](#).

This section expands each of the principles. The principles are based on the UNCRPD and developed through consultation with the Network's membership, input of the expert reference group, extensive consultation within health and partner organisations/agencies, consumers and carers.

1

People with ID have the same access to quality and range of health services as other people

Access to quality healthcare is a fundamental human right.

This was recognised in the UN Convention on the Rights of People with Disability. The Convention was adopted by the United Nations General Assembly on 13 December 2006. Australia then ratified the Convention on 17 July 2008 and it entered force in Australia on 16 August 2008.

Under Article 25 of the Convention:

Persons with disabilities have the right to the highest attainable standard of health without discrimination on the basis of disability. They are to receive the same range, quality and standard of free or affordable health services as provided other persons, receive those health services needed because of their disabilities, and not to be discriminated against in the provision of health insurance (Article 25).

NSW Health recognises healthcare as a fundamental right. This is expressed in the NSW Health (2011) *Your healthcare rights and responsibilities – A guide for NSW Health staff (PD2011_022)*, page 1.

Access to healthcare 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.

2

Health services recognise the poorer health outcomes for people with ID

Socioeconomic determinants (such as lack of suitable housing, low income unemployment) impact negatively on health outcomes. People with ID experience these at higher rates than the general population.

In addition to the presence of more complex and chronic conditions which are often associated with the particular disability experienced by an individual, people with ID may not understand when they have a health problem or how to get help. Difficulty in communicating can compound challenges experienced by people with ID when accessing health services.

3

Health services provide early diagnosis and intervention to enable optimal outcomes

Many chronic diseases and conditions benefit from early diagnosis and intervention. Early intervention allows preventive care strategies to be put in place which may minimise later impacts.

Many behaviours and mental health problems seen in adults with ID have their origin in childhood and left unmanaged are more difficult to treat in adulthood.¹⁹

4

Health services support the cultural and social inclusion of people with ID and their carer

This principle recognises the need for cultural sensitivity in the provision of health supports to people with ID and their intrinsic rights to social inclusion and community participation. This is consistent with the [NDS](#) and the [NSW Disability Inclusion Act](#).

¹⁹ The Royal College of Psychiatrists. Community-based services for people with intellectual disability and mental health problems. London: The Royal College of Psychiatrists; 2015.

5**Health services are delivered in a person and family centred way**

This includes support with communication and decision-making which can assist the person to access health services and treatment. It also includes carer involvement in service delivery where this is the wish of the person with ID. Person-centred service provision in the context of family and carers, enables the delivery of supports which are flexible and responsive to individual need and circumstances.

6**Health services for people with ID are co-designed and integrated across primary, mainstream and specialised care**

Smooth transition between health services allow for integrated care to be provided to individuals. This avoids the need to retell the story and repeat health histories, avoids disruption to health support and enables efficient transition between services, including between child and adult health services.

Integrated care also supports the capacity of the system to deliver health services as close to home as possible. This can enhance timely access, reduce difficulties associated with transport and enhance follow-up and the involvement of the person's support network.

7**Health services are delivered by appropriately trained staff**

Health workers may require training and support to engage and communicate effectively with people with ID. Meeting specific health needs of people with ID may require additional training. Capacity building may be achieved by consultancy support from specialised health services staff and training programs.

8**Specialised health services and the integration of their expertise within mainstream services can improve health outcomes for people with ID**

Specialised ID health services provide essential expertise in understanding, managing, coordinating and supporting the health needs of people with ID especially where complex and chronic conditions are involved.

They provide expert consultation in the care of individual patients as well as build the overall capacity of mainstream health services to support the health conditions of people with ID.

