

advocacy for
inclusion

Submission to
ACT Budget Consultation 2014 - 15

Advocacy for Inclusion
October 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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Summary of Recommendations

Core Recommendation

1. Improving the inclusion of people with disabilities as equal participants and active Australian citizens in all aspects of the community must be the driving principle behind all ACT public policy, including disability specific and mainstream policy.

Key areas for Government action

Recognise supported decision-making

2. Comprehensively review the ACT *Guardianship and Management of Property Act 1991* with a view to replacing substitute decision-making with supported decision-making mechanisms, in compliance with the ACT's obligations under the CRPD and the CRPD Committee's Concluding Observations (October 2013).

Make control and choice real for people with disabilities

3. Resources should be targeted at promoting cultural change to help the disability sector to transition to the new NDIS landscape, where the person with disability is supported to have control and choice as an equal and active Australian citizen, including:
 - 'Control and choice' policy development guide for disability organisations;
 - Cultural change tool kit for disability services;
 - 'Control and choice' self-assessment audit kit should be developed for disability services;
 - 'Control and choice' induction kit for new employees in disability services.
4. The ACT to explore 'risk enablement' as an alternative policy approach to traditional risk management approaches so that people with disabilities can exercise control and choice and operate as active citizens.
5. As part of facilitating cultural change in the ACT, Supporting Self-Advocacy training should become mandatory for paid disability support workers and planning coordinators in the ACT.
6. Allocate increased funding to expand the ongoing provision of Self-Advocacy training for people with disabilities. This training and ongoing support builds skills and supports people with disabilities to assert their preferences and feel confident to take control over their own lives.
7. Funding for training and development in the disability services sector and workforce must be matched by funding for Self-Advocacy training, especially in the lead up to and for the first decade of the NDIS.

Build people with disabilities as representatives and leaders

8. The ACT Government to immediately establish a policy committing government agencies to meaningfully engage and support people with disabilities in representative and leadership roles.
9. The policy must include a quota in community leadership and representation roles that reflects the proportion of people with disabilities in the total population.
10. The policy should also include a 50 per cent quota of people with disabilities in leadership roles pertaining specifically to disability matters, which reflects the diversity within the disability population.

11. Disability representatives should reflect the diversity across the population of people with disabilities:-
- Equal representation of men and women;
 - Aboriginal and Torres Strait Islander peoples;
 - Culturally and linguistically diverse backgrounds;
 - People with various disabilities;
 - A range of age groups.
12. The ACT to fund grass roots, flexible leadership development targeted at people with disabilities, especially those who are currently most excluded from leadership roles. This includes people with significant communication barriers and cognitive impairments.

Access to strong independent advocacy

13. The ACT Government to meaningfully fund the full range of advocacy services in recognition of their critical role in supporting people with disabilities as active citizens, and in regard to the imminent launch of the NDIS, which is expected to double the demand for advocacy.
14. The ACT to allocate 1.3% of NDIS funding pool towards independent advocacy, administered separately to ensure independence.
15. When the NDIS becomes streamlined into a federal program, the ACT should advocate within COAG that this funding system for independent advocacy be transferred to the federal system, and administered separately from the NDIA.

Meaningfully include people with disabilities in all aspects of the community

16. The ACT to actively phase out systems and facilities that segregate people with disabilities from the community and increase supports and resources to support people with disabilities to live, work and be educated in the community as active citizens. This should be done by halting further funding to segregated systems and instead divert it to supports and resources for inclusion, as well as improving the inclusiveness of mainstream policies and programs.

Chronic problems caused by passive citizenship – Address the key pressure points

17. The ACT to progress its current work to reduce the rates of children in out-of-home care by developing policies that promote and support people with disabilities as valued parents, particularly parents with learning difficulties.
18. Urgently amend the *Domestic Violence and Protection Orders Act 2008* (ACT) to incorporate the NSW definition of household¹, which extends to disability specific living arrangements. This must be done to provide equality before the law for people with disabilities who experience violence and abuse in their homes, and enable better community recognition and response.²
19. In collaboration with the Federal Government, the ACT to develop mechanisms for data collection about people with disabilities across the full range of UN CRPD obligations. Data must be disaggregated by age, gender, type of disability, place of residence and cultural background, as recommended by the UN CRPD concluding observations.

¹ *NSW Crimes (Domestic and Personal Violence) Act 2007*, Section 5.

² As previously recommended in Advocacy for Inclusion's *Submission to ACT Budget Consultation 2013 - 14*

Introduction

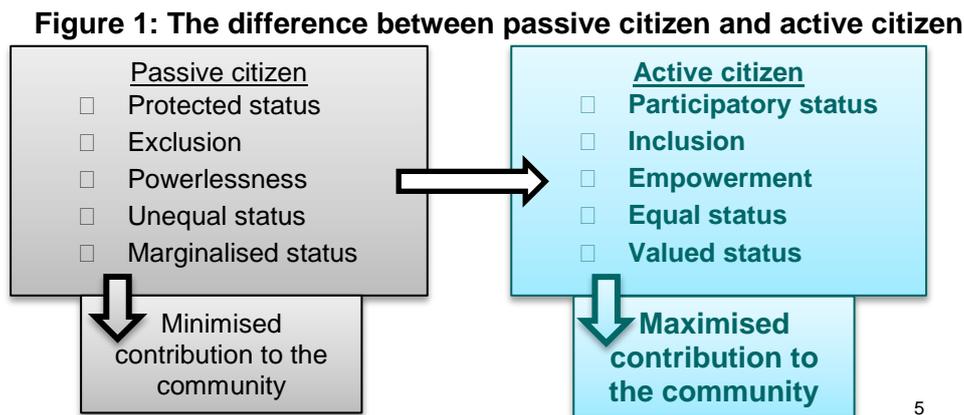
In the ACT, government and community policies and practices oppress and exclude people with disabilities, denying them their right to active citizenship, and causing many to remain largely passive citizens.

