advocacy for inclusion

Ask me. I make my own decisions

Report on the findings of a study into the experience of control and choice of people with disabilities in the ACT

Advocacy for Inclusion

May 2013

About Advocacy for Inclusion

Advocacy for Inclusion acknowledges the Ngunnawal people as the traditional owners of the land on which we work.

Advocacy for Inclusion provides individual, self and systemic advocacy services for people with disabilities. We provide information, education, and representation to effectively advocate for positive and inclusive outcomes for people with disabilities.

We act with and on behalf of individuals in a supportive manner, or assist individuals to act on their own behalf, to obtain a fair and just outcome for the individual concerned.

Advocacy for Inclusion works within a human rights framework and acknowledges the *United Nations Convention on the Rights of Persons with Disabilities*, and the *ACT Human Rights Act*.

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Executive summary

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

Advocacy for Inclusion was approached by Disability ACT in June 2012 to assist with preparations for the National Disability Insurance Scheme (NDIS). After some consideration Advocacy for Inclusion decided to undertake a research project on the readiness of people with disabilities to exercise control and choice over their own lives and supports. Control and Choice is the central underpinning of the NDIS. Advocacy for Inclusion had raised concerns based on our advocacy work that control and choice of people with disabilities is not currently well supported, or strongly exercised, and that the NDIS would not fulfil its intentions without this being remedied.

The findings from this research paint a very concerning picture of the lack of control and choice people with disabilities have over their supports and over their lives. Most had also never heard of the NDIS. It illustrates cultural issues in the community and the disability services sector, which can deny people with disabilities their right to "respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons."[1] This study also uncovers small signs of what is working well and what is helping people to gain more control and choice in their lives.

In this report we draw attention to these issues not to criticise individual approaches of paid and unpaid support people, who are vital in the lives of people with disabilities. Rather, the purpose is to identify potential solutions and invite a total rethink of the current approach to people with disabilities in our community and how supports and services are provided to them, especially in light of the imminent NDIS.

Advocacy for Inclusion strongly recommends that extensive work be undertaken directly 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 workforce is also required to ensure control and choice is supported.

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[1] United Nations. (2006). Convention on the Rights of Persons with Disabilities. *Article 3*

Summary of Recommendations

1. What do participants with disabilities want out of the NDIS?

1.1. The diversity among people with disabilities must be respected and catered for. Preparations for the NDIS in the ACT must be targeted at building services which are flexible and responsive to the personal and changing needs and wishes of consumers with disabilities.

1.2. Preparations for the NDIS must include supporting people with disabilities to identify their own needs, preferences and life goals so that they can then shape their supports packages to suit. An example existing in the ACT that could be tailored to meet NDIS purposes is the PATH (Planning Alternative Tomorrows with Hope) program.

2. Exclusion from the 'ins and outs' of the system – old and new

2.1. People with disabilities should be engaged in conversations and supported to understand key aspects of the disability support system and how it is funded, including their human and consumer rights.

2.2. Mass media is an important means to communicate the NDIS directly to people with disabilities. Governments must communicate about the NDIS via mass media and specifically target people with disabilities. Messages must encourage the concept of control and choice for people with disabilities.

2.3. People with disabilities who are assumed to be unable to understand or be involved in discussions and information sharing about the NDIS have a right to be. The expectation that all people with disabilities have some capacity to be engaged is crucial and must be practiced.

2.4. A circular process should be used to engage people with disabilities in the NDIS who have high support needs and who are not yet engaged. This involves one to one and small group information sessions for NDIS readiness, run on an ongoing basis. People should be able to access information sessions several times to support them to:

- Access the information;

- understand and process the information;

- consider how they want the NDIS to apply in their own lives;

- ask questions and discuss the information.

2.5. Information must be provided in appropriate formats and language to ensure meaningful engagement.

2.6. Information kits for service providers to share information about the NDIS with consumers in house will be useful.

3. Gate keeping and communication

3.1. People with disabilities should have access to the internet and be supported to use the internet such as via assistive technology and mentoring if they desire it. This must be regarded as a key factor of 'inclusion' for people with disabilities.

4. Control and choice over supports

4.1. People with disabilities should be respected as the decision maker for their own supports and lives. This includes over their support budget, staff rosters and how their support needs are prioritised.

4.2. People with disabilities must be enabled and supported to choose their service providers and their direct support workers, and the form that their support takes.

4.3. Where people with disabilities need assistance to direct or manage their supports, service providers and support people must operate under the direction of people with disabilities. This involves for example, drawing up a budget and staff roster with the person with disability and according to their direction.

4.4. People with disabilities need information and support services that enable them to exercise their consumer rights.

4.5. Supporting self-advocacy training should be made widely available for support workers to teach and enhance their skills in supporting the person with disability to exercise control and choice.

4.6. A supporting self-advocacy tool should be developed for organisations to guide organisational approaches to supporting consumer control and choice.

4.7. A 'control and choice' policy development guide should be established for disability organisations.

4.8. A kit should be developed to support cultural change for disability organisations targeted at equipping them for the NDIS and supporting consumer control and choice.

4.9. A 'control and choice' self-assessment audit kit should be developed for disability organisations.

4.10. An induction kit should be developed for new employees in disability organisations to establish their understanding of supporting consumer control and choice.

4.11. Human rights training and resources should be made widely available to disability organisations and support workers, since human rights are fundamental underpinnings of the NDIS.

4.12. Resources for individual support people should be developed to assist them in supporting consumer control and choice such as:

- tools to guide supported decision-making;

- self-reflection exercises for support people to check if they are supporting a person to make their own decisions and exercise control and choice;

- reminders such as wall charts.

5. Control and choice over day-to-day decisions

5.1. Easy English human rights resources should be made widely available to people with disabilities to inform and remind them of their human rights, for example, posters and pocket or wallet cards.

6. Control and choice over big decisions

6.1. Explore 'risk enablement' as an alternative to traditional risk management approaches in order to maximise the quality of life, wellbeing and control and choice of people with disabilities.

6.2. Establish risk enabling tools for organisations and support people in the ACT.

7. Skills in control and choice

7.1. Establish a centralised information system where people can go in person, on the phone, and on the internet to assist with navigating the large and complex disability system, find out about what is available for them, and to what they are entitled.

7.2. Support services to assist with establishing self-management and self-direction systems.

7.3. Establish a 24 hour hotline that people with disabilities and support people can access for information and referrals.

7.4. Resources to assist people with disabilities to identify what control and choice is and how they can exercise this over their support funds.

7.5. The people, agencies and systems around people with disabilities will need to be patient and allow them to make well informed and well considered decisions about their supports and their lives. Some people will take a couple of years to explore and decide how they want their lives too look. They must be supported to plan over extended periods.

7.6. It must not be assumed that because people are afraid of this new system that they cannot learn about it and eventually self-direct their support funds. People must be supported to transition and make the most of the new system.

7.7. Make approaches and tools widely available targeted at supporting people with disabilities to see how they can gain more control and choice over their lives beyond what they imagine possible in the current system.

7.8. Make decision making tools widely available to people with disabilities to guide and remind them about decision making processes. For example:
- wall charts
- tablet applications
- web tools
- information kits
- mind maps.

7.9. Make human rights resources and training widely available in appropriate formats for people with disabilities.

7.10. People with disabilities need positive support and encouragement to take control and choice in their lives. Their right to have control and choice must be communicated to them

- tools such as wallet or pocket cards, posters, and t-shirts that reinforce the right to control and choice

7.11. People with disabilities need ongoing support to build and exercise control and choice over their lives. This includes:

- Self-advocacy courses, where people with disabilities are supported in a group or one to one to learn skills in asserting their wishes;

- Sustaining self-advocacy skills courses and groups, where people with disabilities are supported to remember and reinforce self-advocacy skills;

- Supporting self-advocacy courses for support people to learn how to support people with disabilities to self-advocate and exercise control and choice.

8. 'About me without me'

8.1. As the NDIS is implemented, it is crucial that young people with disabilities are supported to be actively involved in the decisions concerning them so that they have the skills to make decisions about their supports once they become adults.

8.2. Resources targeted specifically to engage young people with disabilities must be made widely available to them.

9. Being assertive, negotiating, making complaints

9.1. Services and resources that support people with disabilities to make complaints and negotiate with their service providers must be made widely available to them.

- independent advocacy services;

- tools that guide the person with disability through the steps of making complaints and negotiating with service providers.

10. Supporting control and choice

10.1. People with disabilities need to be listened to, respected and taken seriously in order to have meaningful influence over the supports they receive, and to take control over their lives

10.2. Supporting self-advocacy courses for support people to learn how to support people with disabilities to self-advocate and exercise control and choice.

Snapshot of the project scope and design

This research was undertaken using qualitative methodology. Individual in-depth interviews were undertaken with people with disabilities to explore their experiences of control and choice over their own supports and lives. A focus group including members of Advocacy for Inclusion's self-advocacy network was also used to assist in discussing and interpreting the findings of this study.

People with disabilities were interviewed directly; however, through interactions in setting up the interviews a great deal of contact was also made with paid and unpaid support people. Those experiences are also included in this report.

See Appendix 1 for the full details on project scope and design.

Participants – who were they?

A total of 20 people with disabilities participated in this study, including 12 females and 8 males. Eighteen of the participants were interviewed individually and were sourced from Advocacy for Inclusion's current and past consumer base and self-advocacy students.

Participants range between 16-67 years of age. They have a range of support needs and half live in supported accommodation. Fifteen were receiving paid disability supports at the time of the interview and the remaining 3 received unpaid support by family or volunteers. Two additional people from Advocacy for Inclusion's self-advocacy network were engaged in the focus group.

It is likely that most study participants will become recipients of NDIS support due to the level of support they currently require. Advocacy for Inclusion uses the social model of disability, so only people who self-identify as having disability have been included in this study.

Participants – why were they involved?

Advocacy for Inclusion works with isolated and highly marginalised people with disabilities, whom we know are not involved in typical government and community consultations concerning the NDIS such as community forums or the 'Your Say' website. These people come to Advocacy for Inclusion for assistance with gaining control and choice over their lives in one way or another. Their stories are often hidden from and unheard by the broader community, yet these people are likely be targeted as NDIS recipients. We set out to interview these people with disabilities to share their perspectives on control and choice, the underpinning of the NDIS.

