NSW GOVERNMENT

PERSON CENTRED APPROACHES
LIVING LIFE MY WAY

Consultations with people with intellectual disability

Final Report

Prepared by the

NSW Council for Intellectual Disability

August 2012

Contents

Throughout the report NSW CID has presented direct quotes and statements from individuals in italics and coloured ***purple.***

Introduction

The New South Wales Council for Intellectual Disability (NSW CID) undertook consultations directly with people with intellectual disability in response to the NSW Government's proposed person centred approach to disability supports. This follows on from initial consultations conducted in late 2011 and sought to gain people's impression of these proposed changes. The consultations happened between April and July 2012.

For the consultation process NSW CID held in-depth interviews and focus groups with people with intellectual disability from throughout NSW. The views of people were canvassed in relation to their current life situation and what changes they would see as necessary, at both an individual and systemic level, to enable not only their full participation in a person centred system but in making choices about their lives.

This report presents people's views on the following:

■ Their lived experience of intellectual disability

■ Information

■ Decision making and choice

■ Choosing and reviewing services

■ Electronic records

■ Community.

Participants were largely keen to see improvements in the quality of their life and were able to suggest numerous strategies to make this happen. People wanted to:

■ *Decide what you want to do for your future and your life.*

■ *Make a big goal and find a way to get there.*

Participants were pleased to be able to take part in the consultations and appreciated the opportunity to have their say on the proposed reforms. As one person commented it was beneficial:

Sitting down with a couple of people, like we are now, and think about what we want for our future, and discuss what we want to get out of life.

Participants

In conjunction with the Department of Family and Community Services – Ageing, Disability and Home Care (ADHC) NSW CID recruited a range of participants that had a variety of life circumstances and experiences.

A total of 69 people with intellectual disability (PWID) took part in the consultations.

A further six people were recruited to take part but withdrew for a range of reasons.

NSW CID spoke to two parents of PWID who had high support needs.

Eight participants had taken part in the first round of consultations.

NSW CID is keen to protect the anonymity of the people who participated in the consultations. For many people they had limited experience in sharing their opinions so freely and were concerned of potential ramifications.

As such, only basic demographic information is provided in this report. It gives an overall perspective of the range of participants who took part in the consultations. Please refer to the table in the appendix for this information.

Some disclosures about personal circumstances needed immediate assistance or a referral for further support. People were referred to advocacy organisations, counselling services and information services.

Process

All participants were given Easy Read information sheets and consent forms before deciding to participate in the process. The recruitment allowed adequate time for people to:

■ Consider if they truly wish to be involved and provide consent

■ Ask any questions about the process (to either people they trust or of NSW CID)

■ Begin to develop thoughts about the topic areas.

It also enabled NSW CID to ensure a diverse range of people were included in the consultation groups. NSW CID contacted numerous organisations, agencies and networks in each region to recruit people. This included disability support organisations, education providers such as TAFE and Special Schools, disability advocacy organisations, information services, Ageing, Disability and Home Care (ADHC) local area coordinators, accommodation services, community centres, local councils, employment support organisations, health centres and home care services.

NSW CID notes that the majority of PWID who were contacted directly were most keen to take part in the consultations once it had been explained to them.

This is good, people getting included.

When services were contacted there was a mixed response to participating. One service stated about the proposed reforms around self-managed supports:

These are not really for PWID, more for people with physical disability.

Another said:

No our people would not be interested.

From another:

They would not understand.

Others were very enthusiastic, with one saying:

It is great these are happening, it is good people will get their chance to have a say about this.

The final makeup of the groups and interviewees included people who accessed a range of different services and organisations, some of which were operated by the government, others were non-government. Some people received 24 hours of support; some people did not access any at all.

NSW CID chose a range of methods to engage with PWID. These included telephone interviews, face-to-face interviews and focus groups. A total of six focus groups and 17 interviews were conducted across the state. Venues were accessible, in a neutral community space and in central locations.