People with disabilities are denied the most basic of rights and freedoms expected by any other Australian citizen. Citizenship is about participating as a full and equal member of the Australian community. It involves reciprocal rights and obligations, uniting all Australians, while respecting their diversity.³ Active Australian citizens enjoy a number of entitlements including the right to vote, sit on a jury, and run for Parliament. These are recognised as fundamental to operating actively in Australia's democratic society.

People with disabilities are a long way off accessing these citizen entitlements on an equal basis with other Australians. They do not even have access to the most basic human rights that form the platform on which citizens can exercise their citizenship rights.

The ACT *Human Rights Act 2004* recognises international instruments; including the UN *Convention on the Rights of Persons with Disabilities (CRPD)*⁴ and other treaties that Australia is party to. Many of these instruments carry an expectation of a continuing improvement in the lives of people with disabilities including supporting them to live and participate in the community as other Australian citizens do.

Importantly, when people with disabilities can operate as active Australian citizens they are able to maximise their participation and contribution to the community. They can become co-designers in policy and program responses to the barriers facing them, which the *National Disability Strategy* recognises is the best way to develop effective social policy responses pertaining to people with disabilities.



Recommendation 1: Improving the inclusion of people with disabilities as equal participants and active Australian citizens in all aspects of the community must be the driving principle behind all ACT public policy, including disability specific and mainstream policy.

The rollout of the NDIS will lead to more people with disabilities having their support needs met. It will provide the opportunity for them to take control and make real choices in their lives. This will be the vehicle that moves people with disabilities into greater independence, and therefore, into the active citizen space. However, people with disabilities will be prevented from taking this opportunity if exclusionary attitudes and practices persist. The system will get bigger but poor practices that make people with disabilities dependent and passive

³ *Australian Citizenship Act 2007*: Section (1), Preamble.

⁴ UN *Convention on the Rights of Persons with Disabilities* <http://www.un.org/disabilities/default.asp?navid=14&pid=150>

⁵ Adapted from: Kim, H. S. (2010). UN Disability Rights Convention and implications for social work practice. *Australian Social Work*, 63(1), 103-116.

citizens will remain. Now is a pivotal time to build people with disabilities as active citizens, so that the benefits of the NDIS can be maximised.

The ACT Government presented an innovative and progressive budget for 2013-14, which recognised the need for change in how disability services are funded. The 2013-14 Budget incorporated the need for change, adjusted for new money entering the ACT for the NDIS and associated costs, and also committed ACT money to ensure this happened through a controlled transition. Advocacy for Inclusion highly commended the Budget at the time⁶. We now recommend that the ACT Government support the well-structured reshaping of fiscal systems by introducing social policy reforms to match it. That is, developing policies that support people with disabilities to be active citizens, who control their own lives and who make positive and meaningful contributions to the community.

There are five critical areas for promoting the active citizenship of people with disabilities in the ACT:

1. Recognise supported decision-making

The current *ACT Guardianship and Management of Property Act 1991* denies legal recognition of decisions by people with disabilities. It allows substitute decision makers to be appointed to make decisions on behalf of people with disabilities. Because the law does not recognise supported decision-making arrangements, it does not support a person's right to exercise their legal capacity using whatever support they might need.

2. Make control and choice real for people with disabilities

There is a pervasive societal belief that people with disabilities, especially those who have high support needs, cannot have control and choice over their lives. People with disabilities are prevented from exercising the most basic of rights and responsibilities which are available to any other Australian citizen. This includes having a choice over with whom they live, and day-to-day decisions like what they will eat for dinner and what time they will go to bed. This is the daily reality for many people with disabilities⁷.

3. Build people with disabilities as representatives and leaders

People with disabilities are underrepresented in community and disability leadership roles. This is particularly the case for people with cognitive and/or communication impairments. Both mainstream and disability specific programs and policies will not be effective in responding to the needs of people with disabilities until there is meaningful involvement at this level.

4. Access to strong independent advocacy

Where people with disabilities are excluded and marginalised, independent advocacy is crucial to advancing the rights of people with disabilities as active citizens. The ACT Government only provides a small amount of ongoing funding for self-advocacy and a further allocation for systemic advocacy for people with disabilities. The ACT is one of only two Australian jurisdictions that does not fund individual advocacy. Independent advocacy in the ACT is under-resourced and unable to keep up with demand. Critically, the demand for advocacy is projected to substantially increase (at least double) with the roll out of the NDIS.

