

DANA Conference presentation – Christina Ryan, Advocacy for Inclusion  
30 – 31 October 2013

Ask Me. I make my own decisions – presentation on the research and report by Advocacy for Inclusion.

### **Who and Why**

In June 2012 Disability ACT asked Advocacy for Inclusion to assist with preparations for the National Disability Insurance Scheme (NDIS).

We work with isolated and marginalised people with disabilities, who aren't involved in government and community consultations about the NDIS. We interviewed these people with disabilities to share their perspectives on control and choice, which is the basis of the NDIS.

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A total of 20 people with disabilities ranging in age from 16 - 67 participated in this study. They have a range of support needs; and half live in supported accommodation. The majority have paid disability support services. Most of our study participants will become recipients of the NDIS due to the level of support they currently require.

Our research confirmed what we already knew: that we should be very concerned at the lack of control and choice people have over their supports and over their lives.

We also found some ideas about what is working well and what sorts of training and resources people might need to help them build more control and choice.

### **Key Messages**

We asked people to tell us what they want out of life: what are their goals and aspirations. They had pretty clear ideas and, not surprisingly, these were very similar to what everyone else wants:

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- To get a job or work more hours;
- To move out of family home or out of a group home into an arrangement of their choosing;
- To go on a holiday of their choice;
- To get out into the community more and socialise; and,
- To learn or maintain living skills and independence.

Finding a paid job was the big one for most people. The barrier to this was not being able to get the support necessary, or finding the system too difficult to navigate.

In fact, not enough support or a difficult system to navigate was the most common barrier experienced by people in our study. People were also worried about expressing their goals in case their service provider didn't come through and they were left in the lurch.

### **What we found**

"Control" is about the person with disability having self-determination; they are the decision maker and are supported to achieve their outcomes. They get support if needed, but not control or pressure from others.

“Choice” means having options like everyone else and the freedom to make a choice without control or pressure from others. For example: who you live with and where.

A really important part of control and choice is that **everyone** can do it including people with “significant” disabilities who everyone thinks can’t.

Some people will need more support than others. Everyone is different.

What is most important is that people around the person believe in their capacity to have control and choice, regardless of their disability, and that they are also supported to have that control and choice.

Participants in this study wanted to be respected as decision makers in their own right – as adults who choose what they want and how it should happen.

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*Interviewer: “overall how much control and choice do you feel you have in your life?” Participant: “Not much.” Interviewer: “why is that?” Participant: “First of all, you got people that tell you what to do!”*

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*“People with disabilities should have more of a say over what we want, not just parents. Parents should back off and let them have a say.”*

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*“It’s good to be able to ask for advice when you want. But I’m just asking for advice and options not direction.”*

Most of the people in our study weren’t sure about how their supports were funded or managed. They’ve also never had any option to hold their own funds or control their supports.

When raised, several people said they would like the option of self-directing their funds. Particularly those who were already on ISPs but hadn’t been told that this was an option.

The majority of participants had never heard of the NDIS until they were invited to be a part of this study. Most support people **had** heard of the NDIS; however, the message had not reached the person with disability directly.

People with disabilities who had heard of the NDIS had learnt about it through the media, or from support people and service providers. They didn’t know what it meant and they really wanted to learn more about it, especially how it relates to them. They didn’t know where to go for information, apart from talking to their support people.

People suggested that small working groups or one-to-one information sessions might be useful, and also some accessible resources like fact sheets to take home.

Some support people didn't think it was necessary to tell the person with disability about the NDIS. Quite a few were surprised that we wanted to talk to people with disabilities and not their support people.

Some support people were angry that they were not being interviewed. They said that since they were the primary person to organise and manage the support, they should be interviewed rather than the person with disability. They said that the person with disability:

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1. didn't know anything about the NDIS;
2. didn't know how their support was organised;
3. The carer or support person knows more about the person's support needs;
4. has a cognitive impairment.

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*"But surely to source your supply of information you would go to what I consider to be a reliable and available source... [carer] and I have the experience and the knowledge of exactly what ticks and what runs in this household."*

We made it clear that we wanted the views and experiences of people with disabilities.

Some people with disabilities were also reluctant to participate; they were worried that they may not know how to answer, that a support person should be in the room with them to help them answer, or that the interviewer should talk to a support person instead to get the answers.

When given time and space and reassurance in their abilities, people with disabilities gave us their views and opinions very clearly.

All participants who were receiving paid supports said that they do not have control or influence over these supports.

People in supported accommodation say that support rosters are made by management staff with no input from them. Service providers didn't involve consumers when organising their support.