Focus Groups

The focus groups were designed to make it as easy as possible to participate. Advice for this was provided by Members of NSW CID, who have an intellectual disability and are experienced at organising workshops and consultations. This assisted with having accessible materials and language in addition with advice on how to communicate the concepts of person centred planning.

Two facilitators ran each session, alternating between one leading the session and the other recording information. Each focus group ran for approximately 3.5 hours and the number of participants ranged from 5–14 people. The sessions ran at a variety of times, (morning, afternoon and evening sessions were run) depending on the preferences of the majority of participants.

Flexibility was built into the focus groups with a range of activities that could be chosen, depending on the group dynamics, communication abilities and interests. The activities were structured to ensure that all the themes be covered and discussed in each focus group (see Appendix for examples of activities). Facilitators were able to gauge as each focus group progressed which themes were being covered and then adapt the remainder of the session accordingly.

Importantly, ample discussion time ensured that other themes that were important to people could be raised. This was vital to ensure that themes relevant to people with intellectual disability could also be included in the consultations.

Information and discussion materials were presented in a variety of formats including DVDs, pictorial, Power Point presentations, role plays, case studies, stories and real life examples. The DVDs used included people with intellectual disability speaking about being in charge of your own support. People are able to identify and empathise more easily with peers and the DVDs evoked much discussion.

A large range of open ended questions were used throughout all sessions. Many people with intellectual disability may automatically acquiesce to yes/no style questions, so this open ended style of questioning was used to encourage deeper thinking and consideration of topics rather than a straightforward 'yes' or 'no' answer. People were also welcome to share information with the facilitators over the breaks and this commonly occurred.

NSW CID also worked with some people who used communication aids or requested to have a trusted support person in attendance. Participants were able to be supported by a person of their choice for the session if they requested this. Support people needed to be briefed to ensure that they enabled participation as per the person's individual communication or support needs rather than 'speaking for the person'. Support people were also required to maintain confidentiality and privacy which was especially important in regional areas. To avoid potential conflict of interest support people did not 'sit in' on all activities or discussions.

All sessions began with explaining the wider *Living Life My Way* process the NSW Government is undertaking. This included a showing a DVD of the NSW Minister for Disability Services Andrew Constance being interviewed about the *Living Life My Way* process by NSW CID Chairperson Fiona McKenzie.

Consent was then explained, including privacy and confidentiality. Participants were also advised of support mechanisms they could utilise if they had issues arising from the session.

Each group established ways to make sure everyone had the chance to contribute and have their say. Due to the amount of content and themes that the focus groups discussed, upon completion of the sessions participants were also encouraged to contact NSW CID should they feel they wanted to raise further points or issues.

Interviews

All interviews were conducted face-to-face in a location chosen by the individual. Interviews generally lasted between an hour and an hour and a half. Similar to the facilitators of the focus groups, the interviewer was able to build in sufficient flexibility to ensure the person was able to participate in a manner which suited them whilst still covering the themes. For example most people were given ample opportunity to discuss their own personal story, with the facilitator using examples from this to link back to the themes or questions. This also allowed for any other important issues relating to the proposed reforms to be raised.

The interviewer used pictorial aids when appropriate. Case studies were also used to help people to understand or consider points. The interviewer was also able to link to examples from the focus groups or other participant's answers to promote discussion when needed.

All participants received a gift voucher to reimburse them for their time and expertise. Limited assistance with transport was available for some participants, others were assisted to utilise public or community transport, whilst some service providers offered to transport people. Facilitators also travelled to meet participants in locations of their choice.

Please see the Appendix for further information and examples of the consultation materials.

Message for the Minister

As an engagement exercise people were asked to take part in an activity which involved writing to the NSW Minister for Disability Services. People were given time to think about one key thing that they thought would make a difference in the lives of people with intellectual disability that they would like to tell the Minister.