5. Meaningfully include people with disabilities in all aspects of the community

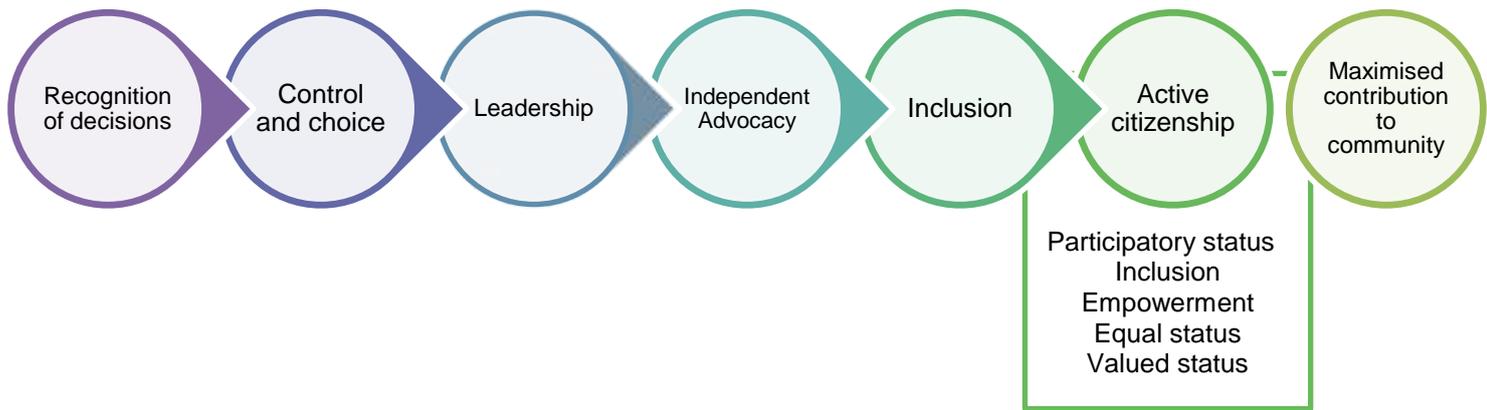
People with disabilities are often excluded from mainstream policies and programs in the ACT. They are segregated from the community, often for their whole lives, through the use of segregated services such as sheltered workshops (Australian Disability Enterprises), special schools, and special transport. People with disabilities cannot operate as active citizens when they are shut out from the community.⁸

⁶ Advocacy for Inclusion. (2013). *Disability analysis of Budget 2013*. <http://www.advocacyforinclusion.org/index.php/88-uncategorized/117-disability-analysis-of-budget-2013>

⁷ Advocacy for Inclusion. (2013). *"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*. <http://www.advocacyforinclusion.org/index.php/publications-home/decision-making>

⁸ See Commonwealth of Australia. (2009). *Shut Out: The experience of people with disabilities and their families in Australia*. <http://www.dss.gov.au/our-responsibilities/disability-and-carers/publications-articles/policy-research/shut-out-the-experience-of-people-with-disabilities-and-their-families-in-australia>

Figure 2: Five key areas for Government action towards Active Citizenship for people with disabilities



1. Recognise supported decision-making

Article 12 of the *Convention on the Rights of Persons with Disabilities* (CRPD) says that people with disabilities have the human right to have their decisions legally recognised, and be supported to exercise decision making capacity. The ACT *Human Rights Act 2004*⁹ and Australia’s ratification of the CRPD oblige the ACT to substantially reconsider guardianship approaches. The UN Committee on the Rights of Persons with Disabilities has now recommended that the Australian Law Reform Commission uses its current inquiry into legal barriers¹⁰ to “take immediate steps to replace substitute decision-making with supported decision-making... in conformity with article 12 of the Convention.”¹¹

*The Committee further recommends that the State party provides training, in consultation and cooperation with persons with disabilities and their representative organisations, at the national, regional and local levels for all actors, including civil servants, judges, and social workers, on the recognition of the legal capacity of persons with disabilities and on the primacy of supported decision-making mechanisms in the exercise of legal capacity.*¹²

People with disabilities are denied their right to make decisions about their own lives through the ACT *Guardianship and Management of Property Act 1991*. This Act allows substitute decision-makers to be appointed to make decisions on behalf of people with disabilities. The NDIS is intended to set the scene for person-centred and self-determined support models that enable people with disabilities to “fulfil their potential as equal citizens.”¹³ People with disabilities will not be able to exercise control and choice under the NDIS if their decisions are not legally recognised and socially valued. Nor can they participate as active citizens. It is time to comprehensively review guardianship legislation in light of progressive movements in the community and to promote the right for people with disabilities to make their own decisions with support.

Because ACT Guardianship law does not recognise supported decision-making arrangements, it does not support a person’s right to exercise their legal capacity with whatever support they might need¹⁴. In the

⁹ See *Human Rights Act 2004*, Section 8 and Section 30

¹⁰ See inquiry details at <http://www.alrc.gov.au/inquiries/legal-barriers-people-disability>

¹¹ Committee on the Rights of Persons with Disabilities. (4 October 2013). *Concluding observations on the initial report of Australia, adopted by the Committee at its tenth session (2–13 September 2013)* (Para. 25)

¹² Committee on the Rights of Persons with Disabilities. (4 October 2013). *Concluding observations on the initial report of Australia, adopted by the Committee at its tenth session (2–13 September 2013)* (Para. 26).

¹³ Productivity Commission. (2011). *Disability Care and Support*. Report no. 54. Canberra.

¹⁴ For more information, see Advocacy for Inclusion. (2012). *Supported decision making, legal capacity and guardianship: Implementing article 12 of the CRPD in the ACT*. <http://www.advocacyforinclusion.org/index.php/publications-home/decision-making>

absence of recognition for supported decision-making, substitute decision-making remains the first viable option for many people with disabilities in the ACT. When a person is brought to the ACAT in need of support, a guardianship order becomes inevitable in the absence of any viable alternative. As a result, many Advocacy for Inclusion consumers who are able to make their own decisions, but who might need some support to do so, are placed under guardianship orders.

The ACT must now actively engage at the local level in transitioning from substitute decision-making to supported decision-making mechanisms for people with disabilities. This must include a comprehensive review of the *Guardianship and Management of Property Act 1991*.

Recommendation 2: Comprehensively review the ACT *Guardianship and Management of Property Act 1991* with a view to replacing substitute decision-making with supported decision-making mechanisms, in compliance with the ACT's obligations under the CRPD and the CRPD Committee's Concluding Observations (October 2013).

Supported decision-making is a relatively new model for supporting people with cognitive impairment to make significant decisions. It involves consultations where specific decisions are addressed, weighed, and concluded by an individual with disability. They do this with support from a trusted person or a network of people whom they have chosen, such as friends, family members or volunteers.