People who live in their own homes and receive services from 'drop in' support workers have more influence over rosters. They are consulted about their support needs and goals. Ultimately, though the service provider still has control and makes the decisions.

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*"I ask to see the timetable they don't send the timetable... [worker] goes 'yes I will' [another worker] goes 'yes I will' but I never see it."*

Some people felt disrespected and identified how they're treated differently from people without disabilities:

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*How would you like it if someone came into your place if you weren't home?" Interviewer: "I wouldn't like it at all." Participant: "You see it's the same thing."*

One participant was resisted when insisting that support workers should not enter his house when he isn't there. He talked about the intrusion and disrespect he felt when this happened yet he felt the service provider thought it was totally acceptable.

People also talked about not being able to choose who supports them.

They felt unable to say that they don't like particular workers, or when they do tell them nothing comes of it. Some people didn't even consider raising concerns because they were accustomed to having no control over who supports them.

Most said they are not supported how they want to be supported or with the activities that they want to be supported with.

Apparently service providers decide how supports will be provided and the consumer is expected to fit into their system:

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*"There is a few times lately that I've wanted to go out ... They said 'well actually it's a residential complex here we're not supposed to be doing that.' I would like to at least go to [name of suburb] shops for a coffee ... Aren't there rules in disability where they've got to take people out into the community?"*

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*"They started running my life from the outside in and not from my point of view. It was the total opposite ... people should ask me 'what would you like to have done today?' and the absence of that question is like a saw in your heart because it is not healthy, not happy, you're sort of regimented. And you never invited that regimentation it's just put upon you."*

For some people, especially those living in supported accommodation, the lack of control and choice runs deep into the smallest details of their lives. This is closely related to the lack of control and choice over their everyday supports.

### **Domestic duties**

People in supported accommodation were kept from domestic duties like laundry, cooking, cleaning and grocery shopping<sup>1</sup>. These tasks were automatically done by support staff, which made people feel even more dependent. The younger people in this study live in with their families and are looking forward to moving out and doing their own domestic tasks as a sign of independence.

People want to be supported to do the things that other adults do. It is much more than a chore; it is a sign of their competence as adults. Being supported to do these tasks also opens up choices, such as the freedom to choose what they want at the supermarket. While

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<sup>1</sup> Advocacy for Inclusion's *Nutrition Project: Where's my 2 & 5?* also found that participants had minimal involvement in meal planning and preparation. See Advocacy for Inclusion. (2010). *Nutrition Project: Where's my 2 & 5?* Retrieved from <http://www.advocacyforinclusion.org/publications/Nutrition/FINAL%20report%20Nutrition%20Project%20August10.pdf>

many need support to do these tasks, this doesn't mean that they can't or don't want to actually do them.

### **Daily routines**

People in supported accommodation say they often have to fit in with the routines of co-tenants and staff rosters, especially in group houses. They arrive at activities late or can't participate in them at all. Some people were particularly frustrated about having to fit vital everyday tasks like using the bathroom into staff availability.

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*"They [service provider] are controlling our movements, controlling what time we get home"*

A number of people find their day is so regimented that they have to get up, and go to bed at set times that don't suit them.

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*Interviewer: "Have you spoken to anyone about the fact that you want to stay up later?" Participant: "I don't think it's going to happen." Interviewer: "How come you think it wouldn't happen?" Participant: "I think it's up to the office."*

"Little" things like this make a huge difference to a person's sense of autonomy and quality of life. A number of people felt that this lack of control is simply 'how it is' when you need support:

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*"I can't get rid of [the need for] help. I don't think you can ever have control to that degree. It still depends on if someone is available to come out at that time ... I understand that I live with people and they also need help."*

People felt that they don't have the right or power to challenge this regimentation. A number referred to what they are not "allowed" to do. To other people it hadn't even occurred to them to question the routines imposed on them by service providers, they're just conditioned to the 'status quo'.

### **Control and choice over big decisions**

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*"I want to spread my wings I just want to be free."*

People told us about significant restrictions on their major life decisions, or of a lack of support to follow those decisions through. This happens directly when others make decisions on their behalf without their permission, or indirectly through the influence of family or support people.

Lack of control and choice over support arrangements is a major restriction on decision making.

A number of study participants were unhappy with their living arrangements and have tried unsuccessfully to move into an arrangement of their choice. Some said that they had never had the opportunity to choose where and with whom they live. They have no control over who lives with them.

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*“The people in my house changed. I was happy before but nobody asked me what I wanted. It made me very angry. It made me very very angry. I complained and [service provider] told me to mind my own business.”*

Other people have to be in their current living arrangement because it meets their support needs. Many people had not chosen their living arrangements but were forced to live in particular arrangements due to a lack of options that meet their needs.