Most people's answers indicated that it was not just the Disability Services portfolio, but other government departments and the community that had responsibility for improving the lives of people with disability as well.

- *Better wheelchair access, you can't get in to lots of shops.*

- *Regular public transport and more of it (Lots of people agreed with this).*

- *Get rid of the mean people, people that put down other people. Start with (town name), then the town next to (town name), then the town after that and the town after that, all the way to Sydney and round the whole world!*

- *Tell the government we do the best we can, every day, the government should spend more. More equipment, chairs getting fixed, more footpaths, taxis, trains (more of them and more accessible).*

- *More opportunities for people with disability, like work.*

- *Give people with disability a fair go.*

- *I have met the Minister. I would tell him, well maybe, give people a bit more money and do the best you can.*

- *Power is getting expensive.*

- *More notice of things changing from the government. Better communication like letters and things, instead of us not being aware of it.*

- *Bring more support in. Classes to help me learn things like computers, reading and writing.*

- *I think, I don't know if the Government could actually change this, but changing attitudes towards people with disability. And also more people learning about people with disability, because there is a lack of education. The other thing should be changed is that people with disabilities should live a normal life. Coming from a disability family especially in my (XX) community, families are really protective of disability kids. And I think people should just live a really normal life, like an able bodied person. Their parents protect them too much.*

Key Themes

- In order to be able to truly engage in a person centred system people with intellectual disability will need:
  - A wide range of information options available to them, not just web based information
  - Opportunities to learn and practice decision making skills
  - Ongoing assistance to try a new way of accessing support.

  Why don't they teach us to do it?

- People with intellectual disability will also need to be given sufficient time to understand what it actually means to be able to have choice in their lives, regardless of what level of control they exercise.

  They need to take the time to help me, take it more slowly, then I get it.

- Being able to hear others experiences and stories about services and supports appealed to many people and they felt this would give them a more accurate idea of what a service was really like.

- If electronic records were to be introduced for people with disability, they would need to have strong safeguards in place to protect people's privacy.

- There is much that the wider community can do, such as improving their attitudes towards people with intellectual disability, in order to be more inclusive. This applies to domains such as employment, transport, leisure and general community activities. This was simply summed up as you:

  Can't get to where you want to go!

All of the above themes are discussed in further detail throughout the report.

Information

Currently people largely sought information in a face-to-face context and from someone they knew or trusted. Many people felt that they were not really aware of the full range of other possibilities or opportunities available to them. People connected the need for information with being able to make good decisions.

I'd like things explained specifically, in detail, fine detail. Not on a piece of paper, someone telling me, explaining things.

People also expressed the desire to be able to access information in a range and variety of methods. Popular choices raised included DVDs, pictorial information, meetings, training, easy-to-read information, a person to talk to, sharing stories with other people with intellectual disability and CDs or audio material.

Unpopular choices included automated phone services, having to wait a long time to see someone face-to-face, letters with difficult or complex language and using a computer.

It's easier to go in to talk to them (rather than ringing up) and actually find out something.

The focus on web based information provision is a concern to many people with intellectual disability. While some people can use computers and browse the web this is only in a limited way. Getting the information that people need and in a format that will work, through internet based information services seems almost impossible.

- *I don't know how to use to computer properly and I got to learn more about it.*

- *Computers? No, they are not my cup of tea.*

Computer literacy varied amongst people, but no one conducted electronic banking or accessed Centrelink records through the internet. About 25% of people regularly used a computer but this was mostly for social activities like Facebook or for playing games.

Computer users liked the idea of a centralised computer information system but still thought they would like to be able to talk to someone in person if they had questions or needed things explained. Non-computer users felt it would not be of use to them and it could mean they would need to rely on others to access information on their behalf.

Many people expressed a desire to have access to new technology, including the support to be able to purchase this and have access to ongoing training or help as they learnt to use this.