Australian citizens in the general population use supported decision-making daily. For example, when making major life decisions (like buying a house or undertaking significant medical treatment) most people will consult with family, partner, and/or friends for advice or greater knowledge. In contrast, people with disabilities face a greater level of scrutiny. They are expected to prove their capacity by acting alone or, if they cannot, they are assumed to be "incapable" and many are placed under guardianship arrangements.

Increasingly, the community and government are acknowledging the need for supported decision-making to be recognised in service systems and legislation. Guardianship is becoming widely recognised as out dated,^{15 16} with the emphasis shifting from people with disabilities as passive service recipients to supporting them to be active members of the community.¹⁷ It is time for ACT legislative and policy mechanisms to actively support this shift.

In the ACT for example, the *Mental Health (Treatment and Care) Amendment Bill 2013* explicitly acknowledges supported decision-making as the first option and substitute decision-making as the last. It was clearly established during the review process that the progressive notions of supported decision-making coming into the new ACT *Mental Health (Treatment and Care) Act* would directly contradict the *Guardianship and Management of Property Act*. Guardianship law will be increasingly unworkable as new structures that recognise supported decision-making are introduced. It is pertinent that the ACT keeps up with these developments and comprehensively reviews guardianship law accordingly.

Supported decision-making arrangements are currently used in parts of Canada, the UK, and other parts of the world and are becoming established in Australia.¹⁹ The Office of the Public Advocate in South Australia has successfully undertaken extensive non-statutory supported decision-making trials²⁰ and an independent evaluation highlights the benefits of supported decision-making agreements, including increased skills and

¹⁵ *Essential Principles: Irish Legal Capacity Law*. (2012). http://www.nuigalway.ie/cdlp/documents/principles_web.pdf

¹⁶ Inclusion Europe. (2008). *Key Elements of a System for Supported Decision Making*. http://inclusion-europe.org/images/stories/documents/PositionPapers/Position_Supported_Decision_Making_EN.pdf

¹⁷ Victorian Law Reform Commission. (2012). *Guardianship: Final Report 24*, Melbourne

¹⁸ Victorian Law Reform Commission. (2012). As above.

¹⁹ Advocacy for Inclusion. (2012). *Supported Decision Making, legal capacity and guardianship*.

http://www.advocacyforinclusion.org/publications/supported_decision_making_legal_capacity_and_guardianship2012final.pdf

²⁰ Office of the Public Advocate South Australia. (2013). *Resources: Supported decision making*.

http://www.opa.sa.gov.au/resources/supported_decision_making

confidence in decision making.²¹ A project with positive outcomes has also been undertaken in the ACT.²² The supported decision-making movement is gaining momentum and community support. Most pertinently, people with disabilities are telling Advocacy for Inclusion that they want to make their own decisions and want support to do so.²³

It is time to comprehensively review guardianship legislation in light of progressive movements in the community and to promote the right for people with disabilities to make their own decisions with support. This is essential to fulfil the purpose of the NDIS. Without acknowledgement of their decisions, people with disabilities will remain disempowered passive citizens. Supported decision-making must become recognised by the ACT as a matter of urgency to support the choice and control of people with disabilities over their own lives and to promote them as active citizens.

²¹ Wallace, M. (2012). *Evaluation of the supported decision making framework: office of the Public Advocate*. Retrieved from http://www.opa.sa.gov.au/documents/11_Supported%20Decision%20Making/8-Final%20Supported%20Decision%20Making%20Evaluation.pdf

²² ADACAS. (2013). *Spectrums of support: A report on a project exploring supported decision making for people with disability in the ACT*. http://www.adacas.org.au/decision-support/copy_of_SupportedDecisionMakingProjectFinalReport.pdf

²³ Advocacy for Inclusion. (2013). *“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. <http://www.advocacyforinclusion.org/index.php/publications-home/decision-making>

2. Make control and choice real for people with disabilities

People with disabilities approach Advocacy for Inclusion because they have little or no meaningful control and choice in their lives. People with disabilities cannot participate as active citizens when they are denied authority over their own lives. Our consumers have never been able to choose where they live, who they live with, what activities they do during the day, what employment they undertake (if any), and even what food they eat. People with disabilities ask Advocacy for Inclusion “do I have the same rights as other people”.²⁴ They can see that their lives are different, and often make the assumption that because the segregation, exclusion, boredom and demeaning treatment surrounding them is accepted by the community, they too must tolerate it.

Disability ACT’s values and visions are progressive and supportive of consumer control and choice²⁵. Control and choice for people with disabilities is the underpinning of the NDIS legislation, which could be instrumental in activating people with disabilities as citizens²⁶. 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.

Practice often does not align with these stated values. Advocacy for Inclusion regularly encounters the false belief among the broader community that people with disabilities, especially those with high support needs, cannot have control and choice in their own lives²⁷. This issue is noted by numerous researchers and writers²⁸²⁹. Across the community, disability is portrayed as a ‘personal tragedy’³⁰. In this context, people with disabilities are widely regarded as passive service recipients who do not know their own best interests.

“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.”³¹

Despite the progressive policy and legislative directions, on the ground there is a ‘doing for’ instead of ‘doing with’ mentality. This is what stops people with disabilities from operating as active citizens – from having authority over their own lives and from contributing to the community as co-designers and leaders. A recent Australian study involving almost 900 people with disabilities and their families shows that these experiences are not limited to consumers at Advocacy for Inclusion:

- 30% of respondents don’t make the majority of their own decisions and 24% are not receiving the help they need to speak up;
- 54% of respondents had no choice about who provided them with personal support and 24% do not receive the level of support they were told they could have³².

