The Access and Equity subcommittee of the Intellectual Disability (ID) Health Network spoke to people with ID and their families and carers on how the NSW health system works for them.

It started with one conversation, and grew from there. A number of consumers and carers involved with the ID Health Network and their associated groups volunteered to tell their stories. For the most part these were the mothers of children or adults who had intellectual disability and complex health issues, including mental health. As a group they cover a variety of situations, conditions and locations. Their experiences have much in common with each other and with the broader population of people with intellectual disability.

Most families began their story back at diagnosis, despite the passing of many years, highlighting the importance of those early conversations around diagnosis, support and guidance.

Most spoke of the importance of communication and empathy in encounters with health professionals. They spoke of the need for system and process changes. Many of the issues raised are not specific to people with intellectual disability, but they take a greater toll on the health outcomes for people with intellectual disability and the family / carer who interact more frequently with health services, and for whom communication is already a difficulty due to the nature of their disability.

Participants said they value partnership and respect when interacting with the health system. There are some exceptional health staff, who have helped them in many ways. They wanted health services to be different for them and for others.

A full copy of the document, Patient Journeys, with background information, can be found on the ACI website.
1. Be seamless person centred / family centred health care

“What our issue is at any time may be really different to the main issue for professionals. No one asks us what our worries are.”

Kassie and Belinda

“Some people have a view of what is the 'best option' for us as a family and for Thomas. It makes me feel more confident and relaxed if the health professional acknowledges Thomas in some way as a person, know his name and talks to him … recognises him as a person and be enquiring about how he manages things. He is a loved person.”

May and Thomas

“Dealing with all this has a big impact on families. Keeping up the mental energy, keeping on top of it is hard. Life is busy and there is always a lot to attend to. You (parents of a person with a disability) are always the odd person out- you are never one of the crowd and that is an important issue.”

Kassie and Belinda

2. Deliver coordinated health care across professionals and agencies

“We really need to have someone to be an 'umbrella' for all these services. There needs to be one main doctor who arranges for everyone involved to speak together once a year. To sit around a table together and to review what progress has been made, what issues there are and what we now need to do. I insist on a yearly review. I think 90% of families initiate these reviews because they act as the case manager /coordinator as no one else is willing to do it.

The introduction of a health summary card for people with complex needs would make an enormous difference for all of our lives.”

Milka and Jess

“The condition Daniel has was only diagnosed 2 years ago…There are six or seven specialists involved: a neurologist, a paediatrician, a geneticist, metabolic team, psychiatrist as well as education services and disability workers. Appointments to review Daniel are set up by each of them separately.”

Veronica and Daniel

“I don’t know what we would have done without our advocate’s help. She was able to go to a higher level in the services and make it clear we needed help from people who were competent and understood. She has been an advocate for us so we can advocate for our son. Only the psychiatrist understood the demands on us having to come to meetings and get scripts filled etc.”

Veronica and Daniel
3. Make use of information technology such as person controlled electronic health records and ehealth

“Each time Geoff goes to hospital it is treated as if it is the first time he has been there. They do not look up his records and see what has happened before. They don’t have any ‘flag’ on his file to say this is what needs to be done if he presents I don’t even think he needs to go for seizures. Why can’t they share information with each other (he goes to 1 of the 3 local hospitals and has numerous presentations and admissions in each)?”

Josie and Geoff

“I’d take my file and my child’s file with me. She had lots of specialists. Saying your story over and over feels like being put on the spot and it can make me feel angry sometimes.”

Richard

“One time in Intensive Care we had to tell the whole story from start to finish five times!”

Veronica and Daniel
4. Deliver coordinated health care across professionals and agencies

“It has taken years to get him to sit in the dentist chair.

The dentist we go to is three hours’ drive away. I drive there because they have a TV screen above the (dentist) chair so the child can watch a movie. I take R to the dentist three times a year not because he needs to go this frequently for his teeth but so that he gets used to going to the dentist. She (dentist) is very supportive of that – she knows and understands him. For instance she knows he likes black so she got some black balloons for him.”

Ivita and Reece

“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.”

Ivita and Reece

“I had to say many times ‘explain it so my wife can understand’.

They don’t know how to modify anything unless you tell them how to do it. They don’t know what Easy Read is! When I show them how to do it (easy read and pictorial materials) they usually get a bit surprised.

When my daughter was younger I had to look after her needs. We had to do everything right so she wouldn’t get sick. I was taught by the staff at the hospital- they said ‘you do this and then that’. I had to make them show me. Then I know what they are talking about.