- *I use my iPad and it reads to me, because I am not so good at reading.*

- *I use the computer only at work. For data entry. But I can find out about what's on at the movies.*

- *Voice computer would help.*

With regards to written information the following was expressed by participants:

■ *People with and without disability don't know what the long words mean.*

■ *Pictures to go with words. It's easier to understand 2 ways.*

Preferred methods of communication and information provision were clear. There was enthusiastic discussion about these at all focus groups.

■ *Videos of what the government do.*

■ *What works best for me is face-to-face.*

■ *Both pictures and videos. Some info on how people did stuff, a step thing – how they got from their first spot to where they are now.*

■ *People like us talking.*

■ *Group meeting, you learn more from different people, different ideas, services.*

■ *I would trust people who have experience.*

■ *Learn in a group; you get a say, learn off others in the group, others might have good questions, share ideas, teamwork.*

■ *Just drop in and talk to the person.*

When getting information face-to-face, people also spoke of the need to be able to have this at convenient times.

■ *Open at 8.30am before I go to work would be good.*

■ *Why not have it like late night shopping on Thursday nights or on Saturday morning?*

Telephones were also discussed at length by most groups. Many people used mobile phones, but this was mostly for phone calls not texting or accessing the internet. People liked when they could talk to a person who was able to answer their specific questions. Automated telephone services with multiple options to select were not useful according to participants.

■ *I hate those press this, press that.*

■ *Too many numbers to call.*

■ *Phone, you can wait for hours.*

Reliance on others for information was something that was raised throughout the consultations. People had a range of strategies for finding out what they needed to know, but there was a level of awareness that this meant it may not always be independent or free from bias. Though for others having people that knew them made a difference when they needed to get information.
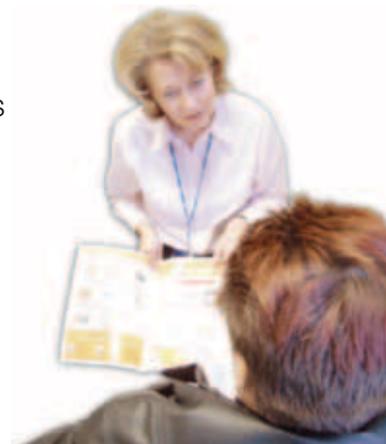
- *Through the organisation I was working for. And now my sister tells me sometimes about things. And also the coordinator from another organisation.*

- *It's my biggest problem. I rely too much on people.*

- *I can look up information on the internet. I can Google. Not a lot of other people with disability can access the internet. So it's a bit like Chinese Whispers.*

- *(Bank Name) opens on Saturday morning, they know me, they bother with me.*

Finally, how to make complaints was an issue that was also raised by participants in the discussions about information. Largely people did not find it easy or straightforward to be able to make a complaint about their support or service or other issues that were affecting their lives.

- *It'd be good to know who to complain to.*

- *Complaints, you need an easy complaint form.*

- *Sometimes you've got to do complaints in writing and you need help with that. Lots of people wouldn't know how to go about writing that.*

In successfully meeting the information needs of this group of people it became clear that having a range of methods, with a particular emphasis on reliable face-to-face information and having sufficient time to explain things to people would be key. This would enable people to feel more confident as they made decisions about not only their supports but their lives.

Decision Making

This was a very popular topic of discussion throughout the consultations. Most people were able to link the need for sound decision making skills in order to be more in charge of their life, supports and the choices related to these.

For some people, who have been in the 'disability system' for a long time and who have not exercised choice and control for a long time or ever, they found it hard to imagine how it would be possible to change service providers or become more independent. Many of the people consulted choose very little in their lives. Some choose what they wear and that's about all the choice and control they have.

- *My service said it is easier if they just do it.*

- *It was my case workers idea that I would like to go to (holiday destination).*

- *Support workers should do it because they know what the government is all about and we don't really know what the government is about, support workers have more push or pull than we do.*

- *Carers do ours (banking) because it's easier and they can get it done quicker. We can't have credit cards or anything like that.*

Discussions about the role of family and their involvement in decision making offered mixed views on how this worked.