9**Collaboration between government and non-government agencies (e.g. schools, supported accommodation services) supports the health outcomes of a person with ID**

Health services working collaboratively where a person with ID is receiving disability and/or education services, can make it easier for the person to:

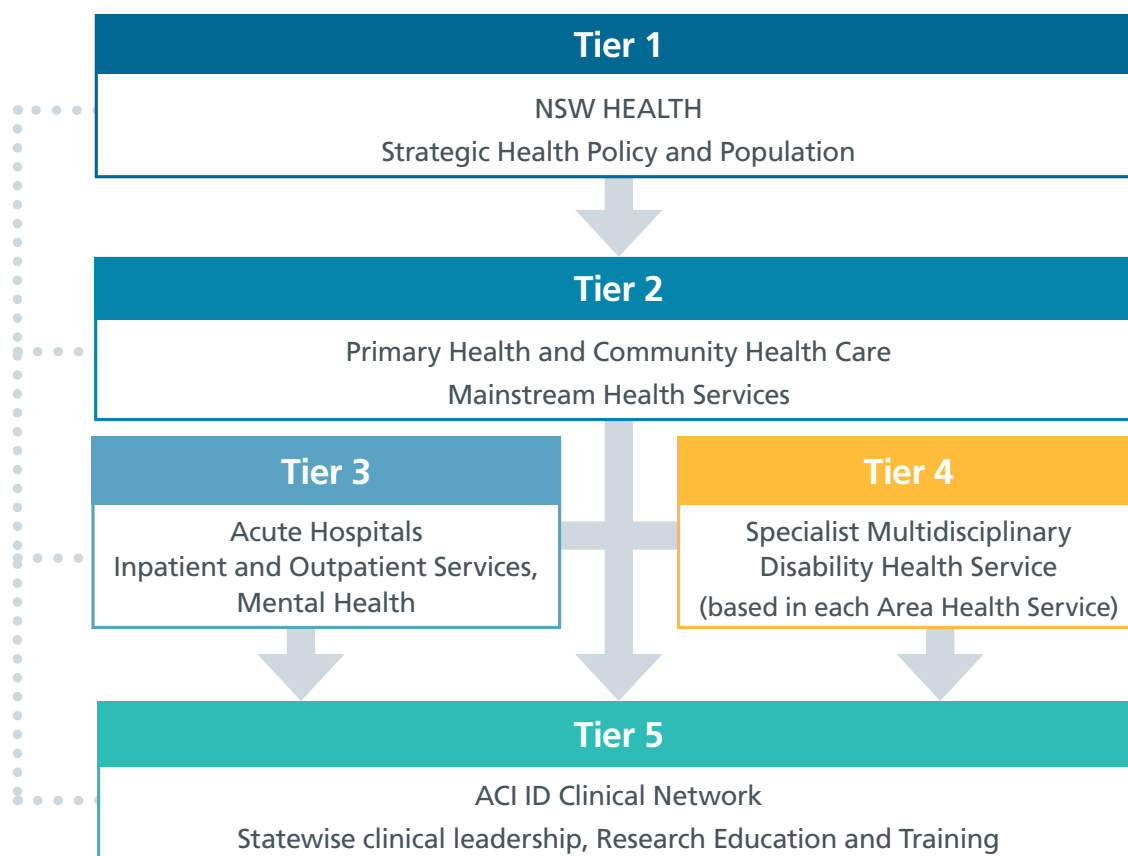
- access health services, including early detection and treatment
- establish pathways of care; undertake follow-up
- achieve positive outcomes in terms of their social participation and/or education.

10**Data is required to inform ongoing health service development, policy and models of care**

Quality research, evaluation and data will inform the development of healthcare services for people with ID. NSW Health patient databases require the capacity to identify and monitor services delivered to people with ID. The patient controlled digital MyHealth Record provides a controlled means of appropriately sharing personal information and supporting seamless integration of healthcare support across primary, secondary and specialised care. This requires that appropriate consent mechanisms are in place.

Appendix 4 – NSW Health service framework for people with an intellectual disability, 2012²⁰

Service framework to improve the health care of people with intellectual disability (July 2012)



The [Intellectual Disability Health Network](#) at ACI was set up under Tier 5, and plays an important role in bringing together best practice and evidence to support outcomes for PWID.

²⁰ Please note that in 2012, the then structure was Area Health Services (not Local Health Districts) and the Network was referred to as a clinical network rather than health network.