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*Participant: “my mum and dad saw [accommodation provider] and thought it would be a good place to live.” Interviewer: “did you want to live there?” Participant: “I thought it was alright but I didn’t feel I had any other options at the time.”*

### **What needs to happen**

People really value the opinions of their parents. They know that their parents care for them and want them to be safe and well ‘looked after’ and a number of people felt that their parents thought the ‘group home’ option would provide this, even though for the person it means less independence and autonomy.

People told us how important it is to have people who support their decisions and encourage them to follow their personal preferences, even in the face of risks.

People demonstrated their extensive understanding of the supports they need. However, most of them had never had the opportunity to dream about their ideal support arrangement, or to have control and make decisions about their support in the ways intended by the NDIS. Two people spoke about their recent experience of planning to move out of a group home into a home of their choice. They said that this was liberating, but it was also quite foreign and shocking to them as they had never such control and choice before.

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*“It felt weird, because I haven’t had to do that before ever. I haven’t ever had to work out my support before. It really took me by surprise. I hadn’t even thought about it [laughs]!”*

It took these people many months with support to decide and plan, where they wanted to live, who they wanted to live with and how they wanted their supports to work. They found it particularly helpful being prompted to consider options that they had never considered or known about before. They are more than capable of making their own decisions but very much valued the guidance, support and reassurance they received from their service provider and advocate.

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*Interviewer: "How would that process have been if you were doing it alone then?" Participant: "It would have been very very hard and frightening."*

More than half of our study participants were excited about the NDIS because they hope it will allow them more control and choice over their supports and their lives.

A few people specifically hoped that they can choose who supports them by employing them and/or interviewing them personally.

Everyone said that they will want help to have control and choice over their supports.

Several types of support were suggested by people:

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1. **Information and assistance to navigate** the large and complex disability system. Most participants spoke of this, especially long term assistance such as by a case worker. People typically use the system for most of their lives and they are frustrated by not having a consistent contact person or agency who can guide them through the maze. Once off or short term assistance is not enough for many people as they soon find themselves lost in the system again;
2. **A trusted agency or person to hold and administer the funds for them, while they decide how it is spent;**
3. **Assistance to hold and manage the funds themselves**, especially assistance with administration tasks and rules;

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4. **A centralised information system** where people can go in person, on the phone, and on the internet to find out about what is available to them and what they are entitled to;
5. **Information and advice (NOT direction) on the financial aspects of their support and how they might best package their support;**

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6. **Information about their rights and responsibilities in the NDIS;**
7. **Moral support and encouragement - someone who affirms the person's abilities and decisions.** As one participant put it:

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*"Simply to agree that we are dealing with things responsibly. That's all. I don't want her [case worker] to have any input, I don't want her to have any decision power. I simply want her support in the decisions that I do make are responsible decisions."*

Most people said that while they are excited they are also a bit freaked out by the NDIS because they have never had this level of control and choice. Some people identified

problems with their current supports but also said that they don't want their support arrangements to change, or indeed to have more control and choice.

This indicates that they might be nervous about the changes that are coming. The idea of having this level of control and choice could be overwhelming given it hasn't been available before. Many people are not ready to envisage how having control and choice could address some of the current problems with their support.

We strongly recommend extensive work be undertaken with people with disabilities to prepare them to exercise control and choice over their supports and their lives when the NDIS is introduced. Extensive work with support networks and the workforce is also needed to ensure control and choice is adequately supported.

## **Conclusion**

Our study participants are seriously restricted in having control and choice over their lives and supports. This is due to under-resourcing, organisational culture, and the approaches taken by support people and services.

People with disabilities face major barriers in getting control and choice over their own lives and supports. They are unable to access the supports they need in the current system and the dominant culture portrays people with disabilities as passive, 'tragic', and unable to run their own lives.

The NDIS provides a framework for change; however, people with disabilities will not automatically have more control and choice when the NDIS is rolled out if a lot of effort is not made to assist them to transition into the 'drivers' seat'.

People with disabilities cannot be expected to easily slide into self-directed or self-managed funding options, to know their rights and feel confident to take control and make choices.

The current system has taught people to take whatever they are given. The system has conditioned and institutionalised them not to make choices and not to take control over their supports. The new system will need to help unlearn this.

A lot of work is needed to implement this structural and cultural change throughout the disability sector, and among people with disabilities and their support networks. People with disabilities must be supported to make the most out of control and choice. Their support networks will also need support and guidance as we make this change.

If we don't get this right then negative social and cultural assumptions about disability will continue under the NDIS. Significant cultural change is fundamental to improving the control and choice of people with disabilities.

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Thank you