Background

Control and choice

Control and choice for people with disabilities over their own lives and supports is an underpinning of the NDIS. Section 4 (8) of the *National Disability Insurance Scheme Act 2013* states that:

> "People with disability have the same right as other members of Australian society to be able to determine their own best interests, including the right to exercise choice and control, and to engage as equal partners in decisions that will affect their lives, to the full extent of their capacity."

This is informed by the fundamental human right for people with disabilities, as per the *Convention on the Rights of Persons with Disabilities*, to be treated with:

> "Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons."[2]

Control and choice is not only a human rights and legislation issue. It is hugely significant to the wellbeing and potential of people with disabilities:

> There is now indisputable recognition that some of the major determinants of our mental health and wellbeing lie within the social and economic domains of our lives, and include social inclusion, having a valued social position, physical and psychological security, opportunity for **self-determination and control over one's life** and access to meaningful employment, education, income and housing.[3]

By **control** we mean that the person with disability has self-determination over their own supports and lives. The person with disability is the decision maker about their destiny and about how they are supported to realise their destiny. They do this freely with support if needed but without control or pressure from others.

By **choice** we mean having options in one's life on an equal basis with people without disabilities and the freedom to choose from these options without control or pressure from others. For example: where and with whom the person will live.

Advocacy for Inclusion emphasises that fundamental to the concept of **control and choice** is the recognition that all people with disabilities, including people viewed as having 'significant' disabilities, can have control and choice in their lives and supports.

Control and choice will not look the same for everyone and some people will need more support than others to exercise it. What is most important is that others believe in the person's capacity to have control and choice in their own lives, regardless of disability, and that they are supported to exercise this capacity to the fullest extent.

Context of disability in Australia – the policy directions

Over recent years people with disabilities have become more politically active and government and organisational policies have started to reflect progressive and human rights oriented approaches to including people with disabilities in the community.

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[2] United Nations. (2006). Convention on the Rights of Persons with Disabilities. *Article 3*
[3] Victorian Government Department of Human Services. (2005). *Evidence-based mental health promotion resource.*
http://www.health.vic.gov.au/healthpromotion/downloads/mental_health_resource.pdf

The *National Disability Strategy* (NDS) is a whole of government initiative that guides social policy to promote social inclusion and the potential of people with disabilities. It aims to ensure that human rights principles are incorporated into policies and programs concerning people with disabilities, their families and support people.

The *Strategy* is based on the social model of disability: "Attitudes practices and structures are disabling and can prevent people from enjoying economic participation, social inclusion and equality. This is not an inevitable result of an individual's impairment."[4] This frames how services and supports should be delivered to people with disabilities, including the NDIS.

Consistent with this, the ACT Government is committed to the vision that: "All people with disabilities achieve what they want to achieve, live how they choose to live and are valued as full and equal members of the ACT community."[5]

'Person centred approaches' have become popular among disability service providers - where the person with disability is viewed as the central decision maker about their supports. It is highly questionable, however, that these 'person centred approaches' have translated into practice. The fast approaching NDIS gives people with disabilities, service providers and support people a framework to put these ideas into practice in a meaningful way.

Context of disability in Australia – the problems in reality

Despite progress in policies, the same cannot be said for the reality among people with disabilities. The disadvantage in Australia among this cohort is well-evidenced. Some examples include:

- A heightened risk of social isolation[6];
- Twenty-nine per cent less participation in the labour force compared to people without disabilities[7]. Australia is one of the worst performers for employment of people with disabilities in the developed world[8];
- Two and a half times the rate of poverty in the general population[9]. The rate of poverty in Australia for people with disabilities is more than double the OECD average[10];
- Lower levels of education[11]; and,
- Higher risk of experiencing violence and abuse.[12]

People with disabilities also face negative attitudes and misunderstandings among the community. A recent study by Scope and Deakin University of 761 Australians with disabilities found that this is the biggest barrier to their inclusion in society[13]. The concept of disability is dominated by medical understandings where people are viewed in terms of their

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[4] Commonwealth of Australia. (2011). *National Disability Strategy: An initiative of the Council of Australian Governments.* Canberra: Author.
[5] Community Services Directorate. (2011). Disability ACT *Vision and values statement.* Retrieved from http://www.dhcs.act.gov.au/disability_act/vision__and__values
[6] Scope & Deakin University. (2013). *Australians fail social inclusion test for people with a disability.* http://ahha.asn.au/news/australians-fail-social-inclusion-test-people-disability
[7] Australian Bureau of Statistics. (2011). Labour force. 4446.0 – Disability, Australia, 2009.
[8] OECD. (2010). *Sickness, Disability and Work: Breaking the Barriers - A Synthesis of Findings across OECD Countries.* Appendix K The disability support pension. Productivity Commission Inquiry Report. No. 54, 31 July 2011
[9] Walsh, J. (2012). Australia's health 2012: Social inequalities, health inequalities. Retrieved from www.aihw.gov.au
[10] OECD. (2009). *Sickness, disability and work: Keeping on track in the economic downturn – Background paper.*
[11] Australian Bureau of Statistics. (2011). Education. 4446.0 – Disability, Australia, 2009.
[12] Hughes, K., Bellis, M. A., Jones, L., Wood, S., Bates, G., Eckley, B., McCoy, E., Mikton, C., Shakespeare, T., & Officer, A. (2012). Prevalence and risk of violence against adults with disabilities: A systematic review and meta-analysis of observational studies. *Lancet,* 379, 1621-29
[13] Scope & Deakin University. (2013). *Australians fail social inclusion test for people with a disability.* http://ahha.asn.au/news/australians-fail-social-inclusion-test-people-disability

medical impairments rather than their personhood. Disability is often portrayed as a 'personal tragedy'[14]. In this context, people with disabilities are widely regarded as passive service recipients who do not know their own best interests.

At the same time, the current disability support system is "underfunded, unfair, fragmented, and inefficient, and gives people with a disability little choice and no certainty of access to appropriate supports"[15]. In this system, less than half of all people with significant disabilities access half the supports they need[16]. Resources and supports for people with disabilities are largely controlled and determined by service providers. People with disabilities simply get whatever is on offer[17].

In practice, Advocacy for Inclusion regularly encounters the belief that people with disabilities, especially those with high support needs, cannot have control and choice over their lives. This includes people working closely with people with disabilities such as their support workers and unpaid carers. This issue is noted by numerous researchers and writers[18].

The backbone for change – NDIS

In 2013 the Australian Government legislated for the NDIS to introduce a new system that "will turn the way we currently provide disability services on its head"[19]. It is a major advancement in the way people with disabilities are supported in Australia, with the primary aim to enable people with disabilities to get the supports they need and exercise control and choice over their lives and their supports. It will do this by giving people with disabilities direct control over the funds that pay for their support. This is called an individualised funding model.

Some people with disabilities will self-manage their funds by being fully responsible for holding and administering the funds. It is likely that most people with disabilities will self-direct their funds, where a person or agency of their choice holds and administers the funds, while they make the overarching decisions about how those funds will be allocated. This contrasts to the current system, where disability services are allocated funds directly to support certain numbers of people.

This new scheme provides the framework that could position people with disabilities as active consumers, who are in the driving seat of their own supports and their own lives. However, it provides only a framework. It alone will not change the prevailing negative assumptions about people with disabilities and the disabling culture that surrounds them. It is a means to an end, not an end in itself[20].

Bach[21] found in his study of people with disabilities who transitioned to individualised funding that some did not gain control or choice over their support. Service providers and support people continued to control the funds, as they had prior to the new model. Some people with disabilities were not even aware that they had individualised funding.

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[14] Barnes, C., & Mercer, G. (2003). *Disability: Key concepts.* USA: Blackwell Publishers Inc.
[15] Productivity Commission. (2009). *Disability care and support: Key points.* Retrieved from http://www.pc.gov.au/projects/inquiry/disability-support/report/key-points
[16] Australian Institute of Health and Welfare. (2009). *Disability in Australia: multiple disabilities and need for assistance.* Disability series. Cat. no. DIS 55. Canberra: AIHW.
[17] Productivity commission.
[18] See for example, Wehmeyer, M. (1998). Self-determination and individuals with significant disabilities: Examining meanings and misinterpretations. The Association for Persons with Severe Handicaps.23(1), 5-16
[19] FACHSIA. (2012). What is an NDIS?. Retrieved from http://www.ndis.gov.au/about-an-ndis/what-is-an-ndis/
[20] Fisher, K., & Campbell-McLean, C. (2008). *Attendant care direct funding pilot project evaluation—final report.* Report for Department of Ageing, Disability and Home Care NSW, SPRC Report Series 11/08. Sydney, Australia.
[21] Bach, M. (2000*). Individualised funding and self-determination: making sure the means does not become the end.* The Roeher Institute. Presented at the First International Conference on Self-determination and Individualized Funding

Similarly, a recent evaluation of a self-directed support pilot in Queensland[22] showed that the self-directed model did increase the level of control individuals had over their funding. However, participants and case workers consistently felt that they needed to get approval from management to see through the participant's decisions even though this was not required by management. This constrained the participant's ability to have self-determination and control over their funds. The evaluation also raised questions about the degree to which some participants felt comfortable to assert their wishes and direct the planning process.

People with disabilities cannot be expected to easily slide into a self-directed or self-managed funding option, knowing their rights and feeling confident to take control and make choices. The current system has taught them to take whatever they are given, which is often not enough to meet their needs. In this sense it has conditioned and institutionalised them not to make choices and not to take control over their supports. The new system will need to help them unlearn this.

Advocacy for Inclusion understands that it will be a shock for many, and although exciting it will be frightening and overwhelming to suddenly have the capacity for control and choice during the initial stages of transition. People with disabilities will not automatically have more control and choice when the NDIS is rolled out if concerted efforts are not made to assist them to transition into the 'drivers' seat' of their supports. This is concerning particularly in light of the predominant understandings of disability noted above, wherein people with disabilities are viewed as passive, 'tragic', and unable to run their own lives. These assumptions will prevail in the new system if they are not actively addressed as part of the system restructure.