- *Family can get in the way. You try to do something and they give you the advice not to do it.*

- *Its part of life, that's how we were bought up – (with others making decisions for them).*

- *I went on holiday once, my father decided.*

- *I liked working in the pre-school working with kids, but then I had to stop that because my family wanted me to work cleaning in the pub.*

- *I want to go on a holiday to Melbourne and catch up with friends. Apparently I could use my (self-managed) funding for that. But my sister sometimes interferes.*

Being able to find a balance or working in partnership with family around decision making was something that many people were interested in but had not yet worked out how to achieve this.

Only a few people felt that they had a certain amount of control over their lives.

- *I'm already in charge of my own money and that, I've been in the workforce for 10 and a half years and if you like to be in charge of your own money it's better than having support to do it. People should get out there and give it a go.*

- *I got to pick my service and my job.*

Everyone was able to identify areas of their lives in which they would like more control. Commonly these were where and whom they lived with, having meaningful employment and managing their financial resources.

- *With or without a disability, you have the right to make choices. Everyone in the community should have equal rights.*

- *That's good, to make your own decision, what you want to do. Excellent!*

- *I'd like to pick where I live.*

- *I'd like to live in my own place. There are two people (where he lives), I really don't like, I'd like to move out. I need a hand with the washing, I want to learn to cook more, have my missus over for tea.*

People were clear about what currently prevents them from being able to make choices. Much of this was based around confidence and skill level, something nearly all participants felt that they would benefit from attending training or having more opportunities to develop these skills.

Other barriers which inhibited good decision making included:

- *(It can be hard) when too much on your brain.*

- *Case worker, gives good info when I see him, don't see him much, he's a bit busy (would help) if I saw him more, each case worker has over 30 clients.*

- *Too much information (makes decisions hard).*

- *It's annoying when people make decisions for you.*

People were also able to identify many ways of improving their decision making capacity. These involved both things they could undertake as an individual well as ideas for others who supported them.

- *They need to take the time to help me, take it more slowly, then I get it.*

- *I'd like more notice (to think about things).*

- *I've learnt a lot through my experiences.*

- *Knowing where you are and what you are doing. You need lots of time to make decisions.*

- *Should have more than one chance. You need help to stay on track, just don't give up.*

- *You should get lots of opportunities to try again. I feel more comfortable, for hard things (choices) getting help from my family or my staff.*

- *Feeling safe.*

- *Having support.*

Some people spoke of the role of advocates and how this had been helpful when they had experienced difficult circumstances.

- *Always there for you, get you out of trouble.*

- *When you're up the creek!*

- *Advocates can weigh it up for you.*

Also important for people was that they were supported rather than penalised while they were learning to manage their own supports. A few people spoke about examples of Centrelink restricting their money when they had not completed paperwork or understood the implications of certain choices. People realised that there would be rules or guidelines about managing your support and money and felt that this was fair. However the information around this needed to be very clear.

Overall there is much change that needs to occur to enable people to become more skilled at decision making, this includes systemic changes. Having this occurring at a pace and style that suits the individual is critical.

Choosing and reviewing services

The notion of people who used services being able to review them appealed to many people. Some people felt that peoples stories could offer a more honest or accurate account of how things 'really work'.

It's good, they know what you are going through. People without disabilities don't know what you are going through.

Others liked the idea of a star rating to indicate the quality of a service. People were unsure how they could share their own stories or access reviews if they did not use a computer.

People also felt that they would still like to be able to visit a service, ask questions and shop around before choosing a service.

