“It has been a privilege for me to have been able to listen to the journey stories that form the basis of this project. I have been humbled by the courage and resilience of the people I spoke to. I hope that this project will assist in some way to improve access to good health services. Thank you for sharing your journey with me.”

Mary Ellen Burke (Interviewer)
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.

Acknowledgements

The Intellectual Disability Health Network Access and Equity subcommittee members involved in designing and compiling this report are:

Barbara Lewis; Jacqueline Small; Linda Wiggins; Tracey Szanto; Wayne Boyle; Bernadette Dagg; Linda Elliott; Jenny Martin; Dawn Nina; Eugene McGarrell; Allison White; Julie Wright.

Foreword

The Intellectual Disability (ID) Health Network, under the NSW Agency for Clinical Innovation (ACI), was established in 2011 to work with consumers, carers and clinicians to improve the health of people with intellectual disability in NSW.

This work grew from a single conversation.

One of the regional members of the Access and Equity subcommittee of the network engaged the sub-committee members with her journey in accessing health services for her adult child.

From there, a number of consumers and carers involved with the ID Health Network and their associated groups volunteered to tell their stories. The Access and Equity sub-committee had captured the stories.

As a group they cover a variety of situations, conditions and locations. Their experiences have much in common with each other and with the much broader population of people with intellectual disability.

This material forms the basis of ongoing work of the Network to improve patient experiences and health outcomes for people with intellectual disability.

In particular, this material is currently being used by the ID Health Network in the development of:

- Health Services for People with Intellectual Disability: Context Report and Toolkit – 2015
- Blueprint for the Delivery of NSW Health Services for People with Intellectual Disability.
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1. Introduction

The people interviewed

The people who shared their experiences included mothers, fathers, siblings and people with intellectual disability, some of whom also had physical disability. Three of the participants lived in rural areas and at least one was from a culturally and linguistically diverse background (CALD). There was a range of ages, and a mixture of male and female volunteers.

The people interviewed for this Project were asked to reflect on their personal journey of interactions with the health services. Interviews were conducted in NSW from June to December 2013. Under the guidance of the ID Health Network Executive, the Access and Equity subcommittee sought to identify:

1. things that facilitated access to health services for people with intellectual disability and their family / carer.
2. barriers or obstacles to obtaining health services for people with intellectual disability and their family / carer.

The experiences of people, and the common themes that arise in those experiences, will help to inform further work of the Network. This work will influence policy and delivery of health services for people with intellectual disability in NSW.

The common themes and experiences

Each journey is unique, however a number of themes and common experiences have emerged. Particular practices and roles assisting access have been identified.

The themes are summarised in this document.

People with Intellectual Disability and their carers describe the following overarching positive themes: that improved their access to health services:

1. an individual who can step outside their role and respond personally
2. a system that functions to “make it work for us” (for example, organising appointments on the same day for all specialists)
3. accessible primary health
4. respectful treatment
5. an attitude of people with an intellectual disability and health providers being “partners in care”.

A common phrase used to describe health services by participants was: “Not user friendly”. In some cases this meant that access to services is fragmented, with poor communication between components, resulting in the person or family needing to ‘work hard’ to get the help they need. There was a common sense of needing to “fail” in order to get real assistance, and of being the ‘exception’ or ‘odd one out’ in interacting with a health system designed for an ‘average’ person.

<table>
<thead>
<tr>
<th>DISTRIBUTION OF PEOPLE INTERVIEWED</th>
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<tr>
<td><strong>Location</strong></td>
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<tr>
<td>Sydney metropolitan area</td>
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<tr>
<td>Rural</td>
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<td><strong>Age range of person with disability</strong></td>
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<td><strong>Person interviewed</strong></td>
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<td>Father</td>
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<tr>
<td>Person with Intellectual Disability</td>
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2. The process of collecting information

The interview was generally at least two hours, conducted face to face, with several follow up conversations to ensure accuracy of information, and consent to use it.

The Picker methodology employed in this work is endorsed by NSW Health. The method deliberately goes beyond questions of satisfaction, and explores patient and carer perceptions and experiences of their care. The method focuses on the patient and carer perceptions, experiences and feelings. It does not seek to discover confidential information about their medical condition, medical history, clinical treatment or clinical outcomes. More information on the methodology can be found on the Gem website.

The interviewer contacted potential interviewees and provided a description of the project, the process of interview, and explained the analysis of information. An interview time was then scheduled if the person was willing to proceed. (See Appendix B for the information sheet that was provided to participants.)

Ten people or their families volunteered to share their experiences. They represented a group of people with intellectual disability and complex health issues who had extensive experience in accessing health services over many visits and interactions.

All identifying information has been changed. All people interviewed have reviewed this information and consented to its use.

3. The journey: introducing the people and their stories

Participants valued respect when interacting with the health system, and of working in partnership with the system. They speak of some exceptional health staff who have helped them in many ways. They also speak of how they wish the health system was different for them and for others.

Whether they are a father with intellectual disability who has a wife and child with intellectual disability, the sister of a brother with intellectual disability, or the parents of a young or adult child with intellectual disability, the people interviewed were all motivated to create a better health system for themselves and others.

Most participants began their story at diagnosis, even when it had occurred many years before. This highlights how important those early conversations around diagnosis, support and guidance are both at the time and into the future.