People with disabilities want to be respected active citizens, who control and make choices in their own lives. Like anyone else, they do not want to be passive recipients of services, who are expected to take what they are given, regardless of their own preferences. People with disabilities are capable of claiming the control and

²⁴ Quote from Advocacy for Inclusion Self-Advocacy student

²⁵ Disability ACT. (2013). *Vision and Values Statement*. http://www.communityservices.act.gov.au/disability_act/vision__and__values

²⁶ Section 4 (8) of the *National Disability Insurance Scheme Act 2013*

²⁷ Advocacy for Inclusion. (2013). *“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. <http://www.advocacyforinclusion.org/index.php/publications-home/decision-making>

²⁸ 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

²⁹ Bigby, C., Clement, T., Mansell, J., & Beadle-Brown, J. (2009). ‘It’s pretty hard with our ones, they can’t talk, the more able bodied can participate’: Staff attitudes about the applicability of disability policies to people with severe and profound intellectual disabilities. *Journal of Intellectual Disability Research* 54(4), 363-376. Doi: 10.1111/j.1365-2788.2009.01154.x

³⁰ Barnes, C., & Mercer, G. (2003). *Disability: Key concepts*. USA: Blackwell Publishers Inc.

³¹ Interview participant: Advocacy for Inclusion. (2013). *“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. (p. 27) <http://www.advocacyforinclusion.org/index.php/publications-home/decision-making>

³² Williams, R., & Fidock, A. (2012). *Quantities of Life: Data from the Tell us Survey*. South Australia: Julia Farr Association Purple Orange.

choice offered to them by the NDIS. However, it is the disabling attitudes, practices and policies surrounding them that get in their way. These old habits will be hard to break.

The Productivity Commission asserts that “against an historical background of lack of choice and control, substantial capacity building and support will be required for many people with disabilities and their families.”³³ A cultural change is needed to promote people with disabilities as active citizens who drive their own lives.

Recommendation 3: Resources should be targeted at promoting cultural change to help the disability sector to transition to the new NDIS landscape, where the person with disability is supported to have control and choice as an equal and active Australian citizen, including:

- **‘Control and choice’ policy development guide for disability organisations;**
- **Cultural change tool kit for disability services;**
- **‘Control and choice’ self-assessment audit kit should be developed for disability services;**
- **‘Control and choice’ induction kit for new employees in disability services.**

Conventional risk management approaches dominate the disability sector and typically treat the person “as an object to be assessed by the ‘experts’ rather than as an agent in their own lives, who is part of a family, community and society, with legal rights and choices.”³⁴ Instead of supporting people with disabilities to take positive risks, approaches tend to be over protective³⁵. These over protective approaches prevent people from making choices and taking everyday risks, such as using the stove to cook a meal. It creates and reinforces the dependence of people with disabilities. Active citizens take risks as a part of their everyday lives. It is a natural and essential part of making choices and having quality of life.

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”³⁶. It is a relatively new concept emerging in the disability field. Researchers consider it a fundamental underpinning of self-directed funding models³⁷. This approach should be explored here in the ACT as an alternative to conventional approaches.

Recommendation 4: The ACT to explore ‘risk enablement’ as an alternative policy approach to traditional risk management approaches so that people with disabilities can exercise control and choice and operate as active citizens.

While support providers, families, and carers can act as major blockers when they are misguided by disabling community attitudes, equally they are crucial to enabling the control and choice of people with disabilities. They must be supported to develop the skills and attitudes required to promote the control and choice of people with disabilities. This in turn will reduce the dependence of people with disabilities on others, and enhance their contribution as an active Australian citizen.

In 2009 Advocacy for Inclusion recognised that people with disabilities need active ongoing support to develop and sustain self-advocacy skills. Having good self-advocacy skills often proves inadequate when the people providing you with essential supports refuse to assist you to follow through your choices. Further, many people with cognitive impairment need ongoing reinforcement of skills due to the nature of their disability, and support

³³ Productivity Commission. (2011). Disability Care and Support. Report no. 54, Canberra.

³⁴ 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

³⁵ Carr, S. (2011). Enabling risk and ensuring safety: Self-directed support and personal budgets. *The Journal of Adult Protection*, 13(3), 122-136

³⁶ Manthorpe, J. and Moriarty, J. (2010). *Nothing Ventured, Nothing Gained: Risk Guidance for People with Dementia*. Department of Health, London. P. 8

³⁷ 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

people are in the prime position to provide this reinforcement. To address this we developed Supporting Self-advocacy training³⁸.

Supporting Self-Advocacy programs target carers, support people, family members and members of the broader community around people with disabilities. This training assists them to recognise the strengths and abilities of people with disabilities, and to support self-determination and self-advocacy. It also helps to challenge the negative perceptions of people with disabilities among the community. The small amount of training available in the ACT has been very well received by the community and should now be delivered more broadly³⁹ and made mandatory for paid workers in the disability sector, including support workers and planning coordinators.

Recommendation 5: As part of facilitating cultural change in the ACT, Supporting Self-Advocacy training should become mandatory for paid disability support workers and planning coordinators in the ACT.

People with disabilities cannot be expected to easily slide out of the current system into a self-directed or self-managed funding option. Nor can they be expected to suddenly know their rights and feel confident to take control and make choices. The current system has taught people with disabilities to be passive service recipients and to take whatever they are given, which is often not enough to meet their needs. Some people with disabilities have never learnt the skills to make decisions about their lives and to assert their will and preferences (self-advocate) in the same way that people without disabilities are expected and encouraged to. 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.