We had a case conference. It was ok for me but my wife found it very upsetting, partly because they spoke in big words.”

Richard

“I did up a chat book a couple of years ago for visits to the GP. We took photos of the surgery, the receptionist the waiting room the doctor all of the people and things he will encounter. Even to get into the doctors surgery I have to do a number of rehearsals with him before we go – making sure he knows who will be there, who is going to touch him and so on. The receptionist and the paediatrician at the country Hospital are great with him.”

Ivita and Reece

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

Josie and Geoff

Intellectual Disability Network Real people, real lives
5. Recognise the important role of the carer and the challenges for the carer in supporting a person in the health system

“You are asking me, I'm the parent and I'm at home with him and you are not listening to me.”

Veronica and Daniel

“GP’s … he knows me, he listens to me, he gets it, and he listens to the grandmother. If I go with a nanny he speaks to them - he shows respect and listens to everyone. And he is accessible.”

Magda and Susie

“I'm in my 60s. The round of medical appointments wears me out. The medical stuff has grown bigger.”

Diane and Ricky

“We are mothers who have read text books and are on the internet and have spoken with specialists, and other staff of the syndrome association and we are collaborating with other families to solve problems. We read academic articles that maybe watered down sometimes - we belong to the syndrome Association and have access to journals, workshops, overseas experts and specialists who come to this country. So we are fairly well informed.”

Lisa and Mitch

“When Belinda was tiny and had her first heart operation the surgeon came out at the end of the operation and gave us feedback on how the operation went, and he said you need to see a success story: he had organised for twins who had Down’s syndrome and had had the same operation as our daughter, a year before. That was really good.”

I would have loved a bit of support from other parents - it’s such a gap, so isolating, exhausting and distressing (being in hospital with your child) - you need some understanding support from your peers. Maybe they (staff) could get people together for a quick cup of tea or suggest we all meet in the tea room.”

Kassie and Belinda
6. Ensure that people from regional NSW can access health services

“We were able to access a special weight management program that went for 12 months. In that year he lost 42 kg. His whole life turned around. We all lost weight.”

Lisa and Mitch

“Recently we were faced with making a major decision about whether to have surgery. The GP did not encourage this so we needed another more specialised opinion. We organised a visit to specialist disability clinic. The cost involved flights to Sydney, accommodation for both of us in a hotel plus taxis to the clinic and back. This amounted to almost $1000.”

Lisa and Mitch

7. Connect professionals across primary, hospital, specialist and community health care

“Oh the day her period began that was the beginning of the end! She was distressed and very disturbed.

I got onto a mother whose daughter is a bit older than mine who I thought may have been able to give me some advice. She hadn’t had to deal with puberty as yet but had found out about a specialist doctor, an adolescent gynaecologist with lots of experience with girls with special needs. I rang her and got a cancellation so now we are on the right track.

My point is why the GP doesn’t know about this doctor.”

Magda and Susie

“The wound was infected and they had told us to go to Emergency yet they had not apparently done any coordination with the Emergency Dept.

We found that no one had made the booking. The staff had not liaised with the sleep clinic and made arrangements for the transfer.”

Kassie and Belinda
8. See the value of specialist intellectual disability health services

“Only this year we have been to a specialist disability clinic. They have been terrific. They have looked at every aspect of her care. They have given advice about where to go for other assistance, about Belinda and about her care, telling us what we may need to do, what we could be doing now, who she should be seeing. They seem to be looking at her as a whole person rather than a specific medical issue, a person who is a member of a family and the practical implications for all the family.”

Kassie and Belinda

“If you had an adult doing the things she was doing they would be committed to a psychiatric unit and have the medication monitored by nurses. Instead of that she is at home and we are monitoring her for the bad effects of the drugs. There needs to be a specialist place to admit kids (with intellectual disability and mental health illness) in this State. When you tell people this story they are incredulous. Their first question is why she isn’t in hospital. The general population is flabbergasted that we do not have basic services for children.”

Magda and Susie

9. Communicate better

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

To stay in the country Hospital I had to go to a pre op meeting. They had a care plan thing where you could write down the 5 important things for the staff to know about the person. So I wrote about his nervousness and don’t like things happening without knowing about it. They have brought it in for children, people with disabilities and mental health problems.”

Vita and Reece

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

Magda and Susie

“Belinda is now 16- I’m worried that there are not many people with skills and interest to move onto. This is the first time I have heard about a Transition person at the Hospital.”

Kassie and Belinda
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.