Many spoke of the importance of communication and empathy in encounters with health professionals. They wanted to be valued and understood as a person / family who attends clinics and appointments. They wanted to be given knowledge and choices. They were often confounded by the way the system presented itself or was arranged in a disjointed way. Many of these issues are not specific to people with intellectual disability, but perhaps they take a greater toll on the health outcomes for people with intellectual disability and their carers, who interact more frequently with health services and for whom communication is already difficult.
A. Diane and Ricky

My son is in his mid-30s. He lives independently from us but does have some support provided in his home and he shares his home with a co-resident who does not have a disability. His father and I live close by and actively support him in negotiating his way through the health system and assisting him with decisions about his health.

He is proud of his independence and conscious of his status as an adult.

Ricky has significant hearing loss and vision impairment. He has a mild/moderate intellectual disability. Although his communication skills are generally adequate for social situations he is not able to provide health service providers with a complete personal history, details about his symptoms or remember details of recommendations or treatments given by the doctor. He relies on notes provided by me to prompt his memory at doctors’ appointments and is keen to have me go to appointments and tests to assist him and to get the full picture.

Maintenance of his health is really dependent on the support I give him.

He has been generally well until the last 18 months when he experienced a number of health problems that appear to be related to early aging.

When he was a child he had a number of interventions and surgeries.

Our family moved a number of times around NSW and then to Sydney more recently. He still sees one Specialist regularly. Ricky arranges his own regular visits to the dentist, the physiotherapist and the General Practitioner (GP) for minor health issues.

He has recently had a number of ‘fainting’ episodes that have occurred on public transport and resulted in visits to his GP who is coordinating the various investigations to track down what is happening. His GP has found some important things wrong which have helped to improve his health.

We are now in our 60’s. At this time his medical issues are increasing. What will happen if we can’t continue giving this amount of help to him?
B. Kassie, Arnie and Belinda

“We have a family of three daughters. Our eldest daughter, Belinda, is now 16. She is a friendly engaged adolescent girl, attends a local high school along with her sisters and has a busy engaged life.

She has a syndrome and multiple associated health issues and has a moderate intellectual disability. There are issues with her sight, hearing, her heart and speech. She has had multiple and major surgery and regularly needs visits to a specialist.

In order to manage the various health needs, she sees ten different specialists and a local GP. I (mum) work part time in a local disability agency to ensure that they can access appointments and services promptly. We (parents) work together to negotiate the complex path through the health system. We work together as a team. Because we have different approaches and personalities, together we can manage to get the best for our daughter and support each other.

We can’t emphasis enough that parents come to this (addressing the specialist needs of their child) for the very first time. We need to know more from the people who have dealt with the health system before - how to troubleshoot. You need to know what you don’t know.”

C. Lisa and Mitch

“Mitch is now in his mid-30s. He is our oldest son – his siblings have moved to the city to study and work. Until earlier this year he lived with us although he was pretty independent. When his father’s work required us to move he moved into a flat with some drop in supports.

He has many health issues including issues with his hearing and speech. Now he has problems with his heart and has developed serious sleep apnoea. He still regularly sees a Specialist. He has a mild to moderate Intellectual Disability. He has good comprehension and learns well. His ability to understand the implications of some medical decisions is limited though. This is really important now as we are considering a lap band procedure to address his weight problems.

The biggest issues for him and us are the limited social life and meaningful lifestyle that is available to him in a country town. He is isolated with few social outlets. To compensate he visits the local shops and indulges in lots of take away foods – really for the social interaction he gets there. He doesn't have regular employment as there isn’t much in the area but he does sell art work on the net which keeps him going!

His current health issues are related to his weight and this has caused serious sleep issues and consequently impacted on his mental wellbeing. The impact of excess weight on other body functions is serious.

As a family we are very informed and up to date with interventions and treatments that have been effective. We are involved with a support organisation and participate in many organisations and conferences related to health and disability. We have always been committed to doing the very best for our son and have high expectations of appropriate services.”
D. May and Thomas

“Thomas is 16 years old now despite all the predictions that he would not live for long. I have told the story of his first few weeks and his diagnosis in other places. I am very committed to telling this story to improve things for other families by assisting medical professionals to understand how to interact and support families.

Thomas has a rare condition caused by a brain abnormality. He has many seizures and needs a complex regime of drugs to manage them all. He is fed through a feeding tube and has other issues such as sleep apnoea.

He has a severe intellectual disability but does seem to respond well to interactions and communication with him. He really enjoys a joke! He knows the routine we have and despite his health issues and physical disabilities has an involved and active lifestyle.

Thomas is very much part of this family. He is a loved person who is central to our lives.

I have learned a lot about dealing with the health services. I work in a children’s service where I can put into practice some of these lessons and teach other to do so too.”

E. Milka and Jess

“We have a family of three children. They are all adults now. The two eldest are married with their own families. Jess is 34 years old and lives at home with us.

I have my own health problems and have difficulties with mobility.

Jess’s complex needs were identified when she was born. She had difficulty breathing and drinking at the same time which gave them the hint. She, and we, spent the first year of her life in hospital.

She has been diagnosed with a complex and serious health syndrome. She is totally deaf, has heart problems and problems with her lungs. Initially she was diagnosed as having another syndrome that has some similar features.

She also sees a specialist because of issues with bone density. A part of her condition is challenging behavior. She responds to her frustrations with some self-injury hitting her head, stomping up and down and sometimes with aggression towards others. She also gets a bit obsessive about some things like milk in the fridge so she pours it down the sink.