- *Looking at what suits the person by checking or emailing. I would like more information. Ask the other people that know, that use the service. It would be good to have that information.*

- *A website where people put their reviews on would be good. But it would not sway me. I would need to see the place. But if it gives information that would be good.*

- *I think sharing information about services is a good idea. The websites need to be accessible. Sharing information about service would help people decide which service to go to.*

- *Go out and suss it out. Be there for a while and find out like that.*

- *Look it up on the internet and then ask other people who know about the service and then go out and check it out.*

Electronic Records

The concept of electronic records was explained to people using pictures and case studies. People's major concerns around this were who would see the records and who would control the records. Having privacy protected was of utmost importance to people.

You would have to be careful other people didn't get on your information.

All groups could identify circumstances where their privacy had been breached or errors had been made in their records by staff or professionals.

Doctors don't always get it right.

The responses to the following questions indicate where some people's concerns lie. How about keeping information on a computer so you don't have to tell your story again? Do you think that's a good idea?

- *This depends on the circumstances. This is a big question. This is very tricky. Maybe there are things that are private. It's hard to predict and confusing.*

- *It's unfair if others look at it.*

- *Would be a bit sad (if someone looked at it that shouldn't).*

- *I don't know that I want that. The behaviours change. If you are really interested you should spent the time. It needs to be updated and how to make sure it is all correct. It may be great in theory, but I don't know about the practise. I think I don't support this.*

- *Not sure. I would not want to share my phone number, mobile, address. That's private. Maybe, where I work, but I don't want them to do something terrible. I want to be careful.*

- *That would work for me. But maybe I need someone else so help me check that the information is right. My private stuff, like having been raped that's private, I don't want people to know about that.*

However there were also some benefits that people could identify in having electronic records.

- *Would be easier for support worker than having a big folder to carry around.*

- *You could tell your story and then you could keep that story on the database.*

- *It could have in it the things you liked.*

People thought that they should be in charge of who has access to the records and not all support staff, family members or government should automatically have access.

People were clear about who should be able to access the electronic record and some safeguards that could be implemented to ensure it worked in people's interests.

- *You should be able to look at it yourself.*

- *Depends on your personality and choices.*

- *The person gives permission, yes or no.*

- *People who know you properly, that you trust.*

- *If they're going to look at information about you, it's better to do it while you're there.*

Feedback also indicated that a 'need to know basis', controlled by the person, would be a reasonable approach to sharing information and what type of information was recorded. One person spoke about a criminal record and was worried people would find out this information in circumstances where it was not relevant. A parent also spoke about their concerns in how challenging behaviour could be interpreted.

I think possibly the medical condition, but nothing private. I don't know. Not judgement like challenging behaviour. Everyone should have control over their story.

Careful consideration in regards to privacy, access and control would need to be paramount in designing any electronic records that would be acceptable to people with intellectual disability.

Community

People had multiple ideas on what could make their community a better place for people with intellectual disability to be part of. They thought these would be good starting point for some of the community development work Ability Links Coordinators or others could undertake.

Suggestions on how to engage with people with disability in the local community included:

■ *I think they (Ability Link Coordinators) should learn about the people and who lives in their area.*

■ *I would love to be involved with that. I would say to have a conference and talk to people with disabilities. And doing training and things like that.*

The key areas that people thought would be an important focus for community work that would benefit people with intellectual disability were:

■ Community attitudes and social opportunities.

■ Employment.

■ Physical accessibility.

■ Transport.

Community attitudes and social opportunities

There was much evidence from the conversations which supported the notion that people with intellectual disability are treated differently and in many instances in a negative manner by the wider community.

■ *Sometimes people look at me strange or run way. Some people think I have an illness. It's not true, it doesn't make me feel very nice inside.*

■ *Some people treat people with disability with disrespect. At (town name) show a person called me and a friend a name. It made me feel disappointed and disrespected. We as people with disability should have the same rights.*

People with intellectual disability also felt that they could play a role in remedying this situation. One person said they would like to:

Get up and speak to people in the community about what it feels like when people are mean to you – see how they would like it.