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[22] Robinson, S., Gendera, S., Fisher, K. R., Clements, N., Eastman, C., & Oprea, I. (2012). *Evaluation of the Self Directed Support Pilot for Children and Young Adults with a Physical Disability.* Social Policy research Centre. http://www.sprc.unsw.edu.au/media/File/Final_SDS_Evaluation_report_Aug_2012.pdf

Study findings

Ten key themes were identified though the stories shared by people with disabilities in their interviews. The *"quotes"* used in this report are the direct words of the people with disabilities involved in this study, unless otherwise indicated.

1. What do participants with disabilities want out of the NDIS?

In the interviews we invited people with disabilities to tell us what they want out of life: what are their goals and aspirations. Participants had clear ideas of their goals and aspirations, and they reflected what most people in the community want out of life:

- 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.

Participants in this study experienced major barriers to realising these goals. Finding a paid job or to work more hours was the most common goal; more than half spoke of this. Most talked about needing support to do this but this support is not available to them or they find the system too difficult to navigate. This was the story for most participants whatever their goals and aspirations. Some people expressed having no involvement in the plans that are in place to help them reach their goal and some spoke of their worries that the service providers they depend on might not *"come through"* with the supports they need to realise their goals.

> *"I will have my own house at [supported accommodation provider]. It will happen but I have to wait. I'm really hoping [provider] will come through."*

Alongside this, participants of this study want to be respected as decision makers in their own right – as adults who can determine their own lives and who can control and choose their own supports.

> *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!"*

> *"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."*

> *"It's good to be able to ask for advice when you want. But I'm just asking for advice and options not direction."*

Discussion

People with disabilities have the human right to determine their own lives and make their own choices[23]. They are a diverse group of people, each with their own personalities, priorities, and preferences. Study participants want the NDIS to be flexible and responsive to this and they want the NDIS to respect them as the central decision maker. To use popular terms, they want the NDIS to be 'person centred'. To realise this, services and supports cannot be pre-packaged for people with disabilities. For example, people want to choose their own holiday destination and whom they travel with, rather than have a holiday program premade for them. People with disabilities must be supported to package their own supports. This will shape the NDIS into what people with disabilities want.

The way forward – recommendations

1. The diversity among people with disabilities must be respected and catered for. Preparations for the NDIS in the ACT must be targeted at building services which are flexible and responsive to the personal and changing needs and wishes of consumers with disabilities.

2. Preparations for the NDIS must include supporting people with disabilities to identify their own needs, preferences and life goals so that they can then shape their supports packages to suit. An example existing in the ACT that could be tailored to meet NDIS purposes is the PATH (Planning Alternative Tomorrows with Hope) program.

2. Exclusion from the 'ins and outs' of the system – old and new

Current disability support system

This section refers only to participants who received paid supports

Most participants who received paid support were unaware or unsure as to how their supports were funded and managed. Some guessed that their supports were paid for by government funding but many found the concept of 'who pays for my support and how is this managed?' quite foreign.

When we asked questions about this we were met with answers such as *"I get it for free"* and *"I pay a contribution"* or simply *"I don't know".* As expected in the current predominately 'block' funded system, the majority have never had the option to hold or control support funds.

Two participants became aware of how their supports are funded under a 'block' system when they decided they want to move out of their group homes. They became familiar with the funding system through this process because the absence of individualised funding posed a major barrier for them in choosing their living arrangements.

Two people have their own 'individual support package' (ISP) and have been active in deciding what service they want to use. However, even these study participants lacked information about how this system works and were unsure how much direction they could have over those funds. One of these participants said that if he had the option of managing his own funds he would do so. When he learnt in the interview that as he has an ISP it is

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[23] United Nations. (2006). Convention on the Rights of Persons with Disabilities. *Article 3*

highly likely that he does have the option of self-direction he was surprised and explained that he had never been informed.

The other ISP recipient felt that they had no option but to merge their ISP with existing 'block' funding at a group home because the ISP was not adequate to support them in their previous home, where they lived alone. For them this meant relinquishing a great degree of their autonomy and direction over their funding and supports, and it was not their preferred option.

Discussion

Under CRPD Article 21 "Persons with disabilities can exercise the right to freedom of expression and opinion, including the freedom to seek, receive and impart information and ideas on an equal basis with others and through all forms of communication of their choice"[24]

However, participants of this study are not informed with key basic information about the disability support system, how it is funded, and how this directly impacts them. Without this knowledge people with disabilities do not know their rights nor how they can exercise their consumer and human rights in this system. This will become a major stumbling block as the NDIS is introduced if it is not addressed.

The way forward – recommendations

1. People with disabilities should be engaged in conversations and supported to understand key aspects of the disability support system and how it is funded, including their human and consumer rights.

2. Mass media is an important means to communicate the NDIS directly to people with disabilities. Governments must communicate about the NDIS via mass media and specifically target people with disabilities. Messages must encourage the concept of control and choice for people with disabilities.

The new NDIS

The majority of participants had never heard of the NDIS until they were invited to undertake this study. The support people of many participants had heard of the NDIS; however, the message had not reached the person with disability directly. This was found for example when interviews were being set up and support people identified their familiarity with the NDIS; however, participants with disabilities did not during interviews. Support people also expressed their own lack of understanding about the NDIS.

People with disabilities who were aware of the NDIS had learnt about it through the media, support people and service providers. They were unsure what it means and expressed a strong desire to learn more about it, especially how it relates to them. They were unsure where to go for this information, apart from talking to support people about it. Study participants suggested that small working groups or one-to-one information sessions would be useful, along with some accessible resources such as fact sheets to take home with them.

Some support people believed that it was not necessary to engage the person with disability directly in discussions about the NDIS. This became apparent at the initial point of contact, when it was difficult to communicate directly with the person with disability to invite them to

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[24] United Nations. (2006). Convention on the Rights of Persons with Disabilities. *Article 21*

participate in this study. For these people contact was initiated through a support person. A number of support people expressed confusion that this study sought the views of the person with disability rather than that of the support person.

Some support people expressed anger that it was not they who were being directly interviewed. They expressed the view that since they were the primary person to organise and manage the support, it was logical that they were interviewed rather than the person with disability. They were also concerned that the person with disability would not know how to answer for various reasons including:

1. They do not know much or anything about the NDIS;
2. They do not know about the management and organisation of their support;
3. The carer or support person knows more about the person's support needs;
4. The person has a cognitive impairment.

> *"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."*

Having this knowledge or unimpaired cognitive abilities was not a prerequisite for participating in the study. Advocacy for Inclusion made clear that it was the views and experiences of people with disabilities sought by this study.

A carer supporting a young person with disability in their interview came to the realisation that they had not yet considered that the person with disability should be engaged in the NDIS discussions:

> *"Interesting you know, I never thought about what he understood of the NDIS. Because I've got a fairly good handle of it because I've certainly been putting my bit in and sending information and questions and stuff so that's something I have to work with him on: giving him more of an understanding."*

Some people with disabilities themselves were reluctant in their ability to participate, raising concerns that they may not know how to answer, that a support person should be in the room with them to help them answer because of this, or that the interviewer should talk to a support person instead to get the answers needed. Deferring to others also occurred during the interviews, including in response to questions about the person's opinion on how much control and choice they have in their lives, and about their individual goals and aspirations. When allowed the time and space and given reassurance in their abilities, these people were able to express their views and opinions very well.

Participants shared positive examples of how people with disabilities are engaged and supported to understand the NDIS and how it relates to them. Some said that their service provider informed them of the scheme and held in-house information sessions, which they found helpful. One particular service provider had begun discussions on how this opens up new opportunities for individuals and for the organisational structure. This level of inclusion and information was only mentioned by two participants who are with this particular service provider.

Discussion

There was an apparent assumption that the participants of this study cannot or do not need to be included in information sharing and discussions about the NDIS. They seem to be constructed as passive service recipients who do not know their own needs, views and preferences. Yet, they do have views, opinions and experiences but those of the participants in this study seem to be devalued and even deemed irrelevant.

It seems that the current system, which offers little control and choice for people with disabilities, has excluded the participants of this study from being meaningfully involved in the structure of disability support systems. They do not know how they come to receive supports, or how this directly impacts the supports they receive, and indeed the level of control they are entitled to have. People with disabilities simply get what they are given without any expectation that they should question or know how and why it works that way. Advocacy for Inclusion has the impression that people with disabilities and support people do not see that this could or should change when the NDIS is introduced.

The way forward – recommendations

3. People with disabilities who are assumed to be unable to understand or be involved in discussions and information sharing about the NDIS have a right to be. The expectation that all people with disabilities have some capacity to be engaged is crucial and must be practiced.

4. A circular process should be used to engage people with disabilities in the NDIS who have high support needs and who are not yet engaged. This involves one to one and small group information sessions for NDIS readiness, run on an ongoing basis. People should be able to access information sessions several times to support them to:

- Access the information;

- understand and process the information;

- consider how they want the NDIS to apply in their own lives;

- ask questions and discuss the information.

5. Information must be provided in appropriate formats and language to ensure meaningful engagement.

6. Information kits for service providers to share information about the NDIS with consumers in house will be useful.

3. Gate keeping and communication

Many participants in this study, particularly those living in supported accommodation, did not have ways of communicating with the outside world that were private and easily accessible. Some did not have independent access to the telephone and a number did not have access to the internet at home even though they would like to access the internet. These people had the skills or potential to develop computer and internet skills. Indeed some said that they had done computer courses.

'Gate keeping' was a prominent issue in the initial stages of this research, when Advocacy for Inclusion set out to invite participation. On a number of occasions Advocacy for Inclusion

could not contact the person with disability directly but only through other people such as support workers, parents, carers or guardians. It was at the discretion of this these third parties to pass the message on to the person with disability. On 4 occasions it was made clear to Advocacy for Inclusion that the parent or guardian of the person with disability did not want them to participate in the interview and prevented them from doing so.

Discussion

CRPD Article 9 says that states parties must undertake efforts "To enable persons with disabilities to live independently and participate fully in all aspects of life, States Parties shall take appropriate measures to ensure to persons with disabilities access, on an equal basis with others… to information and communications, including information and communications technologies and systems"[25]

It is striking in this day and age, with the internet being a major tool for communication and access to information, that people with the desire and ability to use it do not have access. A great deal of information and consultation about the NDIS is on internet websites and is circulated via email networks.

Without access to the internet people with disabilities are excluded from a major aspect of the contemporary social world. This is directly resulting in forced dependency on other people to access the internet on their behalf, or to obtain information and make it available.