She has an intellectual disability and functions somewhere between 12 and 30 years of age! She uses a blend of sign language and her own idiosyncratic signs and gestures. She loves being busy and spends lots of time on her PlayStation, IPAD playing DVD’s and watching TV.

We go to a local medical Centre for basic things like prescriptions or a cold or something. We have a wonderful paediatrician. He refers us to other people but draws it all together for us.”
“Susie is the third of four children. Until recently she lived at home with us and attended a local school. She is now in an emergency respite placement because her behaviour became too difficult to manage at home.

Susie is 12 years old. She has Developmental Delay and Autism.

From the time of her birth she has had seizures and required lots of intensive intervention. Basically from the beginning, life has been traumatic.

We were immediately referred to a specialist. I was discharged from hospital with a tiny baby on medication. The doctors apparently were concerned because I wanted to know all the details of what was happening and the medication they wanted to give her. This was interpreted as being overly anxious so I was referred to a psychologist!

Basically we managed by spending money and having the assistance of several nannies!

When she hit early puberty her behaviour deteriorated and we could no longer cope.

We have sought help from a range of specialists – an adolescent gynaecologist, paediatrician, Occupational therapist, behaviour support practitioner Psychiatrist and Speech pathologist. As well as these there have been great people at school, the GP, friends who have assisted us. No one has really been able to give us the help we needed when we needed it.

I have been desperately trying to get support and services she needs with little direction and help. Getting help from an advocate recently has made a big difference in our lives.

Susie has settled down a bit now and seems happier with the more stable and predictable routine in Respite.”
G. Richard and family

“I have a disability – intellectual and physical. My ex-wife has a disability. One of my children has problems concentrating although she is doing well at university. Another one of my children has an intellectual disability and another has both a physical and intellectual disability.

I’m divorced. Over the years we have had lots of contact with health services.

I’ve had many operations over the years. I have difficulties with my eyesight and have needed dental work.

I had a bit of an idea about health services and how the hospital works. My wife didn’t and needed help to understand what was being discussed and decided on.

I work in Self Advocacy and do lots of education through organisations for people with intellectual disability

I recently had a stroke but am now fine.

We (all family) use the same GP – he is good, knows me well and all my family. He speaks to the children directly asking them what they want.

We have had lots of involvement with the hospitals with my child who was born with very serious issues requiring lots of surgery. She had lots of treatment and operations over time.

It is very important to me to manage my health care and decisions myself. I do need support and assistance to get to places sometimes and to understand what is being discussed. A support person is there for me but the doctors have to talk to me and not to the disability support people, about me.”
"My son, Daniel, is 9 years old now. He is the youngest of several children. He is a beautiful looking kid. He has a very rare metabolic disorder. This hasn’t been known about for very long and in fact he was only diagnosed a couple of years ago.

This means that he has an intellectual disability. .

He was 12 months old before we thought there was anything wrong. I have a background in child care so was really aware of his development. No one believed me though. When he was 3 and I was still concerned we went to a paediatrician, in a medical centre and although he thought there was nothing wrong I was still sure there was.

We have always accepted that he had a disability but that didn’t explain what was wrong and all the things that happened to him.

The real journey we have been on is to find out what is wrong and then to get help to do the best things for him. This has been really difficult for all of us.

He has very disturbed behaviours which escalate in intensity and severity and then usually he has seizures. They are so bad that he has to go to hospital. This involves presenting to emergency departments and trying to get help.

We have regular visits to a neurologist, paediatrician, and metabolic team and of course the GP for other issues. Recently we have also had input from a Psychiatrist.

We have been offered assistance from a speech pathologist, a physiotherapist and a behaviour support specialist.

The best thing to have happened is getting assistance from an advocate who has really helped us when we were at the point of collapse."

H. Veronica and Daniel
When Reece was born we lived in a small rural town. When he was born I was given a little booklet with contact numbers for the syndrome association and a welcoming poem! The nurses basically left me alone but kept an eye on me in case I went postnatal or something! This was my introduction to the world of disability. No one spoke to me personally.

When he was old enough to go to school we moved to a large country town so that we can access the services that are right for my son. I also separated from my husband.

Reece is now 12 years old. His major problem is high levels of anxiety related to medical procedures including visits to the doctor or dentist, having blood taken or any intervention. He doesn't like unexpected things happening or being touched.

When he was little he needed to have lots of blood tests. He was scared. He has many health problems.

Even to get into the doctors surgery I have to do a number of rehearsals with him before we go. He has to know who is going to be there and how they might touch him, what will actually happen. I've found that developing a social story for major visits helps.

It really makes a difference if I can prepare him and people can be really nice and friendly to him, understanding his anxiety. Until he gets to know the person he will not allow them to get near him.

We are involved with a rural outreach organisation. We come to Sydney for a week once a year for a thorough medical review. They work out who we need to see at a case conference they hold at the beginning of the week. They organise transport and other support if we need to go to specialists outside their organisation.”
“I am Person Responsible for my brother Geoff who is now in his 40s. He lives in a group home managed by an NGO. He used to live at a large metropolitan residential service and was one of the first people to be relocated to community houses. The group home is really good for him. He has a moderate intellectual disability, severe epilepsy, and osteoporosis. He can communicate verbally but not very well.

For most of his life I was involved in his medical care and assisted mum by going to appointments with them. I always advocated for him to get the best care and treatment he could. He still sees specialists.