People with disabilities need supports to develop the control and choice skills they have typically been denied. Self-advocacy training is an example of the programs needed to build assertiveness skills and knowledge of their rights among people with disabilities. Particular attention must be applied to supporting those who are most unengaged⁴⁰ and disempowered to exercise control and choice. These are the people comprising a significant portion of the NDIS recipient target group, and who are typically assumed to be 'unable' to make choices and be self-determined. Many will need intensive, practical and ongoing supports, especially those who do not learn well via conventional "class room" style teaching, and those who may need ongoing support to retain skills. Some people with disabilities will require information in alternative communication formats for example, the use of new technologies such as iPads and communication cards.

While there has been substantial commitment by both ACT and Federal governments for training, restructuring and workforce development for disability services in the lead up to the NDIS; there has not been a similar level of commitment to prepare people with disabilities for the new world of choice and control. Without concerted efforts placed into developing these attitudes and capacities, the NDIS will become a bigger version of the old system. The Productivity Commission asserts:

*Consumer choice also generally leads to more efficient outcomes, as people are usually better placed to know what would meet their needs than service providers ... the lack of choice adds to inefficiency in the current disability support system.*⁴¹

The Productivity Commission advised that the benefits of the NDIS would exceed the costs through the increased engagement of people with disabilities⁴². Capacity building will pay for itself when people with

³⁸ Advocacy for Inclusion. (2012). *Developing Supporting Self-Advocacy training: Why and how*. Presentation to the World Congress on guardianship, Melbourne.

www.advocacyforinclusion.org/index.php?option=com_content&view=category&layout=blog&id=48&Itemid=59

³⁹ Advocacy for Inclusion. (2013). *"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*. <http://www.advocacyforinclusion.org/index.php/publications-home/decision-making>

⁴⁰ The term "unengaged" is used to apply to people who have never had an opportunity to be engaged, as opposed to "disengaged" which implies a former level of engagement that no longer exists.

⁴¹ Productivity Commission. (2011). As above. p. 151

⁴² Productivity Commission. (2011). As above. Chapter 20.

disabilities are enabled as active citizens, and make their maximum contribution to community life. Advocacy for Inclusion has observed an emerging pattern of reduced reliance on individual advocacy services by people with disability who have ongoing access to self-advocacy training targeted appropriately to their individual learning needs.

Recommendation 6: Allocate increased funding to expand the ongoing provision of Self-advocacy training for people with disabilities. This training and ongoing support builds skills and supports people with disabilities to assert their preferences and feel confident to take control over their own lives.

Recommendation 7: Funding for training and development in the disability services sector and workforce must be matched by funding for Self-advocacy training, especially in the lead up to and for the first decade of the NDIS.

3. Build people with disabilities as representatives and leaders

“In the development and implementation of legislation and policies to implement the present Convention, and in other decision-making processes concerning issues relating to persons with disabilities, States Parties shall closely consult with and actively involve persons with disabilities, including children with disabilities, through their representative organizations.”⁴³

People with disabilities, especially those with cognitive and communication impairments, are almost totally excluded from leadership and representative roles. A current example is the ACT NDIS Expert Panel, focussing on the biggest disability reform in a life time, comprises only one quarter people with disabilities, and only one woman with disability. Disability representation should include men and women equally, people with different types of impairment, and people from diverse cultural backgrounds, to reflect the general population. The Expert Panel does not meet these expectations.

More often than not people with disabilities are excluded from these roles or their involvement is tokenistic. It is not good enough simply to have a person with disability in the room when they are not supported to meaningfully engage in the matter. This is not an effective way of resolving the social issues they encounter. They know their own needs best and should be supported to contribute their expertise⁴⁴.

People with disabilities must be included as co-designers in responding to the issues that concern them. The *National Disability Strategy 2010-2020*, to which the ACT is committed, says that governments will provide people with disabilities appropriate support and adjustment to participate in the design, funding, delivery and evaluation of policies and programs. The UN Committee on the Rights of Persons with Disabilities concluded:

*The Committee recommends that the State party, in partnership with persons with disabilities through their representative organisations, including children with disabilities, establish engagement mechanisms for ensuring meaningful participation in the development and implementation of legislation and policies to implement the Convention.*⁴⁵

Figure 3: Case study

Current situation with lack of leadership support:

Danni was invited to sit on a government reference group regarding a disability policy matter as he has lengthy experience in the area, and knows many other people in a similar position. Danni has an intellectual disability and has never been involved on a reference group before. The evening before the meeting the government agency emails Danni the relevant papers. They are not written in plain English and Danni has low literacy. He is not provided with any support to read and understand the papers, nor does he have enough time to seek this support. When Danni gets to the meeting he isn't prepared and the conversation moves too quickly for him. Every now and then the Chairperson asks for his input. Danni doesn't have anything to say because he doesn't understand what is being discussed. He decides not to attend the next meeting as he was so embarrassed by his lack of ability at the first.

Alternative situation with appropriate leadership support:

Danni is sent a hard copy of the meeting papers in Easy English, the format accessible to him, with plenty of time to prepare. The Government agency pays for Danni's chosen support person to help him read and understand the papers, and prepare his comments and questions. During the meeting his support person helps him remember what he wants to say by asking him questions and pointing out his relevant notes. He is able to participate as an equal on the reference group and the other members are impressed by the insights and knowledge he offers.

⁴³ Article 4.3 UN Convention on the Rights of Persons with Disabilities <http://www.un.org/disabilities/default.asp?navid=14&pid=150>

⁴⁴ *National Disability Strategy 2010-2020*

⁴⁵ Committee on the Rights of Persons with Disabilities. (4 October 2013). *Concluding observations on the initial report of Australia, adopted by the Committee at its tenth session (2–13 September 2013)* (Para. 11).

Active citizens are not tokens. They represent themselves and are part of solving their own problems. As the NDIS is rolled out, the control and choice of people with disabilities, and leadership and representation by people with disabilities becomes even more pertinent. This is also important in building an equal and valued status for people with disabilities in the community.