Another person spoke about an idea she was working on with an advocacy agency:

I am to start a disability group with (name of agency) to educate people without disability. It would work if for example, if people, able bodied ones, have a few hours a week to talk to people with disabilities. Maybe it's like if you are a citizen in Australia, you do that.

A parent noted that:

It is all about perceptions. People without disability need to take the time to get to know people with disabilities.

Social opportunities included more ways to be involved in the community alongside people who did not have a disability. This included sporting, recreation, volunteering and leisure pursuits.

■ *There's not much to do round here, unless you are a big drinker.*

■ *Offer classes and things for people to learn in the mainstream. Budgeting, craft and we could explain to the mainstream people we could make friends and we could explain we are like you guys and you can get the understanding of the disability and be just gentle and not talk too angry.*

Many people spoke of loneliness and isolation and had a real desire to have more relationships in their lives.

■ *I'd like to make more friends.*

■ *It's a bit upsetting because I want to do what normal people do. I feel wired hanging out with people with disability. I want to be more independent. Make my own friends.*

■ *Help to get new friends.*

Other people spoke about how they faced multiple disadvantages with regards to being able to take part in their community due to their culture.

If you are from a non-English speaking background – it's very difficult and it's like two barriers. The government should also work on that.

Employment

Many people wanted to find meaningful work. Strategies suggested to enable this included having better quality job support agencies, more variety of work on offer and employers being more open to employing people with intellectual disability.

■ *My goal in my life is to get a job and to hold it down.*

■ *I would love to do retail. I put resumes in and don't hear from them. Out of five I heard back from one and it was a rejection.*

■ *(I'm) trying to get work but the government don't let you do it.*

■ *Getting a job, it's hard to be accepted in the workplace.*

■ *I wanted to do lawn mowing but no one would take me on.*

Many people were currently connected to employment agencies or further education, but it had not proven very satisfactory in helping them to achieve their work goals.

- *Shake up the job providers, they are a bit slow. More choice, they let you down when you're really eager to do it.*

- *I'm sick of TAFE, didn't teach me what I needed to learn. I couldn't read when I got here, but I learnt eventually. I've done heaps of courses, but they still haven't got me a job.*

Some people who attended the consultations were currently in employment. When asked if they would continue working if they won the lotto the answer was mostly yes, especially for those in open employment. Main reasons given included friendships, having something to do and that they really enjoyed their work. This demonstrates the value, beyond fiscal benefits, that employment can bring for people with intellectual disability.

- *Getting the money and mixing with other people.*

- *It's not sitting at home being bored, watching cartoons.*

- *Meeting new people.*

The people who did not agree had either been in the same role, usually in supported employment for a long period; or were not paid as much as they felt they were entitled.

- *It's the same thing, gets boring after a while.*

- *I work for money – it could be more.*

Physical Accessibility

Conversations about accessibility focused on improving the amount of places that were accessible in the community as well as ensuring that places that claimed to be accessible actually had wide enough aisles, doors and entrances.

Even at Big W the aisles are not really that big and they are supposed to be, but they get away with it.

People expressed how limiting their options could be when there are only a few places they could regularly access. It did not help with having choice about how they spent their time or being exposed to new opportunities or social connections. This was raised equally in both regional and urban locations with people feeling they were excluded from a wide variety of settings.

Asked how this could be improved and the answers were straightforward:

- *Better wheelchair access, you can't get in to lots of shops.*

- *Yes! More ramps.*

- *More buses and trains more accessible for wheelchairs and more ramps, it's really hard for people in wheelchairs.*

Transport

All groups said that this needs to be improved by increasing the frequency, reliability, routes, accessibility and affordability of public transport. Lots of people agreed with one person's statement that there needed to be:

Regular public transport and more of it.