When he was about 3 he began having seizures. From then on he was in and out of hospital for years when they were trying to get a diagnosis which never happened. Mum and dad were told that he would probably die by the time he was seven or eight. This lead to him being really indulged and getting away with everything. His behaviour became a real problem!

He has uncontrolled epilepsy and was tried on lots of different medications and regularly has to go to hospital because of the severity of the seizures. Mind you they don’t really ‘treat’ him but monitor his recovery.

When he got into his teens his moods became volatile and he became very difficult to manage at home. The only way mum could manage was for him to have respite. When mum became ill he had to go into care.

He has become more disabled as he has become older. His seizures regularly result in admission to hospital. He has osteoporosis with complications.

I have my own family with adult children and a full time job to maintain. As his needs increase I am finding it more difficult to do all the things for him and the time it takes to look after him at the hospital.”
4. Communication

“Not everybody knows the health system and know what is going on. As the parent, I am the carer for my child. If you have never met me you can’t assume I am proactive. You can’t assume that all carers will behave in a particular way, they may not. I look up things, research them. Not everyone does that. Doctors assume that the carer understands the jargon they are using and that the parent has a level of literacy, and that is often wrong. You need to check if they (parents) do understand what has been said, or how to get to the place, and even who you are going to see.”

Vita and Reece

“I always have my diary with me. I usually tell them when I am free”

Richard

“I’d take my file and my child’s file with me. Mostly they (health professionals) would just want to ask questions. She had lots of specialists. Then ask us the questions they really need to know. Saying your story over and over feels like being put on the spot and it can make me feel angry sometimes.”

Richard

“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. If you ask for a Panadol and the nurse forgets you have to go and follow her up and get it.”

Vita and Reece

“One time in Intensive Care we had to tell the whole story from start to finish five times! The specialists were standing next to each other and I was going through the whole story with the neurologist. And then when he finished the metabolic specialist who was standing on the other side of the bed said, ‘so can you just go through the story from the beginning’.”

Veronica and Daniel

“On the day her period began that was the beginning of the end! She was distressed and very disturbed. I rang the GP and was told to give her the Pill. I had to ring back and tell them that it had not helped in fact it had made it worse as the bleeding was not stopped. 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

“He (GP) 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 had to say many times ‘explain it so my wife can understand’. They (health staff) talk to the support people not the parents. I used to get really mad at that. Our support people would say ‘talk to them. They’re the parents’. Over time they did begin to change and talk directly to us. We had to say ‘the support people are here to support us, to explain if we don’t know you (health staff) need to talk to us.’”

Richard

“With a lot of health professionals in the bush English is not their first language. It is hard to find someone who your child can understand and you yourself understand. You are prepared to take any service you can get but if you had a choice it’d be nice to have one that you could relate to. Language is not the only thing but it is also knowledge of cultural appropriateness and social understanding.”

Vita and Reece

“There are big issues with the poor spoken English of some doctors and nurses in these hospitals. I can’t understand what is being said much less Geoff with his disability. And the whole understanding of disability is different in different cultures. The populations in Hospitals are multicultural and the different cultural values impact on the care given to him.”

Josie and Geoff

“When in hospital: They could give you some preparatory information like ‘get yourself up and awake because it’s likely that Dr x will be doing his rounds at 7am. We can’t guarantee it but it’s likely.”

Kassie and Belinda

“This is the first time I have heard about a Transition person at the Hospital. Why is that?”

Kassie and Belinda

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

Vita and Reece

“Naturally we read everything we can and keep up to date with developments with this condition. We often have information or questions that the metabologist can’t answer or hasn’t heard about. The original metabologist we had was really wonderful. She knew something odd was going on and persevered and researched until she ‘discovered’ what it was. Since then she has handed us on to someone else.”

Veronica and Daniel

“There is no benefit in attending all these follow up appointments for me or my son. Especially when I have to drive for 40 to 60 minutes for no outcome. If they are not going to listen to what I have to say what are we doing here?”

Veronica and Daniel

“I know health professionals are often rushed. If they only have 10 minutes, tell me and let’s use it for the reason I have come to see you.”

May and Thomas
“They don’t have to live day to day with this situation. They may be doing brain surgery or whatever they do. I’m living with all this stress - do I really need to go to the hospital to see you twice a week.”

Veronica and Daniel

“Some people have a view of what is the ‘best option’ for us as a family and for Thomas. This was most apparent when he was taken to the GP. 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 … recognise him as a person and be enquiring about how he manages things. He is a loved person.”

May and Thomas

“During the hospital stay there were lots of people coming in and swaning around, doing procedures but none of them were talking to the patients. No one seemed to have read Reece’s care plan. The idea was great but it wasn’t done in practice. At the pre op meeting I spoke to the doctor’s underling. We went through and made plans. They were all disregarded on the day: it would be good if you were spoken to and listened to.”

Vita and Reece

“They each act as gatekeepers for the health services: the doctors are interested in their medical specialty.”

Veronica and Daniel

“Emergency Department are interested in keeping him out of the hospital, even the secretary can help or hinder access. The current secretary really looks after me.”

Veronica and Daniel

“I know what to keep an eye on because of information from the syndrome association. My association with them leads me to know what I have to keep on top of. They point me in the direction of appropriate literature so you can be proactive.”

Vita and Reece

“We went for a pacemaker check-up the other day. She only has a couple of years before she needs another one. We would like her to have that where they know she and I can stay in the bed near her, she knows the place and really I think she is not up to being in a ward of adults. They say she is 16 and she will have to go. I asked the specialist what happens when we finish with you.”