The ACT Government must immediately establish a central policy that commits government agencies to engage and support people with disabilities as co-designers in leadership and representative roles. The proportion of people with disabilities on Government boards and reference groups regarding general community matters, which are non-disability specific, must reflect the proportion in the general population. To genuinely take leadership over disability matters, people with disabilities must comprise at least 50 per cent of representative and leadership roles in any bodies pertaining to disability matters.

Recommendation 8: The ACT Government to immediately establish a policy committing government agencies to meaningfully engage and support people with disabilities in representative and leadership roles.

Recommendation 9: The policy must include a quota in community leadership and representation roles that reflects the proportion of people with disabilities in the total population.

Recommendation 10: The policy should also include a 50 per cent quota of people with disabilities in leadership roles pertaining specifically to disability matters, which reflects the diversity within the disability population.

Disability representatives must also have established connections with the community, such as being a recognised member of a representative disability organisation. This is to ensure that people with disabilities are represented by people who are in touch with current issues and priorities across the population of people with disabilities.

People with disabilities are a diverse group. They come from different life experiences, age groups, and cultural backgrounds. Disability leaders must be diverse in order to truly represent people with disabilities; however, this is not currently the case. Existing ACT policies commit governments to ensure gender equality on government boards and reference groups⁴⁶. This too must be applied to the engagement of people with disabilities, to ensure that men and women with disabilities are engaged equally at the representative and leadership level.

Recommendation 11: Disability representatives should reflect the diversity across the population of people with disabilities:-

- **Equal representation of men and women;**
- **Aboriginal and Torres Strait Islander peoples;**
- **Culturally and linguistically diverse backgrounds;**
- **People with various disabilities;**
- **A range of age groups.**

There is a lack of leadership programs targeted to meet the needs of people with disabilities. Mainstream leadership programs can appear intimidating and unwelcoming. They are typically targeted at people who are verbally articulate, confident in large groups, and suited to the classroom learning format. Usually they are delivered over a short-term. Conversely, many people with disabilities use alternative communication formats, feel more comfortable in small or one to one sessions, and are best suited to practical learning formats such as mentoring. In particular, many require ongoing support in their leadership roles, especially those with cognitive

⁴⁶ACT Women's Plan 2010-2015. (p. 11)

http://www.communityservices.act.gov.au/__data/assets/pdf_file/0016/122506/ACT_Womens_Plan_2010_-15.pdf

impairments (as demonstrated in Figure 3). Leadership programs must be tailored and flexible to suit these diverse needs.

Due to their marginal position in society, many potential ACT disability leaders are kept far away from leadership roles. Negative attitudes mean that they are often not trusted to make decisions about their own lives, let alone decisions that affect the community more broadly. People with disabilities begin to realise their own leadership potential through Self-advocacy training, which has only been available in Canberra for a few years. Self-advocacy training can act as the catalyst and essential preparation stage for leadership development.

Programs must be directed at the grass roots, where people with disabilities have significant but unrecognised potential for leadership. This includes people with cognitive and/or communication impairments who are sorely lacking in leadership roles, and those who live in highly dependent environments like disability group houses. Disability ACT has recognised this issue; however, adequate resources have not been allocated to skilling and supporting people with disabilities to act in leadership and representative roles. People with disabilities are not active citizens until they have meaningful involvement at the leadership and representative level, and participate in addressing their own matters. Nothing will change until significant and real resources are committed to this outcome.

Figure 4: Grass roots leadership and representation development for people with disabilities

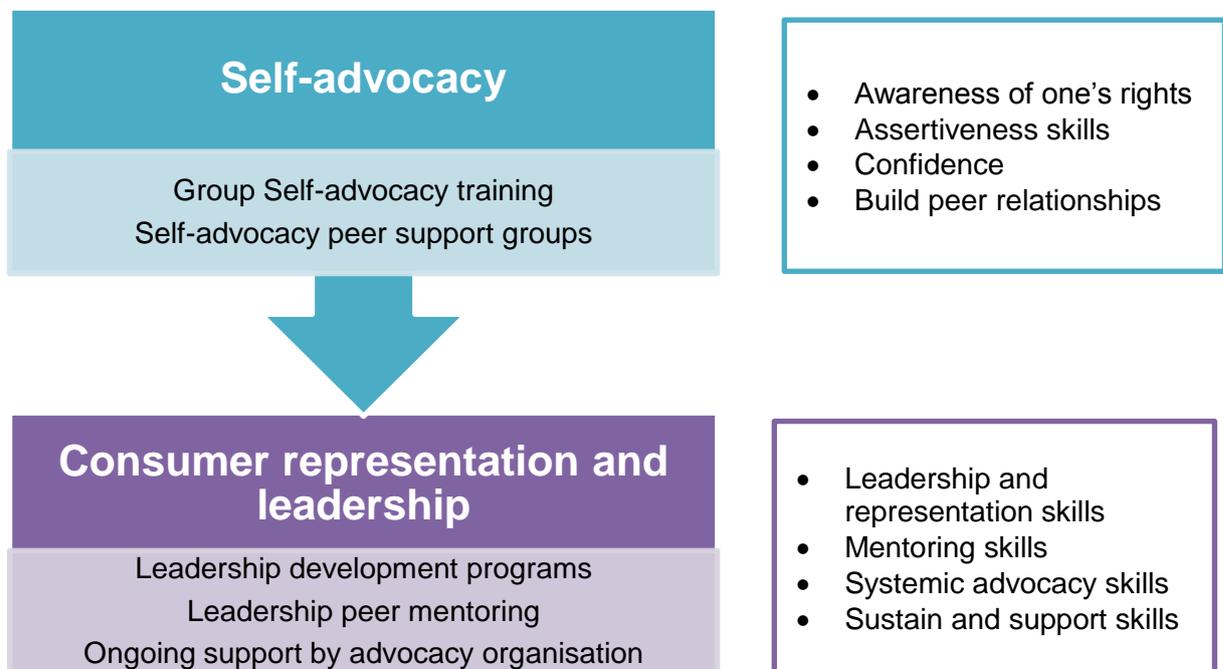


Figure 3 demonstrates the relationship between self-advocacy training and leadership development. Grass roots training is targeted at those who may not yet be leadership ready, but whose potential to become leaders can be nurtured through self-advocacy training and then become established through leadership development. Not everyone will progress to leadership, just as not everyone in the broader community progresses to leadership roles, but at present there are no structures or consistent supports to develop this at all for people with disabilities.