Similar to physical accessibility, not having access to transport and needing to rely on services or community transport meant that many people had major restrictions on where they could go and what they could do. A few people expressed interest in using their support money to purchase a vehicle or sharing a vehicle with someone else so that they could have more flexibility in their transport arrangements.

Some others were able to travel more independently in the community, either walking or cycling, but there was also room for improvement in these areas.

■ *Making more bike paths for people who don't drive.*

■ *Transport is a big lack, I have to ride my bike, there's a big lack of bike paths.*

Summary

NSW CID has deliberately included a large amount of direct quotes from people with intellectual disability in this report. The intention of this is to let the voices of people with intellectual disability have a direct impact on the readers of this report, especially those who are decision makers in relation to developing and implementing person centred approaches.

The quotes do indicate that while people with intellectual disability welcome the promise of change and improvement in their lives, they are mindful from their past experiences that numerous barriers can easily prevent this from occurring.

Introducing a range of enabling factors and safeguards as part of this reform process, as suggested by the participants in these consultations, would certainly go some of the way towards people with intellectual being more control of their lives.

Successfully doing this would definitely help people in their quest of:

Trying to get my own life!

Appendix

Example of focus group activities

Activity 1 – If you won the lotto

As an ice-breaker activity participants were asked to think about what they would do if they won the lotto and then to share their thoughts with the group. This encouraged people to speak up and feel comfortable with the group as well as focus on something that would be important to them in their lives.

The majority of answers indicated quite modest aspirations. These were primarily based around choosing a new place to live, including the people they lived with, employment and holidays.

Activity 2 – Making choices

A range of large pictures were placed around the rooms that depicted people engaged in everyday activities such as working, being at home, meal times and leisure pursuits.

People were firstly asked to place a post it notes on a picture that represented an area in which they had control over in their lives. These were then discussed in the group. People were then asked to place a post it note on a picture that represented an area where they would like to have more control of in their lives. Again these were discussed with the group.

This activity allowed people to begin to think about choices and decision making. It enabled people to explore some of the dynamics of decision making and how this occurs in their lives.

People indicated that had most choice over tasks such as what they wore or what they ate for breakfast. People would like to have more choice about where they lived, including who they lived with, employment and the services they use.

Appendix – Participant Information

Number of People with Intellectual Disability who took part: 69

Sex	Female: 38	Male: 31				
Age	Range: 17-65	Average: 36				
Location	Urban: 21	Semi Regional: 22	Regional and/or Remote: 26			
Cultural Background	ATSI: 0	CALD: 8	Caucasian: 59	Did not disclose: 2		
Living Arrangement	Lives with Parents/Family: 30	Lives in supported accommodation: 26	Lives alone with drop in support: 2	Lives alone: 8	Nursing Home: 1	Did not say: 2
Employment	Open: 6	Supported: 22	Day Program: 16	Transition to Work Program: 5	Seeking: 8	Other: 12
	Other included did not say, full time parent, carer for others, retired, studying etc. Many people in this category were also seeking work.					
Support (Formal support funded by Government)	Some of the support types listed were Community Participation Program – both centre based and self-managed model, Active Ageing Program, Home Care, Advocacy, Employment Agencies, Recreational Services, Day Programs, Business Services, TAFE, Accommodation Support and Respite. It was difficult to ascertain exact details on these as some people received support from multiple agencies but were unable to identify who did what. Other people only identified their support by the name of the agency that provided it. Support came from both a mix of both Government and Non-Government providers.					

Two parents of people with intellectual disability were also interviewed and the above data reflects their children's information.

This report has been published by the NSW Council for Intellectual Disability for the Department of Family and Community Services, Ageing Disability and Home Care as part of the *Living Life My Way* consultation process.

An Easy Read version of this report will also be available.

August 2012.

NSW Council for
Intellectual Disability

Phone: (02) 9211 1611 or 1800 424 065 (Regional Areas)

Email: info@nswcid.org.au

Website: www.nswcid.org.au

NSW
GOVERNMENT