Kassie and Belinda

“By the time you’ve waited an hour or more (in the waiting room), the child is over it and misbehaving. I understand that they are busy. It is not really related to the disability.”

Kassie, Arnie and Belinda
“Another time the neurologist said to us that maybe Daniel’s behaviour hasn’t really become worse but that we think it’s worse because we are tired of the behaviours and the seizures and nearly losing him. He thought we perceived it to be worse but it probably wasn’t! That day I wasn’t so polite!”

Veronica and Daniel

“After difficult procedures you are told ‘here are the dates for your follow up appointments’. You are never asked when it would suit you to come in; ‘here is your time. 2pm on 2nd November’. There is no reference to your availability.

This is why I chose to work part time in the job that I have so I could take advantage of any time available. The assumption is that you will fit in. You always go on a waiting list. I’m available for any cancellation and I get there!”

Kassie, Arnie and Belinda

“Every time your child’s medications changed you have to fill out forms for school, day programs, for respite, for holiday programs and Saturday morning program. And they all have to be signed by the doctor- every one of them. So you have to make a special appointment in the spare time you have in your day, to go to the doctors. I don’t know what other people do, but it takes time, filling the forms for the doctor so he can just sign them.”

Magda and Susie

“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

“One of the big issues for us now is that Mitch is considered to be able to provide his own consent and as an adult he has the right to privacy. This works against his better health care. He presents well but he doesn’t understand the implications of his actions or the decisions he is making. He has sleep apnea but he won’t wear the mask – lots of people won’t. The mask doesn’t fit his little face. He has no insight into the impact of sleep apnea on his heart problems.

He said he wanted to speak to the doctor at the specialist disability clinic alone yet he isn’t aware of the issues with his weight and the need to do something to effectively manage his weight. Because he is now so heavy there are OH&S issues for people coming to work with him to provide support in his home. If he doesn’t have support the will not be able to live independently and his health will only get worse.”

Lisa and Mitch

“When she has these bad migraines she needs medication ... she can sleep it off. The hospital won’t do this anymore because addicts take advantage of it. They end up giving her something else that stops her vomiting but doesn’t help with the head, so she is still in a lot of pain. So we wait two or three hours before they give her a drip/injection. Within 15 minutes she goes to sleep. They then say ‘now she is calmed down you can go home!’”

Milka and Jess
“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

“Many doctors act like ‘I’ve written the prescription so off you go and do it’. When you begin and ask ‘why, what will happen’ – they think you are a nutter!”

Magda and Susie

“I don’t know what we would have done without our advocate’s help. She ‘forced’ the health professionals to talk to each other and to actually help us. 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. She has also understood the complex needs of our whole family not just Daniel’s medical needs. So she helped get a case manager who has been really good through the disability services and the health worker has now agreed to coordinate medical things. Only the psychiatrist understood the demands on us having to come to meetings and get scripts filled etc.”

Veronica and Daniel

“Getting a mobility sticker has been a boon. It has changed my life. One less thing we need to worry about- I can park somewhere and not worry about a fine if the waiting time is extended; at W they don’t charge when they see the mobility sticker. It’s more about getting the extra time rather than the parking.”

Kassie and Belinda

“Some health professionals don’t have any perception of the rest of your life and the impact of all the things on us …what happens between appointments.”

Veronica and Daniel
6. Integrated care

“Some health professionals don’t have any perception of the rest of your life and the impact of all the things on us. I had a really bad week last year. Daniel had lost it completely. He had some seizures. He was distraught and very disturbed. The specialist was not on duty so we saw his Fellow. She then said to me ‘we are neurologists, not behaviour specialists and he doesn’t belong here.’ I had, in desperation, asked for some advice and this is what I got.”

Veronica and Daniel

“The issue of transition to adult services is one that has not been resolved yet. Because she has a very specific set of issues related to her diagnosis she requires treatment by people who know about the conditions and treatments. These people are at the hospital and there’s her paediatrician. There are no people to move to as an adult.”

Magda and Susie

“Belinda is now 16. I’m worried that there are not many people with skills and interest to move on to.”

Kassie and Belinda

The condition Daniel has was only diagnosed 2 years ago. It is a rare and ‘new’ metabolic disorder. Everyone is learning about the condition. There are six or seven specialists involved: a neurologist, a pediatrician, 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. They seem to have a wait and watch role. We expect them to be actively assisting us to help him and to manage. When he is in a crisis they don’t seem to know what to do.

Veronica and Daniel

“I’d only go to the GP for regular illnesses. They each have their own little area of expertise and interest and they don’t stray from it (referring to Specialists).”

Veronica and Daniel

“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.”

Milka and Jess

“GP’s need to take the role of case manager. This thing of the GP thinking about you for the 15 minutes of the appointment … has to change. With complicated cases they need to take on the role of coordinating all the specialists.”

Magda and Susie

“The receptionists can make or break it!”

Magda and Susie
“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.”

Kassie and Belinda

“After the operation we were told that in an emergency we should go to Emergency department. This was a total disaster! We waited in Emergency for 5 hours. By the time they got to us they told us that they couldn’t do anything now but that they could make an appointment for us the next day with treating doctors!

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.