Furthermore, the internet will be a vital tool for recipients of the NDIS in applying for assistance, and in managing or self-directing their own funding. The internet has been used extensively for consultations and information sharing about the NDIS, including the 'Your Say' website, e-bulletins, chat rooms and email circulations. With access to the internet these participants could have been informed and engaged about the NDIS many months earlier.

The way forward – recommendations

1. People with disabilities should have access to the internet and be supported to use the internet such as via assistive technology and mentoring if they desire it. This must be regarded as a key factor of 'inclusion' for people with disabilities.

4. Control and choice over supports

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

People in supported accommodation explained that support rosters are made by organisational low to middle management staff with no meaningful input by people with disabilities. Study participants said that service providers did not meaningfully involve consumers when organising their support.

People who live in their own homes and receive services by 'drop in' support workers described having more influence over rosters, where consumers are consulted about their support needs and goals, but ultimately the service provider still has control and makes the decisions about how supports are implemented. One person with an individual support

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[25] United Nations. (2006). Convention on the Rights of Persons with Disabilities. *Article 9*

package (ISP) explained that the service provider agrees to do a budget *with* him and send out a timetable so he can have input but they never follow through:

> *"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."*

Not a single participant in this study described a situation where the service provider drew up a support budget or staff roster in partnership with the person with disability. Participants consequently described a strong sense of lacking control and choice over their everyday supports, including how they are supported, what they are supported with, when they are supported, and by whom. A number of people living in groups homes have not even thought about 'who makes decisions about my support' because the option for them to make or influence these decisions has never been available to them.

One third of the participants said that they have limited or little control and choice over their lives because the service provider has the control over how their supports are delivered.

> *Interviewer: "Overall how much choice and control do you feel you have over your life?" Participant: "At the moment with [service provider] over my life it's practically none with them… you just feel like you're boxed in you can't do anything. And sometimes you're boxed in and you just feel awful, you know. No one should feel like they're suffering no one should feel like that."*

> *"I choose where I want to go and if I want to go to work or if I go home [to family home]. But the way of [service provider] – about where I live and who I live with I haven't got [control and choice]. It's about 50/50."*

Some participants felt they were treated with disrespect and identified how they are treated differently from people without disabilities:

> *Participant: "I wasn't home at one stage and the next minute they [support worker] were already inside the house and I've got no idea how they got in. I rang up [the service provider] and said they have to wait in their car until I get home and that's that. 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."*

The participant was met with resistance when he asserted that the support workers should not enter his house when he is not home. The participant alludes to the intrusion and disrespect he felt when this happened yet he felt the service provider thought it was totally acceptable.

By whom

Participants identified a lack of ability to choose who supports them.

They felt unable to tell their service provider that they do not like particular workers, or when they do this is not responded to. Some people had not even considered raising concerns because they had become accustomed to having no control over who supports them even though they would like to have a choice.

Interviewer: "Do you ever have times when they've [service provider] told you that there is a support worker coming in that you don't' like?" Participant: "Oh yes. Then I just say sorry I don't want that person." Interviewer: "What does scheduling [department of service provider] do?" Participant: "Then they have to look for someone else." Interviewer: "Is there ever a time when they still come in? Participant: "They still come in but in that case it has already happened to me twice."

Participants believed they had no choice over supports and workers because of three common reasons:

1. The person's home is also regarded as a workplace where fairness and equity for staff is an issue for the organisation, and its consumers are expected to observe these structures.

    "I'm not allowed. Oh boy. I can't favour some people over other people… It is very hard. You have to put up with people you don't like"

    "There was one guy and he took drugs at work. Methamphetamines or something I thought. Anyway one day he came in and I did not want him to hoist me. It took us two years to get rid of him. There were two of us me and someone else complained. Two years to get rid of him because he worked for the government and they would not get rid of a government worker unless we like proved it when we did many complaints and all… He worked five or six days a week."

2. Disability supported accommodation homes are staff directed; standard practice involves the organisation rostering the staff and the consumers have no meaningful input;

    Interviewer: "Do you have the option of choosing who comes to your house and when?" Participant: "I don't think so. Because at our house we have 24 hour support…" Interviewer: "is that something you'd like to have more options and choice in when it comes to who comes to your house and what time?" Participant: "no because it is all organised." Interviewer: "But if you had the option of actually being involved in organising it…Would you like to be able to make those decisions?" Participant: "Yeah if we could but I don't think I would be allowed to."

One person living in a group home expressed frustration that his support worker controls his lifestyle choices and inflicts his religious beliefs on him. When he was asked what he would change about his support he said that he would not change anything because*: "I still have to get used to it and that's the way they do things and I have to abide by it actually."*

One person is confronted with resistance even when she simply asks who is coming in to support her:

"Sometimes I say to the staff 'who's on in the afternoon or who's on in the morning?' and they say 'why do you want to know?' And I say 'cause I just want to know who's on so I'm not nervous if we've got strange people or if I don't know them.'"

3. There are not enough workers to be 'choosy' about who you get.

> *"I don't get to say who I want…. 'Cause they said I can't 'cause they got not enough workers"*

People also linked having a lack of control over who supports them to having workers who do not do a good job.

> *"When I had a bit more control over who was working for me I would be able to ring the agency and say no I don't think that worker is any good. That means they would have more care. You know like here I came back here from [holiday] and the place was a horrible mess. You might ring the agency and say you did not want these workers here. They would not let the place become a mess. So by not having that there seems to be like a poor work ethic or lack of responsibility. They don't care that much about the quality of their work."*

> *"the carers that I have, they hardly… well one person not listen to me and they leave me down the shops with all my shopping and well some carers come late and some carers turn up early and go early and they don't turn up at all sometimes and they don't ring me up and let me know."*

What I am supported with and how

Most participants described how they are not supported in the ways they want to be supported and with the activities that they want to be supported with.

Commonly this seemed to be related to a lack of decision making power over supports. In some cases, it is apparent that service providers have already decided how supports will be provided and the consumer is expected to fit into their system:

> *"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?"*

> *"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."*

In other cases a lack of resources, or how the service provider prioritises support needs, is a clear barrier to control and choice:

> *"They [support workers] don't help me with my email no more… cause they said 'we don't have enough time'"*

> *"I used to have [service provider] come and take me out for the day and go shopping and go to the movies. But I don't anymore. I want that more; I enjoyed that."*

Discussion

Participants describe circumstances where a number of their human rights have been breached:

- CRPD Article 3 "Respect for inherent dignity, individual autonomy, including the freedom to make one's own choices, and independence of persons." [26]

- *Universal Declaration of Human Rights* Article 18: All people have the right to freedom of conscience and religion. [27]

- CRPD Article 19 "Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community."

- CRPD Article 22 "No person with disabilities, regardless of place of residence or living arrangements, shall be subjected to arbitrary or unlawful interference with his or her privacy, family, home or correspondence."

The stories of these participants reveal how people with disabilities, especially those in supported accommodation or other residential care facilities, can experience a total lack of control over their homes and supports, a lack of privacy, and a lack of respect for their inherent dignity. Their homes are regarded as workplaces and participants and organisational systems, and negative or controlling support worker attitudes and beliefs have been imposed upon them. The organisational cultures of support and accommodation providers impinge on the control and choice of people with disabilities.

The way forward – recommendations

1. People with disabilities should be respected as the decision maker for their own supports and lives. This includes over their support budget, staff rosters and how their support needs are prioritised.

2. People with disabilities must be enabled and supported to choose their service providers and their direct support workers, and the form that their support takes.

3. Where people with disabilities need assistance to direct or manage their supports, service providers and support people must operate under the direction of people with disabilities. This involves for example, drawing up a budget and staff roster with the person with disability and according to their direction.

4. People with disabilities need information and support services that enable them to exercise their consumer rights.

5. Supporting self-advocacy training should be made widely available for support workers to teach and enhance their skills in supporting the person with disability to exercise control and choice.

6. A supporting self-advocacy tool should be developed for organisations to guide organisational approaches to supporting consumer control and choice.

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[26] United Nations. (2006). Convention on the Rights of Persons with Disabilities. *Article 3*

[27] United Nations *Universal Declaration of Human Rights*. Article 18

7. A 'control and choice' policy development guide should be established for disability organisations.

8. A kit should be developed to support cultural change for disability organisations targeted at equipping them for the NDIS and supporting consumer control and choice.

9. A 'control and choice' self-assessment audit kit should be developed for disability organisations.

10. An induction kit should be developed for new employees in disability organisations to establish their understanding of supporting consumer control and choice.

11. Human rights training and resources should be made widely available to disability organisations and support workers, since human rights are fundamental underpinnings of the NDIS.

12. Resources for individual support people should be developed to assist them in supporting consumer control and choice such as:

    - tools to guide supported decision-making;

    - self-reflection exercises for support people to check if they are supporting a person to make their own decisions and exercise control and choice;

    - reminders such as wall charts.

5. Control and choice over day-to-day decisions

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

Domestic duties

Some participants in supported accommodation were excluded from domestic duties such as laundry, cooking, cleaning and grocery shopping[28]. In a number of cases these tasks were automatically done by support staff, which led to people feeling more dependent. Three of the 4 younger people in this study live in their family homes and spoke of looking forward to moving out and doing their own domestic tasks as a sign of independence.

The people in this study want to be supported to do the things that other adults do. For them 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 their choices, such as the freedom to choose what they want from the grocery store. While many may need support to undertake these tasks, this did not mean that they were completely unable or were disinterested in participating in them.

What and when I eat

Some people spoke of having their meals already pre-planned for them by support workers or a dietician. This is because they live in a group home, where other tenants have particular

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[28] 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

dietary concerns that must be addressed, or where there are *"too many people"* to cater for everyone's individual choices on a given day:

> *Participant: "The way [supported accommodation] is run it is all run by a dietician. They have a menu." Interviewer: "so the dietician has already pre-chosen everything?" Participant: "yes". Interviewer: "so do you get to make any choice about that?" Participant: If I wanted maybe but I don't know there's too many people."*

Participants who were not included in grocery shopping tasks were particularly limited because they were not able to choose what was available at home in the first place. One person, for example, had to eat 'diet food' because this is what the staff buy to meet the dietary needs of other tenants.

