From August 2013 to February 2014 the ACI Intellectual Disability (ID) Health Network mapped health services for people with intellectual disability in NSW. To do so they consulted the key nominated contact for each Local Health District (LHD) in NSW. The consultations involved more than 80 people across the 19 LHDs. As part of the consultation process, clinicians and managers suggested way to improve the health system for people with intellectual disability.

Comments have similar themes to those made by consumers and carers in interviews with them about their health journey.

Clinicians gave the following responses to the question:

*Do you have any suggestions for improving services for people with Intellectual Disability, their families and carers' unmet needs?*

Those consulted expressed a keen interest in knowing more about how to work with people with intellectual disability and their carers to improve their health outcomes, reduce hospitalisation and to make reasonable adjustments to their services in order to improve the services they offer.
The Agency for Clinical Innovation (ACI) works with clinicians, consumers and managers to design and promote better healthcare for NSW. It does this by:

- **Service redesign and evaluation** – applying redesign methodology to assist healthcare providers and consumers to review and improve the quality, effectiveness and efficiency of services.
- **Specialist advice on healthcare innovation** – advising on the development, evaluation and adoption of healthcare innovations from optimal use through to disinvestment.
- **Initiatives including Guidelines and Models of Care** – developing a range of evidence-based healthcare improvement initiatives to benefit the NSW health system.
- **Implementation support** – working with ACI Networks, consumers and healthcare providers to assist delivery of healthcare innovations into practice across metropolitan and rural NSW.
- **Knowledge sharing** – partnering with healthcare providers to support collaboration, learning capability and knowledge sharing on healthcare innovation and improvement.
- **Continuous capability building** – working with healthcare providers to build capability in redesign, project management and change management through the Centre for Healthcare Redesign.

ACI Clinical Networks, Taskforces and Institutes provide a unique forum for people to collaborate across clinical specialties and regional and service boundaries to develop successful healthcare innovations. A priority for the ACI is identifying unwarranted variation in clinical practice and working in partnership with healthcare providers to develop mechanisms to improve clinical practice and patient care.

Dental assessment and treatment is difficult in a hospital setting for people with anxiety. If a dental assessment can be combined with other procedures requiring sedation this benefits the patient. Dental education, also often works this way i.e. combined with other education on ID.

Better communication between health professionals and patients and their families / carers is important for any health care model to work. The health system needs to respond to patient feedback and so people with intellectual disability should have the opportunity to give feedback in ways they can understand.

Patients who understand the system or who have strong advocacy skills fare better in accessing services. This suggests a need for better transparency of the system as people with ID can be disadvantaged in this.

Access to mental health services is important for many people with ID. A collaborative approach that includes mental health clinicians relies on the awareness of health staff. Interagency pathways would support patient care in this area. Good community supports for people with ID and mental health concerns are a factor in preventing inappropriate hospitalisation, but not all community health programs are available for people with ID.

E-Health records, on-line resources, web–based information and further use of videos were all suggested as ways to improve service delivery for people with an intellectual disability.
Although regional and rural areas have fewer specialised services, most clinicians have well developed generalist skills which serve their communities well. They appreciated being able to access specialists in a consultative capacity when needed. Rural and regional clinicians felt there was a need for increased consultation with them on health issues and central policy development.

Training for rural health staff was often identified as difficult to access and expensive. Service inconsistencies and gaps exist between regional, rural and metropolitan areas and there is a need for incentives to attract service providers, allied health and other clinical staff to regional and rural areas.

Regional and remote areas have fewer specialist services for people with ID. Clinicians with generalist skills sometimes rely on consultation with specialist services in metropolitan local health districts, or with a “fly-in” service.

Some local health districts do not have access to behavioural supports

Respondents raised concern over the applicability of Activity Based Funding to community based services. Some families rely on Private Health Insurance to make up for service gaps. Multidisciplinary clinics, which are generally the preferred model of care, are often not possible in regional and remote areas due to service gaps.

Any tool for working with Aboriginal people with ID needs to be culturally sensitive.

The guidelines for working with the Aboriginal peoples and communities could also be modelled for working with the culturally and linguistically diverse communities.¹

When a child has relied on a paediatrician and specialist services for their health care, it may be difficult to engage with a general practitioner (GP) as they leave paediatric services and enter the adult health system. A reactive response to health issues can then develop in adulthood when there is no GP involvement. This can lead to unplanned presentations to hospital.

Community Paediatrics was valued but seen as difficult to access.

The health system was generally seen as confusing and fragmented, with different eligibility criteria and multiple layers.

Many Clinicians mentioned the need for a key contact to assist people with an intellectual disability and their families and carers to navigate the pathway through the health system.

There is an identified need for early intervention support services which offer more than assessment or one off interventions.

Access to case management in the early diagnosis period was highlighted as important for families.

Transition to school services and school support are areas of need.

Transitioning out of school and paediatric health services is a period of vulnerability for people with ID. Often extra support and services during this stage of development, including for challenging behaviours, is needed. There is confusion around guardianship and consent protocols for this age range in particular.

It is difficult to develop a model of care for some people with chronic and complex health concerns, like people with ID. Their supports cross disciplines and require input from a variety of agencies, carers and clinicians.

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## Coordinated health care across professionals and agencies

For effective integrated care there needs to be:

- accessibility to the required services
- collaboration between the services
- multidisciplinary clinics
- case management.
Preventative and population health and policy

A health pathway focusing on preventative health for PWID would avoid unnecessary hospitalisation and improve health outcomes.

Activities and processes driven by policy and monitored for effectiveness are the best model for health service delivery.

Primary health

Primary Health relies on service maps and Clinical Pathways for patient assessments and referrals. History taking relies on a well-informed carer to be present. Unplanned presentations to the ED increase when people with an intellectual disability are less able to access quality primary care.

Acute care services

The Emergency Department (ED) can become the default service accessed by a patient with intellectual disability, when they have no GP and no health plan. Admission to a hospital for a patient with ID involves complex planning and handover, continuing throughout the patient journey through to discharge into the community. To prevent unnecessary admissions requires group home support staff who recognise early warning signs of deteriorating health, or a good GP relationship. A key contact in the health system is a possible solution that could assist with streamlining ED assessment for possible admission. The PWID is likely to be well known to a key contact. A PWID who is non-verbal or has a support worker who is unfamiliar with their health history can result in admission and discharge being more complicated. Discharge is often delayed by lack of access to quality of care in the community, compounded by a lack of case co-ordination.

Clinicians are keen to learn more about avoiding unnecessary hospitalisation and pathways and processes into, through and out of acute care. This will be especially important as a variety of NGOs will be partners in the process over time.
Specialist services

Specialised services are valued by clinicians for their oversight and consultation services. They assist with GP engagement and offer a parent / child centred model. They offer a model of integrated care which includes the school and NGOs.

Specialised services available for PWID at a local level are often clinician driven, which means they are not funded or secure, and often rely on word of mouth for referral.

Workforce, education and research

There was strong consensus that general awareness training and development of communication skills is needed for all health employees working with people with ID. That training needs to be evaluated at local health district level.

Clinical staff thought web based training would assist regional and rural staff with training access.

A clinical competency document for health and other agency staff would be useful to identify skills needed when working with PWID and their families / carers. Particular gaps in knowledge included:

- how to effectively work with carers in the health system
- better understanding of guardianship and consent issues.

Models of care need to be evidenced based.

The universities offer good post graduate courses in disability studies, but further disability integration at undergraduate level is needed.

The ID Network is a link to broader developments and fosters opportunities to influence change.