After her operation, we had to go to another ward of the hospital for the sleep study. We packed up all our goods and chattels and went over. It was a surreal experience. 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

“Her journey is so tiring – we have to make four or five visits for any of these things.” Milka and Jess

“Four months ago we had our first and only case conference. This is the only time the health people have talked with each other and us.”

Veronica and Daniel

“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

“Rural GP’s don’t see enough people with this syndrome to be aware of and up to date with specific health issues they may face such as early ageing. They have to rely on me a lot. 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. The doctors are often amazed – sometimes they appreciate the information we can give them.”

Vita and Reece

“The ambulance service also has a gatekeeping role. Our closest hospital is a metropolitan hospital and they will not take him to his treating metropolitan hospital. Inevitably he is taken to treating metropolitan hospital, often by helicopter. His father has had to take on the role of strong advocate. He has to demand that notes are read, the involved specialist is called and that they take his history into account and that he go to the place where he is known.”

Veronica and Daniel
7. Reasonable adjustments and upskilled staff

“You come in, they ask, “what do you want” and you go out. 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

“There was a time when they wanted to get mid-stream urine and gave him a plastic cup and asked him for ‘a sample’– he has hearing problems and he didn’t understand what was wanted. I had to loudly tell him ‘it’s not a matter of scooping the wee out of the toilet bowel after you’ve gone but putting your dick in the cup’”

Diane and Ricky

“I think they avoid dealing with him because they don’t have much experience with people with Disabilities. They let me do it all.”

Josie and Geoff

“I go to the hospital when she is having a severe migraine; she lays on the cool floor, she may be throwing up all over the place and we just have to wait. They can’t give her a bed to lie in so … they don’t understand and more importantly she doesn’t understand why she can’t be in a bed or allowed to lay down with the light out!”

Milka and Jess

“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.”

Veronica and Reece

“You don’t find many people like this who will go out of their way to accommodate different needs. Mostly they seem to be more concerned about whether it will make them extra money - it may not really be like that but it seems that like service is driven by the ‘market’.”

Veronica and Reece
“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.”

Richard

“We had a case conference. It was ok for me but my wife (with ID) 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.

It makes such a big difference if the child can be prepared and the people he meets will be nice and friendly. Health people do need to be aware of the child’s needs and explain in a suitable way. If the child needs visuals they should use visuals and if the child needs if they should chat to the child. Having a distraction like an Ipad also helps.”

Vita and Reece
8. Information technology, ehealth and person-centred electronic health records

“Then they start asking us the information that’s in the file, it is really hard to remember everything.”

Richard

“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)? He just has to wait till it’s his turn in the queue, and by then he has recovered, and is set home.”

Josie and Geoff

“Why don’t they coordinate the appointments? I have to travel across the city for each appointment, take him out of school and then repeat the same things each time instead of only once.”

Veronica and Daniel

“There is a lot of documentation which they (health professionals) don’t read or try and scan it while they are seeing you. Even though you have provided all the information they then ask you to tell them the information.”

Magda and Susie

“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
9. The importance of the carer

“You tell them what has been happening at home for example 'he has been having absences' and the neurologist would say ‘that doesn’t sound like an absence’. You are asking me, I'm the parent and I'm at home with him and you are not listening to me.”

Vita and Daniel

“My daughter went into emergency respite and they had difficulty managing her behaviour. These were not new behaviours but really the reason for going into respite. The service was concerned about the medication she was getting. So I made at least half a dozen calls to the prescribing doctor with no luck. The team Leader called and got through and between them they decided on the medication regime. I was not in the loop.”

Magda and Susie

“I usually don’t have anything to do with the GP. Geoff usually sees her in my working hours. Recently the support service made a specialist appointment on a day I couldn’t go –so I don’t know what happened.”

Josie and Geoff

“To attend all these appointments and to support Daniel we both have to take time off work. This puts us under a lot of pressure both financially and emotionally. We have other children who need to have a life too and to follow their interests and talents. This all costs time and money and energy.”

Veronica and Daniel

“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

“I’m in my 60s. The round of medical appointments wears me out. The medical stuff has grown bigger. With recent episodes I was here and noticed that. Often I am interstate and other family members, who we might ask, also travel a lot. I was terrified really - it was just lucky that I could come to him as I was nearby.”

Diane and Ricky
10. Regional access

“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

“Despite the fact that I am giving consent for the procedures fully understanding the issues, they (local hospital) won’t do it. I have to go to the tertiary hospital. They do it.”

Milka and Jess

“When he was a child he needed to have regular operations. We couldn’t have done this unless we had private health insurance. Now that he is an adult we have also relied on private insurance.”

Lisa and Mitch

“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
11. The role of specialist 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 problems) 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

People from other agencies, my friends and I have made application to the specialist unit.

Magda and Susie
12. Discussion

The ten in depth interviews with people with Intellectual Disability and their family / carer describe some consistent themes. They spoke of wanting to improve the system and of their experiences with some exceptional health staff and services.

Introduction

The people interviewed described the complexity of health needs for people with intellectual disability, due in part to:

- the number of health issues and health support required.
- the impact of health issues on the daily life of the person with intellectual disability and their family or carer.

Services generally

Accessing support services requires, in the words of one participant, "a ridiculous amount of paperwork". There are disability service specific forms which need annual reviews, others need updates whenever there is a change in treatment. They usually involve signatures from a medical doctor. Accessing respite services for example requires a medical summary, current medication listing including a “Webster pack” of medications, epilepsy, behavioural support and mealt ime management plan, among others. This is time consuming for families and for health professionals, and usually requires GP appointments just for forms and signatures.