Daily routines

> *"Sometimes I have to wait. It impacts when I have a drink, have stuff to eat, going to the bathroom. Just general stuff."*

Participants who lived in supported accommodation explained that they often have to fit in with the routines of other co-tenants and the staff rosters, especially in group homes. This means that they arrive at activities late or cannot participate in them at all. Some people felt particularly frustrated about having to fit vital everyday tasks into staff availability such as using the bathroom. One person explained that their everyday movements are controlled by the rules of the group home they live in:

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

Three people explained that their day is so regimented that they have to go to bed and get out of bed at set times that do not suit them.

> *Participant: "I'm in bed by half past 8." Interviewer: "And what time would you like to stay up until?" Participant: "Ten." Interviewer: "And how would you go about achieving that goal?" Participant: "Can you give me some ideas?" Interviewer: "What is the reason you don't stay up until 10 o'clock now?" Participant: "I need two people to get me into bed and on and off the toilet. Every night at half past 7 [support provider] comes and put me on the toilet and shower and they have to leave by half past 8." 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."*

"Simple" things like this make huge differences 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:

> *"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."*

It is true that everyone has to fit in with other people to some extent, regardless of disability. However, it is clear that the support arrangements in supported accommodation can be particularly regimented and limiting far beyond what people without disabilities experience. Some people felt frustrated by this but had framed it in their minds as the 'facts of living with disability', which they must somehow 'live with' rather than constantly fight against.

Some people felt that it is not within their rights or power to challenge this regimentation, a number referring to what they are not *"allowed"* to do. For other people it had not even occurred to them to question the routines imposed on them by service providers, rather they seem conditioned to it as the 'status quo'.

Discussion

This lack of control and choice for participants in their day-to-day activities is well summarised by a member of the self-advocacy network:

> *"It's about disabled people not knowing what their rights are."*

It is also about people with disabilities living in circumstances that are heavily controlled and directed by other people, such as supported accommodation. Participants' lives are regimented and controlled down to the finest detail of when they go to bed each night and what food they will eat. This is an issue also noted by other writers[29]. It reflects the relative powerlessness experienced by people with disabilities when they are dependent on others for essential supports. They are institutionalised by these organisational structures imposed on them.

As the NDIS introduces self-directed funding, people will need assistance to understand the options that this model of funding brings. This includes assisting people with disabilities to know and understand their rights. It involves assisting people to challenge what is known to them now as the 'facts of living with disability' to see new ways of living that are more compatible with their personalities and preferences. To use popular terms, this is what is needed to achieve 'person centred' approaches.

The way forward – recommendations

1. Easy English human rights resources should be made widely available to people with disabilities to inform and remind them of their human rights. For example, posters and pocket or wallet cards.

6. Control and choice over big decisions

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

Participants describe significant restrictions on their major life decisions or a lack of support to follow decisions through. This happens directly because others make decisions on their behalf without their permission, and indirectly through the influence of significant others such as family or support people on whom they rely.

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[29] See for example Chenoweth, L. (1995). The mask of benevolence: Cultures of violence and people with disabilities. *Journal of Australian Studies, 1*9(43), 36-44.

The lack of control and choice over support arrangements also contributes substantially to restrictions on decision making. Participants cited issues with choosing where and with whom they live, lifestyle choices and risk taking as particular areas of concern.

Where and with whom I live

A number of 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 and this impacts on them enormously.

> *"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."*

> *"At the moment I share a house with 5 other people but if I was in my house by myself then I could make decisions without having to ask anybody else."*

Other people expressed that they had to move into or stay in their current living arrangement only because it meets their support needs. Many people had not freely chosen their living arrangement but were essentially forced to live in particular arrangements through a lack of options that meet their support needs.

> *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."*

Discussion

The CRPD states that people with disabilities have the right "to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement"[30]

'Block' funding has created a system where specialised disability supported accommodation group homes are ready made for people to 'fit' into. People often go where there are vacancies and have few other options to choose from. This means that people are effectively forced to live in particular living circumstances in order to receive disability supports. This is reflected in other Australian studies[31] and in the findings of this study, which show the lack of control and choice people have over their living arrangements.

The Shut In Campaign is a collaboration between advocacy organisations and people with disabilities. Shut In defines institutions as:

"Segregated accommodation or congregate care facilities that exist only to provide people with disability with social supports. These facilities can be called 'cluster housing', 'villas', 'key-ring facilities', 'boarding houses' or 'group homes'. They have the effect of segregating and isolating people with disability from the community, of denying people with disability the

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[30] United Nations. (2006). Convention on the Rights of Persons with Disabilities. *Article 19*
[31] See for example, Fidock, A., & Williams, R. (2009). *Tell us survey report 2: Having choice and control.* Adelaide: Julia Farr Association.

same housing options as other people living in the community and of forcing people with disability to live together in order to receive social supports."[32]

Under self-directed funding models people with disabilities take their funding packages to the home of their choice, and then develop the support model of their choice and live with other people (with or without disability) or alone according to their choice.

Lifestyle choices

Many participants felt a lack of control and choice over their lifestyle and self-expression. The issues involved are various since people with disabilities are not a homogenous group; each has their own unique preferences and personalities. The following examples show how the practice of service providers treating the person's home as a 'work place' interferes with the lifestyle of consumers.

> *"The bureaucracy they have going now ties them up in knots and then they pass the knots on to a prospective client… they coming into somebody's house and then all of a sudden when those workers come in it's no longer your private house it becomes their territory. I feel so imposed upon."*

> *Participant: "I said to [support worker] 'how would I get on about getting a puppy?' She said you would have to speak to [network manager] and [team leader] first…. [team leader] has already told me that if I do it's not to come inside the house… [team leader] said 'maybe' 'cause I want to get a dog and she said if he's [the new worker] animal friendly I might be able to get a little dog."*

Another person was seeking to move out of their current group home and hoped to get a pet:

> *"Is there a reason you can't have a pet now?" Participant: "Because another resident has allergies. Interviewer: "did you choose to live with the other resident?" Participant: "Not really."*

Another participant explained that they can only access and administer their medication under community nurse supervision because the nurses are concerned that the person will make a mistake with the dosage. This significantly limits their lifestyle choices because they are unable to go on a holiday; an activity that was previously a core part of their lifestyle.

> *Participant: "I disagreed with the whole thing… because remember we were talking about what would the nurses think if I did the stuff [administer medication] myself and they said no I couldn't do it…?" Interviewer: "So you'd actually prefer to have tried it by yourself, is that what you're saying?" Participant: "Yes. I don't think um what's her name? [Community nurse] won't support it I've got to stay with the nurse all the time… [community nurse] won't let me do anything because she has to make sure I have my [medication] every day."*

For one person, the moral values of the supported accommodation provider interfered with their personal relationships and lifestyle choices:

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[32] Shut In. (no date). *Information about institutions*. http://www.shutin.org.au/

"I want to find someone [service provider] who is not so strict on their rules... If I get a girlfriend I feel too embarrassed to bring her back to the house. It's against their religion for one thing. I have to take her somewhere else…It's the way that they operate there's nothing I can do about it."

Another participant spoke of feeling restricted in her relationships and her sexuality by her parent:

"When it comes to relationships and boyfriends and things like that; my mum doesn't like things like that at all."

Taking risks

Participants spoke of the barriers they face when it comes to making life decisions that are risky. They did not use the word 'risk' but described ways that other people are over-protective and discouraging when they want to make a decision that seems 'risky' in some way. The participant noted earlier, who wanted to go on a holiday but whose nursing support interfered with this, is a good illustration of the role service providers play in this. A number of participants noted that their parents worry about them excessively, and this significantly influences the decisions they make:

"My mum is overprotective of me because I have a disability. Sometimes she is a bit controlling … People with disabilities should have less being told what to do. I know sometimes I make the wrong choices and decisions in life but it's just life experience."

Participant: "First of all I told my parents. They were a bit frightened … they worried that I wouldn't be looked after properly … I still wanted to move out [of the group home] but it was very hard to convince by parents. But after a while my parents came around." Interviewer: "How did that impact then, when they started to feel more comfortable about it?" Participant: "Better, because I wasn't worried about them. Because I knew they were happy."

The opinions of parents are highly valued by these participants. They know that their parents care for them and want them to be safe and well 'looked after' and for several people their parents felt that the 'group home' option would provide this, even though for the participant this meant less independence and autonomy. Two participants note the significance of having people who affirm their decisions and encourage them to follow their personal preferences in the face of risks.

For one person having a guardianship order[33] in place meant that guardians could legally make decisions on the person's behalf if they felt it involved a safety issue:

Participant: "I've got the power to go over my mum and dad. I wish I did have that". Mother: "don't forget your mum's your guardian mate… If it's a safety issue we will make that decision immediately otherwise anything to do with [participant] he makes the decision we just want to be able to provide him with the

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[33] A guardianship order is made when a person is deemed to lack decision making capacity by the Civil and Administrative Tribunal.

*information and if you like the pros and the cons of decisions and
then he makes them."*

Discussion

Western societies tend to be 'risk averse' and this impacts the ways that people with disabilities are supported. Instead of supporting people with disabilities to take positive risks, approaches tend to be over protective[34]. This impacts on the person's quality of life because risk taking is an everyday fact of life and can bring enjoyment and benefits.

The above findings illustrate the role support people can play in supporting people with disabilities to make their own decisions. However, it also illustrates how 'best interests' approaches and guardianship orders can prevent people with disabilities from making 'risky' decisions.

Advocacy for Inclusion works on numerous cases where the idea of 'reasonable risk' (dignity of risk) is conservatively viewed among support agencies, families and carers of people with disabilities. This means that people with disabilities are prevented from taking risks that people without disabilities take and that may be highly beneficial to their wellbeing, especially when a guardianship order is in place[35].

The NDIS intends to introduce more options for people with disabilities, including new options that seem 'risky' because they have not been tried before by the individual or even by anyone in the current 'block' funded system. If people do not take 'risks', the circumstances for many people with disabilities will hardly change and they will find themselves taking the 'safe' options, which may hinder their independence, autonomy, and quality of life. In effect they will be kept highly dependent as they are now, rather than supported to engage with the community and all of the risks and joys that this brings.

The NDIS will not work to its potential if people are too afraid to support people with disabilities to take 'risks'. Encouragement from support agencies and support people to take risks is crucial for people with disabilities, especially those who depend on these agencies and people to follow through with 'risky' decisions.

Conventional risk management approaches are typically technical and can treat the person "as an object to be assessed by the 'experts' rather than as an agent in their own lives, part of a family, community and society, with legal rights and choices."[36]

In contrast, 'risk enablement' ''is based on the idea that the process of measuring risk involves balancing the positive benefits from taking risks against the negative effects of attempting to avoid risk altogether''[37]. It is a relatively new concept emerging in the disability field. Some researchers consider it a fundamental underpinning of self-directed funding models[38]. This approach should be explored here in the ACT as an alternative to conventional approaches.

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[34] Carr, S. (2011). Enabling risk and ensuring safety: Self-directed support and personal budgets. *The Journal of Adult Protection, 13*(3), 122-136

[35] See Advocacy for Inclusion. (2012). *Supported Decision Making, legal capacity and guardianship*.
http://www.advocacyforinclusion.org/publications/supported_decision_making_legal_capacity_and_guardianship2012final.pdf

[36] Neill, M., Allen, J., Woodhead, N., Sanderson, H., Reid, S. and Erwin, L. (2009). Feature: a positive approach to risk requires person-centred thinking. *Tizard Learning Disability Review, 14*(4), p. 19

[37] Manthorpe, J. and Moriarty, J. (2010). *Nothing Ventured, Nothing Gained: Risk Guidance for People with Dementia*. Department of Health, London. P. 8

[38] For example, Carr, S. (2011). Enabling risk and ensuring safety: Self-directed support and personal budgets. *The Journal of Adult Protection, 13*(3), 122-136

The way forward – recommendations

1. Explore 'risk enablement' as an alternative to traditional risk management approaches in order to maximise the quality of life, wellbeing and control and choice of people with disabilities.

2. Establish risk enabling tools for organisations and support people in the ACT.

7. Skills in control and choice

Participants demonstrated their extensive knowledge and understanding of the supports they need. However, most of the participants 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 that the NDIS intends. Two participants spoke about their experience planning to move out of a group home into a home of their choice and expressed how although this was liberating, it felt foreign and shocking to them having never had the experience before.

> *"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 participants many months to decide and plan, with support, where they wanted to live, who they wanted to live with and how they wanted their supports to work. For them it was particularly helpful being prompted to consider the options that they have never considered or known about before. They are more than capable of making their own decisions but very much value the guidance, support and reassurance they received from their service provider and disability advocate.

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

Perhaps because of this lack of experience, several study participants did not understand 'control and choice' necessarily as circumstances where they are choosing, where they are deciding, and where they are controlling what is happening in their lives. For example, when asked if they had control over their supports, 3 people said yes because they are *informed* about their supports in advance.

> *Participant: "I choose my own [support workers] just by talking to [service provider]." Interviewer: "What do you say?" Participant: "I just say to them 'who's going to be helping me to day with the house support and who's going to be helping me with the groceries?' They just say something like 'you've got this person coming in today and you've got this person coming in for your shopping tomorrow'."*

When people were prompted to think about whether they feel this is really control and choice over these aspects of their lives they identified that simply being informed is not having control and choice.

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

people spoke specifically about their hope that they will choose who supports them by employing them and/or interviewing them personally.

All of these participants said that they will want help to have control and choice over their supports. They named several types of support they feel they will need:

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 themself, especially assistance with administration tasks and rules**;

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**;

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**:

   > "*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 participants said that while they are excited they are also daunted by the NDIS because they have never had this level of control and choice over their supports. A few participants identified the problems with their current supports but also stated that they do not want their support arrangements to change, or to have more control and choice over it. This incongruence indicates that they might be afraid of the changes to the system. The idea of having this level of control and choice may be overwhelming since they have not experienced it before, and they might not be able to see now how having control and choice could address the problems with their support.

Discussion

This study demonstrates how people with disabilities can have their lives and their supports run for them, rather than with them. The current disability system is based on this philosophy. As a result, many people with disabilities will not know the extent of control and choice they are entitled to have over their support funds when the NDIS is introduced. Many will not have the skills to speak up and take charge, or even know that this is an option, especially if they are unaware of the NDIS and what it means for them. This makes them highly vulnerable to continuing to live as passive service recipients.

There is also the risk that people with disabilities will not be supported to overcome their initial fears as they transition into the new system and that it may be interpreted by others as an unwillingness or inability to direct their own funds. It may also be assumed that people with disabilities are unable to direct or manage their own funds when they demonstrate their lack of experience in this area or do not assert themselves due to a lack of awareness about the extent of control and choice available to them.

There is also the danger that people with disabilities will be rushed into making plans and decisions when they need considerable time and support to consider the options they have never had before. For many this will be a major learning experience and it will take time for them to gain the skills and confidence to self-direct their funding packages.

The way forward – recommendations

1. Establish a centralised information system where people can go in person, on the phone, and on the internet to assist with navigating the large and complex disability system, find out about what is available for them, and to what they are entitled.

2. Support services to assist with establishing self-management and self-direction systems.

3. Establish a 24 hour hotline that people with disabilities and support people can access for information and referrals.

4. Resources to assist people with disabilities to identify what control and choice is and how they can exercise this over their support funds.

5. The people, agencies and systems around people with disabilities will need to be patient and allow them to make well informed and well considered decisions about their supports and their lives. Some people will take a couple of years to explore and decide how they want their lives to look. They must be supported to plan over extended periods.

6. It must not be assumed that because people are afraid of this new system that they cannot learn about it and eventually self-direct their support funds. People must be supported to transition and make the most of the new system.

7. Make approaches and tools widely available targeted at supporting people with disabilities to see how they can gain more control and choice over their lives beyond what they imagine possible in the current system.

8. Make decision making and tools widely available to people with disabilities to guide and remind them about decision making processes. For example:
   - wall charts
   - tablet applications
   - web tools
   - information kits
   - mind maps.

9. Make human rights resources and training widely available in appropriate formats for people with disabilities.

10. People with disabilities need positive support and encouragement to take control and choice in their lives. Their right to have control and choice must be communicated to them

- tools such as wallet or pocket cards, posters, and t-shirts that reinforce the right to control and choice

11. People with disabilities need ongoing support to build and exercise control and choice over their lives. This includes:

- Self-advocacy courses, where people with disabilities are supported in a group or one to one to learn skills in asserting their wishes;

- Sustaining self-advocacy skills courses and groups, where people with disabilities are supported to remember and reinforce self-advocacy skills;

- Supporting self-advocacy courses for support people to learn how to support people with disabilities to self-advocate and exercise control and choice.

8. 'About me without me'

Many participants spoke of being excluded from decision making and planning activities that directly concern them. As explored earlier, many participants are excluded from the decisions made about their supports and their living arrangements. Another example is the participant who wants a dog:

> Participant: "[Team leader] said 'maybe' 'cause I want to get a dog and she said if he's [the new worker] animal friendly I might be able to get a little dog. They were going to bring it up at the meeting." Interviewer: "Do you go to that meeting or is it just for staff?" Participant: "Just for staff."

One person felt that much of her life is run by other people – things are done 'about her without her'. She expressed feelings of powerlessness and indignity.

> Participant: "They make the decisions for me." Interview: "How come they do that?" Participant: "I don't know." Interviewer: "How does that make you feel?" Participant: "What would you reckon?" Interviewer: "Not very good that's what I would reckon." Participant: "Uh-hmmm." Interviewer: "Is that right?" Participant: "I am able to make up my own decisions."

Two young people described being excluded from meetings at school, such as Individual Learning Plan meetings, and meetings with support agencies involved in their lives:

> Participant: "But he still doesn't meet with me." Mother: "He did initially." Participant: "But still that means he meets with you it means nothing about me. It means he meets with you by talking to you not to me."

This participant found it very upsetting that his case worker stopped meeting with him directly. He wanted to participate in these meetings but the case worker and mother had decided that his case had come to the point where this was no longer necessary, yet the involvement of his mother was still necessary.

Discussion

The lives of people with disabilities being 'about them without them' is a common thread throughout this study. It highlights the devaluing of people with disabilities and the denial of their control and choice over their own lives.

Young people without disabilities may experience similar issues to the young people in this study as they become more independent while still living at home and being supported by their parents or guardians. However, it was apparent during these interviews that having disability is a compounding restriction on a young person's control and choice because of their need for ongoing support and the dynamic that brings into the relationship with their parents or guardians.

The way forward – recommendations

1. As the NDIS is implemented, it is crucial that young people with disabilities are supported to be actively involved in the decisions concerning them so that they have the skills to make decisions about their supports once they become adults.

2. Resources targeted specifically to engage young people with disabilities must be made widely available to them.

9. Being assertive, negotiating, making complaints

Participants experience a range of barriers to asserting themselves, negotiating and complaining to organisations and service providers. Some talk about feeling uncomfortable about complaining because of the potential repercussions:

> *"I don't like complaining because every time you complain you feel like you're a problem."*

> *"They say that everyone has the right to make a complaint and for them to hear about it but in cases like this you know it is difficult ... Sometimes I just can't complain to the agency. Like I complained once to the agency and it just fell on deaf ears."*

Many participants explained that complaining and negotiating with service providers is difficult because the provider does not take appropriate action, or takes no action, or does not take the complaint seriously. Participants do not seem to be respected as people with consumer power.

> *"I complained and [service provider] told me to mind my own business. My father helped me. He complained but nobody listens."*

> *Interviewer: "Do you feel that you ever negotiate with [service provider] about the support you get?" Participant: "They'd probably say no you've got to go to bed at this time and get out of bed at this time."*

One person explained that they are frequently late to appointments and meetings due to support staff not attending to their needs on time. Yet, this issue does not seem to be taken seriously by the service provider:

> *"I intercom them earlier at 9 o'clock or something or 9:30 to say I'm real busy today I need your help getting to the toilet by two people so I need to get hoisted at 11:10. I was being nice and giving them forewarning. That kind of thing I find unacceptable. But I've complained about this and they are not interested."*

Participants also expressed their gratitude for the supports they do get. For some this gratitude prevents them from raising complaints or negotiating:

> *Interviewer: "have you ever tried negotiating with them [philanthropic organisation]?" Participant: "I have a couple of times but nup… he just nod his head and said 'no'. I didn't say anything 'cause I didn't want to upset them really." Interviewer: "You didn't want to upset them?" Participant: "No, well they've been good, so-."*

Discussion

The central function of the NDIS is to fund long-term high quality care and support for people with significant disabilities.[39] To achieve this high quality support, recipients will need the capacity to negotiate, complain and be assertive. These are fundamental skills needed to operate effectively in a market based scheme like the NDIS.