Some people thought pathways to care would be helpful in understanding how the system operates, to empower them to manage their own healthcare. Health management plans were identified as useful. Often the health service receptionist is a key contact for information.

Negotiating the system

For some families, the experience of negotiating the system was overwhelming, often while still coming to terms with an unfolding diagnosis, confronted with the needs of their child.

Many of the carers felt that health services were not designed for the needs of people with intellectual disability. Situations which they find particularly difficult include:

- waiting lists, when the person is coping with so many health and possibly behavioural issues
- busy waiting rooms (e.g. GP surgeries and the emergency department)
- the frequency of GP visits for small issues such as getting regular scripts and getting paperwork signed
- the rotation of medical staff.

People with intellectual disability and their families often used their acquired knowledge of negotiating the health system to support others and make changes to the system. They are involved in peer support groups, parent support groups, working groups and committees, consulting on redesigning education for health and disability staff, helping associations such as the Downs Syndrome Association, writing books and presenting papers. Some have found employment in disability related work.
Importance of initial diagnosis

When asked about their journey accessing health services, families tended to begin with the birth of their child. All other reflections proceeded from that point to the present, irrespective of the current age of the child with intellectual disability. They are well rehearsed at “telling their story”. Nonetheless, the person’s early experiences did provide a context to understand the significance of subsequent events, decisions and their cumulative impacts. This highlighted the importance of support in the days after diagnosis.

Some families commented on how the immediate focus on the needs of the child meant they felt unsupported as parents. It was often a crisis point which prompted discussions about broader family impacts (such as sibling and parent mental health) and subsequent helpful interventions and support.

Health information

Carers valued the opportunity to discuss concerns or questions about treatment recommendations as many had read extensively about their son or daughter’s condition. People with intellectual disability and their family / carer wanted more and appropriate information, such as other support agencies for people with intellectual disability (for example; respite, disability services, and educational options). Many relied on, and valued highly, peer relationships and support organisations for information and understanding.

Some people commented on how they were overwhelmed, exhausted and too stressed to be able to repeat health information and history several times, especially in acute situations. They felt this would be unnecessary if health professionals had improved communication channels between themselves and their teams. Mention was made of acute presentations of chronic diseases, where the “current situation” was the focus, without the context of history and the benefit of family knowledge of options and impacts.

Communication and staff attitudes

Listening skills and respectful attitudes were vital characteristics of the exceptional health professionals spoken of by those interviewed. People spoke of staff who treated them with respect, listened to their concerns and priorities, consulted with them and made adjustments to include them and their family / carer. This was true across a wide variety of health contexts, for example case conferences, emergency departments, and diagnostic and treatment phases of their journey, and with different types of staff across all levels of expertise.

However the attitudes of health staff were seen by some carers as the biggest obstacle to accessing health services.

People with intellectual disability and their families / carers expressed a need for more use of alternative or augmented communication systems, easy read materials and instructions, diagrammatic presentations and alternative communication amongst health professionals. This would enable people with intellectual disability to be more involved in discussions with health professionals about their health and treatment plans.
Flexibility

Limited flexibility in how health services were delivered was a source of frustration for all. Some felt a “fast track” pathway to assessment was warranted for people with intellectual disability in the emergency department and that flagging for intellectual disability would assist with treatment.

The involvement of the person with ID themselves in their healthcare decisions respects their rights of self-determination, but health services have difficulty knowing how to achieve this. People interviewed felt decisions about further treatment options should also involve discussions which reflected an understanding of the importance of this person to their family.

Some families want to remain in the familiar paediatric health system – a system which is based around the role of the family and carer, and where challenging behaviours are accommodated. The co-ordination and monitoring role often performed by the Paediatrician and Geriatrician was sometimes lacking between these age groups. People interviewed thought that access to information and services became difficult in the new and unfamiliar adult system, for the patient and their family.

No one interviewed was aware of the assistance offered by NSW Health for transition from paediatric to adult health services.

Some carers said their own ageing is a factor in being able to care for their family member.

People with intellectual disability and their family or carer felt health professionals were often unsure of the role of Guardian and Person Responsible and of their own ability to assess the capacity of adults with intellectual disability to give informed consent.

Specialist services

Most families were unaware of specialist disability health services for people with intellectual disability. Those who had been referred to them were convinced of the benefit to them of the clinical expertise of the team members, and of the integrated care offered. They thought the whole of life approach to care and treatment resulted in health, emotional and social issues being understood and addressed, as well as value given to the significant role of families/ carers.

Rural services

There was concern that people in regional and remote areas of NSW need greater access to specialist services that work to support their local services. Some suggested increased use of telehealth to assist this process.

One rural family said that their only available access to appropriate and effective services was through the Emergency Department of the specialist children’s hospitals. Frequent presentations to hospital for similar health issues for people with intellectual disability suggests there could be greater emphasis on targeted preventative work, communication and pathways of care. Suggestions for health service improvement included staff training, more streamlined procedures and policy development to support better care.
Access to mental health services

Access to mental health was described as complicated by:

- diagnostic over-shadowing, which is when the person’s disability is seen as the cause of all problems. This overlooks the fact that the person with intellectual disability may also be affected by the same health issues as people without intellectual disability
- limited numbers of health professionals and services equipped to assist people with intellectual disability who also have mental illness.