"The current disability support system is underfunded, unfair, fragmented, and inefficient, and gives people with a disability little choice and no certainty of access to appropriate supports"[40]. Because of this, people with disabilities in Australia are not accustomed to a system where they can negotiate with providers, or complain and go elsewhere if a service is not performing to their satisfaction. If people with disabilities are not supported to know their rights and be assertive they will continue to accept unsatisfactory services and the system will not improve.

Advocacy for Inclusion observes a reluctance to make complaints and negotiate regularly amongst our consumers. Support services are vital to the survival and wellbeing of people with disabilities; yet people with disabilities are not positioned to easily complain and negotiate with service providers without fear of repercussions. People are concerned about damaging their relationship with a service provider or of being seen as a 'difficult client'. It is one thing to have complaint mechanisms in place for consumers, but whether these mechanisms are meaningful and user friendly is a separate issue entirely, as captured by the quotes above.

The way forward – recommendations

1. Services and resources that support people with disabilities to make complaints and negotiate with their service providers must be made widely available to them:

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[39] Productivity Commission. (2009). *Disability care and support: Key points*. Retrieved from http://www.pc.gov.au/projects/inquiry/disability-support/report/key-points
[40] Productivity Commission. As above

> - independent advocacy services;
>
> - tools that guide the person with disability through the steps of making complaints and negotiating with service providers.

10. Supporting control and choice

Participants in this study spoke of the significance of support people who help them to take control and make choices in their lives. The main examples of this are:

- **Positive people who believe in the person**

  "I feel better. A bit like everyone is behind me."

Participants spoke about the importance of having positive and supportive people around them who encourage them and affirm their goals and abilities. For a number of participants these supportive people help them to persevere with their aspirations despite the influence of other people who doubt them or in circumstances where it seems things will not work out.

- **People who listen to the person, respect them and take them seriously**

  "So one day I really said a real need for help. And [worker said] 'oh do you want meals on wheels and do you want a personal alarm and do you want somebody to help you at the pool and do you want-' She was just totally giving giving giving all the way."

During this study we frequently heard participants say things like *"nobody listens"*. People spoke of stating their needs and wishes to service providers and support people but felt that they were not heard and no meaningful action was taken to address the issues. People with disabilities need to be listened to, respected and taken seriously in order to have meaningful influence over the supports they receive, and to take control over their lives.

- **People who provide information and explain the options**

Like most other people, participants of this study want advice and information from other people to help them make significant decisions. This includes information about what their options are for example the support services available, and information about their rights and what they are entitled to. People with disabilities do not want to be told what to do but want to be given good information and guidance.

- **People who help to navigate the system**

  "Get me out in the wide world. See what's out there for me and give it a go."

  "What would be good for me is if I had a case worker or someone who knows things like what I can apply for."

The disability system is complex and difficult to navigate. A number of participants referred to this as an issue. They only know of the services they are currently accessing and they are not sure where to begin looking for other options. People familiar with the system who help them to navigate the system are highly important. This includes people who provide practical

assistance such as investigating and making contact with local services which might be of interest to the person.

The need for a case worker or case manager was mentioned by many participants, because they are seen as people who know about the services available and which ones are reputable. They are seen to be people who know where to look and how to access supports.

- **People who stand up for the person such as complain on their behalf**

    "She calls them up and tells them that 'this is not on'"

A number of participants spoke of support people, particularly family members, who help them to stand up for their rights. This was commonly because people felt they were not listened to by service providers and they needed someone to back them up. The significance of independent advocacy, which provides individual support to people with disabilities free of conflicts of interest, also came up in the interviews:

    "It helped enormously because you know without it I would have had the weight on my shoulders I would have got blasted by them. They would have tried to pull the wool over my eyes."

Participants spoke of how individual advocates affirm their abilities and goals, help to prevent negative reactions by the service provider simply by 'being in the room' when pursuing an issue, and help get paid and unpaid support people 'on board' if they are reluctant or sceptical of the person's wishes.

The way forward – recommendations

1. People with disabilities need to be listened to, respected and taken seriously in order to have meaningful influence over the supports they receive, and to take control over their lives

2. Supporting self-advocacy courses for support people to learn how to support people with disabilities to self-advocate and exercise control and choice.

Conclusion

Participants in this study are significantly restricted in having control and choice over their own lives and supports. This seems to be due to under-resourcing, organisational culture, and the approaches taken by support people and services, which do not maximise control and choice.

More broadly there are considerable barriers facing people with disabilities in regards to their control and choice over their own lives and supports. They are widely unable to access the supports they need in the current system and dominant societal understandings of disability portray 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 concerted efforts are not made to assist them to transition into the 'drivers' seat' of their supports.

People with disabilities cannot be expected to easily slide into a self-directed or self-managed funding option, knowing their rights and feeling confident to take control and make choices. The current system has taught people with disabilities to take whatever they are given, which is often not enough to meet their needs. In this sense 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 them unlearn this.

Negative social and cultural assumptions about disability will prevail under the NDIS if they are not actively addressed as part of the overall system restructure. Significant cultural change is paramount to improving the control and choice of people with disabilities.

Substantial work must be done to implement this structural and cultural change throughout the disability sector, among people with disabilities and their support networks to promote people with disabilities as the drivers of their own lives and supports. Individuals with disabilities must be supported in meaningful ways to make the most out the control and choice now promised to them. Their support networks will also need support and guidance to make this transition.

Appendix 1 - Project design

Qualitative methodology

As this study sought to explore the perspectives and experiences of people with disabilities, qualitative methodology was employed. Qualitative research is used when we want to hear people's voices and share their stories rather than measure or quantify[41].

Participants

Who was targeted?

Advocacy for Inclusion works with isolated and highly marginalised people with disabilities, whom we know are not involved in typical government and community consultations concerning the NDIS such as forums or the 'Your Say' website. These people come to Advocacy for Inclusion for assistance with gaining control and choice over their lives in one way or another. Their stories are often hidden from and unheard by the broader community, yet these people have significant support needs and are likely be targeted as NDIS recipients. We set out to interview these people with disabilities to share their perspectives on control and choice, the underpinning of the NDIS.

Sampling method

Approximately 38 people with disabilities from Advocacy for Inclusion's past and current consumer base and self-advocacy training students were invited to participate in interviews via an information letter. Follow up phone calls were made to all invitees and for many initial contact could only be made directly with a paid or unpaid support person. It was made clear to support people and invitees that the views of the person with disability were sought by this study and we encouraged prospective participants to participate independently if possible.

We also welcomed people to have a support person with them in the interview if they wished to do so. Twenty-two people accepted and four people dropped out for various reasons including other commitments (1), guardians declined to consent (2), or the person decided that the research was not relevant to them (1).

Advocacy for Inclusion's self-advocacy network was approached informally and they agreed to participate in a focus group to discuss the interview findings.

Who participated?

A total of 20 people with disabilities participated in this study, including 12 females and 8 males. Eighteen of the participants were interviewed individually. Two additional people from Advocacy for Inclusion's self-advocacy network were engaged in the focus group (there was some overlap of interview participants and focus group members). Five of these participants nominated to have a support person of their choice present with them in the interview.

Data collection

Interviews

Semi-structured in-depth interviews were conducted individually with 18 of the participants from 25 September through to 7 December 2012. Interviews were audio recorded. Audio recordings were listened to and key sections were transcribed from each for analysis.

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[41] Liamputtong, P. (2013). *Qualitative research methods* (4th ed.). Melbourne: Oxford University Press.

Part of the interviews involved collecting demographic data including age, cultural background, and gender. It also involved collecting data about participant support needs and arrangements. This information was collected only from the 18 people who participated in the individual interviews (see appendix 3).

The interviews mainly focused on these key explorative question areas, which were used in the interview guide:

- Control and choice over life goals and plans
- Control and choice over support arrangements
- Control and choice over life generally
- Skills and confidence to have control and choice over individualised funding
- Awareness of the National Disability Insurance Scheme
- What is supportive and helpful to the person in maximising control and choice in these areas

Focus group

One focus group was conducted with Advocacy for Inclusion's self-advocacy network in April 2013. The purpose was to seek their assistance in understanding interview findings and in considering recommendations for this report. During these discussions focus group members engaged in rich conversations about their own experiences of control and choice, which they gave permission for us to also include in our report.

Interactions with support people

The interactions with support people during interviews and also at initial points of contact when inviting and setting up interviews are included in this report.

Advocacy for Inclusion's individual advocacy work

The discussions in this report incorporate the experiences of Advocacy for Inclusion in our advocacy practice with people with disabilities, without any reference to particular cases. This is clearly distinguished in this report from the data collected in the interviews and focus group.

Data analysis

Transcripts from the interviews were analysed using thematic analysis. This is where the researcher reads and rereads the transcripts to make sense of them and find repeated patterns of meaning across the participant group[42]. We looked for explicit meanings – what is directly said by the participant – as well as implicit meanings – meanings that underlie what is said by the participant. This is done with consideration of the social, historical and cultural context. Themes emerge through this analysis and these themes are reported in this report.

The self-advocacy network was consulted in a focus group to gain their assistance in discussing findings in the interviews, which contributed to the researchers' final decision on themes.

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[42] Liamputtong, P. (2013). *Qualitative research methods* (4th ed.). Melbourne: Oxford University Press.

Appendix 2 - Ethical considerations

The two major ethical considerations in this study were privacy and confidentiality, and informed consent.

Privacy and confidentiality

The reporting methods of interview findings were made clear to participants prior to their interviews. The findings of this study have been de-identified to protect their privacy and uphold confidentiality.

Informed consent

National Statement on Ethical Conduct in Human Research states: "People with a cognitive impairment, an intellectual disability, or a mental illness are entitled to participate in research."[43] It also states that the capacity for people with disabilities to consent can vary and must be accounted for. Consent from participants was sought with careful consideration for these issues.