The Carer

The fragmentation of services creates stress for a career is in addition to the need to listen, understand and contribute to medical appointments. One family said they were sometimes left to manage as best they could, despite being able to predict what their needs would be in these situations. Few people interviewed knew about the NSW Health Carer Support Workers located in each Local Health District.

Family members expressed fear about the future as they age, given the current reliance on them, Some carers commented that it has often meant balancing the needs of other family members. They spoke of decisions around employment options for family members and carers and about where they live, in order to access the required services.

The material gathered from the interviews with people with intellectual disability and their carers about their experiences of accessing NSW health services, forms the basis of ongoing work of the NSW Agency for Clinical Innovation Intellectual Disability Health Network, to improve patient experience and health outcomes for people with intellectual disability.

13. Next steps

In particular, this material is currently being used by the ID Health Network in the development of:

- Health Services for People with Intellectual Disability: Context Report and Toolkit – 2015
- Blueprint for the Delivery of NSW Health Services for People with Intellectual Disability.
Appendix A - Suggestions

Suggestions gathered from the people interviewed in the course of the interview.

Ms Mary Ellen Burke, who conducted the interviews, has gathered suggestions for change made by participants into two headings.

Practical suggestions

• Provision of an introductory booklet on how the system works.
• Introduction to peak and family support organisations.
• Provision of a Case Manager to co-ordinate care for people with chronic and complex health issues.
• Case conferences to allow consultation and sharing of information.
• Health Professionals to allow time for reading patient history prior to the appointment.
• A “flag” or electronic indicator on the person’s file when they access health services, to indicate their need for reasonable and appropriate modifications to accommodate their special needs.

Educational support suggestions

• Education for health staff about the particular needs of people with intellectual disability and their family / carer.
• Communication skills for health staff interacting with people with intellectual disability.
• Pathways about health care for people with intellectual disability.
• Guidelines for health staff about how to adapt their practises and procedures for people with intellectual disability.
• Guidelines on how to include the family / carer of people with intellectual disability, in health service provision.
My journey – access to health services project

Request for your participation

Invitation

You have been recommended as someone who might be interested in talking about your journey and experiences with the health system.

By telling your story, you will be helping us to know how to improve access to health services for people with an intellectual disability? We are asking only ten (10) people to tell us their story.

Before you decide whether or not you wish to be involved, please read the information below, or speak with me to understand why we want to hear your story and what it will involve. Please discuss it with others if you wish. You are under no obligation to share your story with us. We will not identify you, your family member or the individual health professionals you have been in contact with.

What is the purpose of this project?

We are keen to hear about how the system works for you as a carer, as you access health services with someone with an intellectual disability. From your own experiences, we hope to identify where we have got it right and where we need to make improvements, to improve access to health services. The story you tell may be about health services in the community or those in the hospitals.

Who is conducting the project?

The Intellectual Disability Network of the NSW Agency for Clinical Innovation (ACI – http://www.aci.health.nsw.gov.au), has been established to work with health professionals and the community to implement state-wide improvements in the care and health of people with intellectual disability across all ages. Ms Mary Ellen Burke, an Independent Consultant, has been engaged to hear and analyse the journeys of ten people with intellectual disabilities and their carers in accessing health services.

Why have I been invited to participate in this study?

You have been recommended through your involvement in the Intellectual Disability Network or through working closely with someone who is involved with the Network.

Can I decline to be involved, now or later?

Yes. Your participation is voluntary. You can also withdraw from the story telling process at any time or withdraw your de-identified story from inclusion in the resource which will be developed.
What is required of me?

Should you choose to be involved, you will need to put aside an hour of your time to speak with Mary Ellen Burke. Mary Ellen is keen to meet face to face with each person in their own community. This is to make it as easy as possible for you. If you would rather just speak over the phone, she will listen to your story this way.

You will need to sign a consent form saying you understand this information sheet and agree to be involved.

You can read the de-identified story which Mary Ellen writes up after speaking with you, and edit it.

How will I benefit by being involved?

You will contribute to improving access to health care for people with intellectual disability through sharing your story.

What happens with your story?

Mary Ellen Burke will listen to ten carers tell her their stories.

She will then de-identify the people and places and gather them into a written resource. We will not identify you, your family member or the individual health professionals you have been in contact with. She will then analyse the stories to find out how things work well and how they can be improved.

You will have the opportunity to review your de-identified story before Mary Ellen presents the de-identified stories and their analysis to the Intellectual Disability Network. We are keen to share these stories by putting them on our website.

This will help us to understand and improve the way we deliver services and train people in Health in NSW.

Is there a time frame?

If you are interested in telling your story you should email Mary Ellen Burke at xxx within the next week as she is speaking to interested people, at a time which suits them best.

What about confidentiality?

It is our intention to de-identify the stories for any future use. The information drawn out of the collected stories identifying trends and issues in accessing health services will not be individually identifiable.

After the story telling

You may find that talking about your journey raises some concerns for you. If you want to talk to someone about this please let Mary Ellen Burke know.

At a later time, if you change your mind regarding your choices, you need only contact Mary Ellen Burke or Tracey Szanto (details below).
Further information

If you would like any additional information about NSW ACI, the Intellectual Disability Network or this project please do not hesitate to contact Mary Ellen Burke at xxx or Tracey Szanto, on 02 9464 4632 / 0408 365 528.

Thank you for your interest in this project.

We very much value your comments and are hopeful you will be able to participate.

Warmest regards,

Tracey Szanto

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26 June 2013.