Information was provided to each of the participants prior to seeking their consent on the nature and methods of the research, how they were to be involved, and what the potential risks and benefits were for them in participating. This information was provided to them in formats appropriate to their communication needs. It involved a two way communication process with participants to establish a sense of 'mutual understanding' between the researcher and the invitee about the research and the invitee's wishes[44]. As Advocacy for Inclusion already had an established and positive relationship with each invitee, we had a good understanding of how to best engage them in these processes so that they could be properly informed.

It was made clear at numerous points during the invitation and interview process that it was the person's free choice as to whether they would participate or not. It was made clear that if they declined it would not impact any advocacy supports they may have been receiving from Advocacy for Inclusion at the time. Where a person had a guardianship order extending to issues such as participation in this research, the above process was undertaken to ascertain the person's wishes. Formal consent was also sought from their legally appointed guardian.
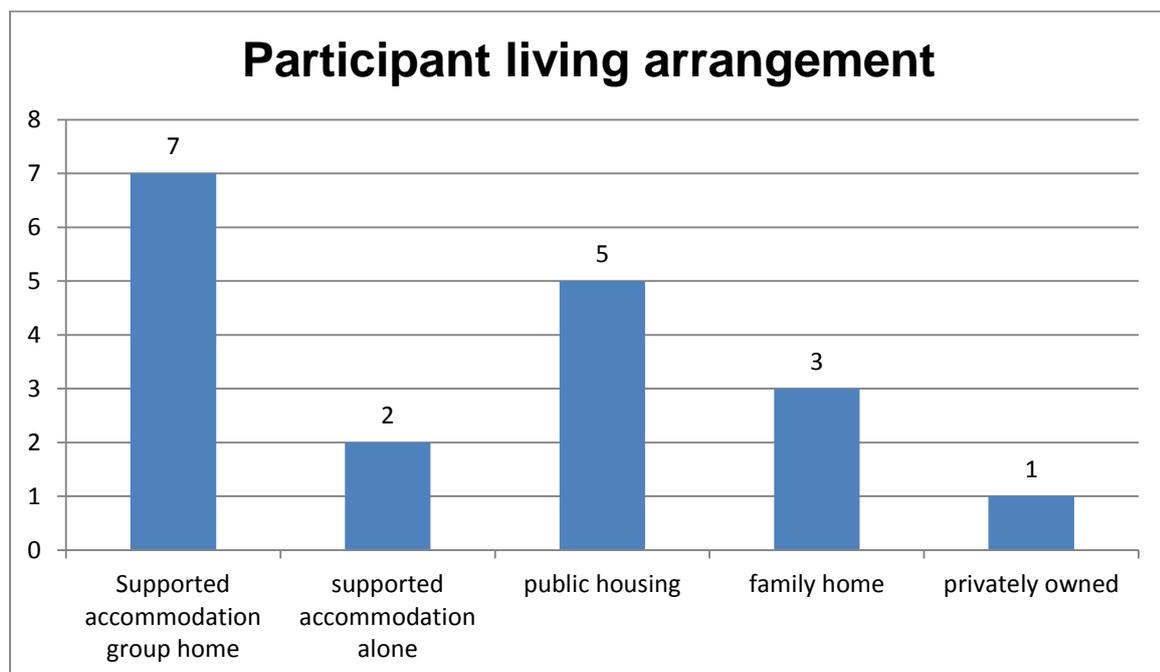
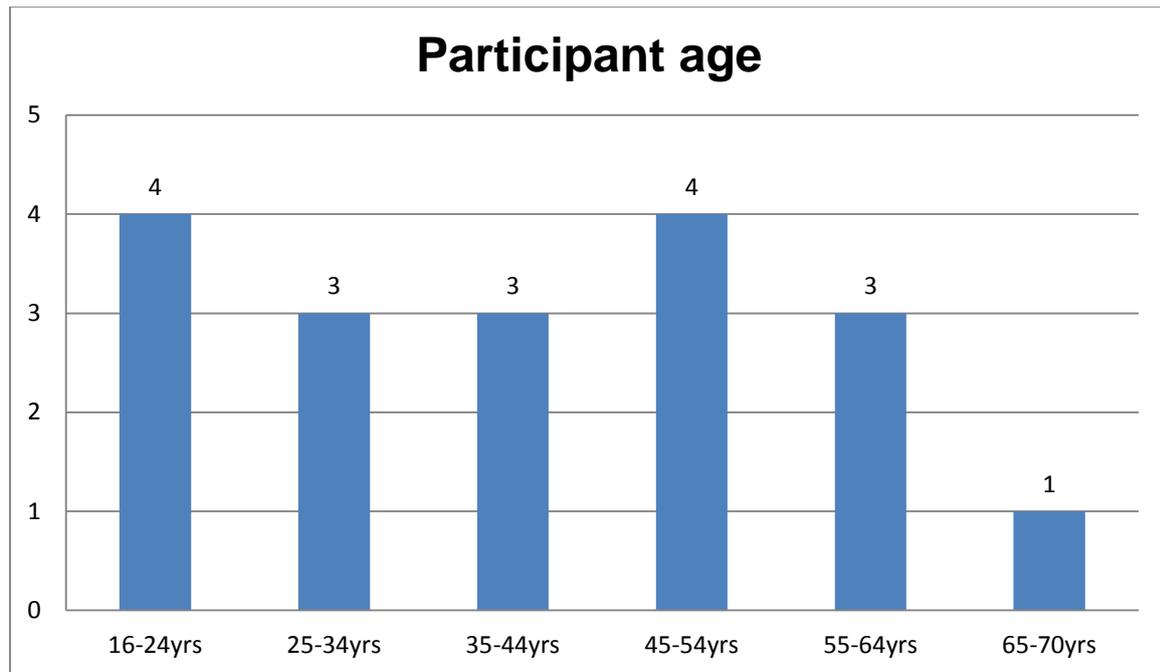---

[43]National Health and Medical Research Council. (2007). National statement on ethical conduct in human research. Retrieved from http://www.nhmrc.gov.au/guidelines/publications/e72
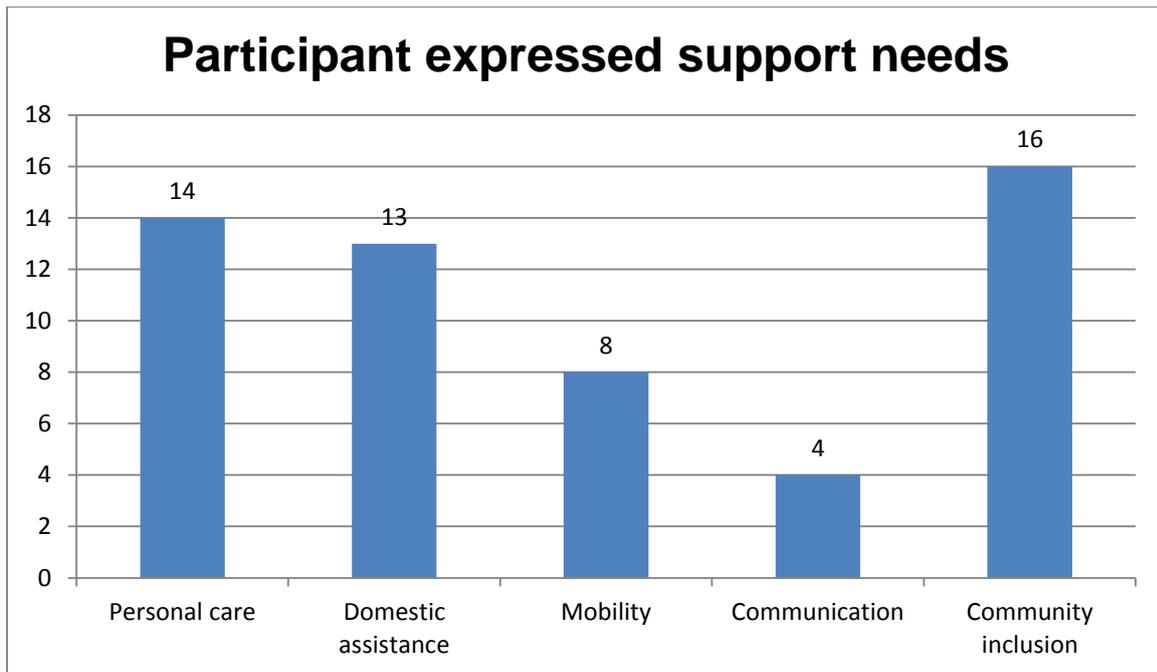[44] National Health and Medical Research Council. As above.

Appendix 3 - Additional participant demographic information

Participant cultural background	
English speaking background	12
Aboriginal and Torres Strait Islander	1
Culturally and linguistically diverse	5

Participant age

Age range	Count
16-24yrs	4
25-34yrs	3
35-44yrs	3
45-54yrs	4
55-64yrs	3
65-70yrs	1

Participant living arrangement

Living arrangement	Count
Supported accommodation group home	7
supported accommodation alone	2
public housing	5
family home	3
privately owned	1

Participant expressed support needs

Category	Value
Personal care	14
Domestic assistance	13
Mobility	8
Communication	4
Community inclusion	16

Expressed support needs include those which are met and unmet. All participants identified with having at least one of these support needs. Most participants identified the need for more than one support type.

Appendix 4 - Glossary

Block funding – Government funding is allocated to a service provider in a 'block' for numerous consumers to access. The service provider makes decisions about who will access their services in accordance with their funding obligations.

CRPD – Convention on the Rights of Persons with Disabilities.

Individualised funding – Government funding is allocated to individuals, not the service provider.

Individual Support Package (ISP) – a term used to describe individualised funding packages in the ACT.

Self-directed funding – The person with disability makes decisions about their individualised funding including what support services and aids they purchase, and how their supports are packaged. They choose an agency or person to hold and administer the funds on their behalf and under their direction.

Self-managed funding – The person with disability makes decisions about their individualised funding including what support services they purchase and how their supports are packaged. They are responsible for holding and administering their individualised funding, including tasks such as directly employing workers.

Supported accommodation – In this paper the term 'supported accommodation' refers to an accommodation arrangement which is predominately directed by an accommodation support service provider, which provides residential support to tenants. Typically, in the ACT, one to six individuals live in these arrangements.

Supported decision-making – The person with a disability makes their own decisions about their lives with support from trusted others to gather and consider information and weigh up pros and cons of decisions.