Recommendation 12: The ACT to fund grass roots, flexible leadership development targeted at people with disabilities, especially those who are currently most excluded from leadership roles. This includes people with significant communication barriers and cognitive impairments.

4. Access to strong independent advocacy

Independent advocacy is grossly under-resourced in the ACT. Advocacy for Inclusion has no option but to decline individual intakes frequently as we do not have the advocates to meet the demand⁴⁷. To operate as active citizens, people with disabilities need to challenge the negative attitudes and exclusion they face in the community. This is a huge job. They need back-up to support their voices to be louder and to be heard. Independent advocacy provides this back-up.

There are several types of advocacy. Each is as important as the other in promoting the rights of people with disabilities as active citizens, and the development of quality and sustainable disability systems. Four⁴⁸ of the recognised forms of advocacy are available in the ACT, but only 3 are funded by the ACT:

- **Individual advocacy** enables people with disabilities to provide feedback about the disability sector through intensive one on one support to raise and resolve service issues. Referrals are commonly made by government officials or service providers, who mostly refer only those issues that are difficult to resolve or in which they have a conflict of interest. Thus individual advocacy operates primarily as a trouble shooter or circuit breaker.⁴⁹ This type of support will be essential in the new NDIS system; there will be plenty of service glitches as twice the number of people with disabilities and services learn the ropes.
- **Self-advocacy** trains and then provides ongoing support for people with disabilities to advocate on their own behalf.
- **Representative advocacy** is advocacy by disabled people's organisations – advocacy for people with disabilities by people with disabilities. This is crucial to advocating the rights of people with disabilities from the perspective of people with disabilities and to supporting disability leadership. Under internationally recognised benchmarks DPOs are managed and governed only by people with disabilities.
- **Systemic advocacy** supports people with disabilities to collectively influence the systems, legislation and structures concerning them. Advocacy organisations, as independent agencies, need to be funded to undertake consultation directly with people with disabilities in ways that are accessible and meaningful to them.
- **Legal advocacy** supports people with disabilities with the legal aspects of discrimination and other matters. This is highly important as many people with disabilities rely on service providers for a life-time and may encounter legal issues that are not covered by legal-aid. Due to the economic disadvantage of people with disabilities they are also less able to afford legal representation not subsidised by government.
- **Family advocacy** supports families to advocate on behalf of a person with disability.
- **Citizen advocacy** matches a person with disability with a volunteer who provides long-term advocacy support.

Currently, the ACT Government only provides a small amount of ongoing funding for self-advocacy, representative advocacy and systemic advocacy for people with disabilities. The ACT is one of only two Australian jurisdictions that do not fund individual advocacy. As a result, independent advocacy in the ACT is under-resourced and unable to keep up with demand.

⁴⁷ A tracking audit undertaken in early 2013 showed that for every person with disability who could be supported through individual advocacy, Advocacy for Inclusion had to turn away two other people who desperately needed our advocacy assistance.

⁴⁸ A new organisation, ImagineMore, is now working in the ACT to establish in the family advocacy area.

⁴⁹ DANA. (2012). *Independent Advocacy and the NDIS: A paper to consider the role of Independent Advocacy when there is a National Disability Insurance Scheme*. <http://www.dana.org.au/publications/submissions/>

Recommendation 13: The ACT Government to meaningfully fund the full range of advocacy services in recognition of their critical role in supporting people with disabilities as active citizens, and in regard to the imminent launch of the NDIS, which is expected to double the demand for advocacy.

The *National Disability Strategy* commits the ACT government to “Support independent advocacy to protect the rights of people with disability” (page 41). Additionally, the ACT *Disability Services Act 1991* Schedule 2 (11) stipulates that “Services should be designed and administered so as to ensure that people with disabilities have access to advocacy support where necessary to ensure adequate participation in decision making about the services they receive”. The continuing lack of funding is unacceptable and contradicts these clear ACT Government obligations and commitments.

Critically, the demand for advocacy is projected to substantially increase due to a range of factors⁵⁰. Some of these factors include:

1. The population of people with disabilities is increasing⁵¹ and the demand for advocacy will naturally increase with this.
2. With the roll out of NDIS the amount of people receiving disability services will at least double⁵². With the increase in service users there will be an increase in advocacy demand.
3. The NDIS brings a major change to the way the disability system operates. The Disability Advocacy Network Australia (DANA) advises that:

*A key role of independent advocacy organisations is supporting consumers to understand and negotiate the changes that occur in the service systems those consumers depend on. Changes to eligibility provisions, to the types of supports that may be accessed, to the individuals and organisations involved in providing those supports, and to the mechanisms available for consumer input to decision-making processes – all these changes represent challenges as well as opportunities for consumers.*⁵³

Further, to achieve the high quality, sustainable support intended by the NDIS⁵⁴, recipients will need the capacity to negotiate, complain and be assertive – they will need to operate as active citizens and active service users. Yet, the disability support system preceding the NDIS is “underfunded, unfair, fragmented, and inefficient, and gives people with a disability little choice and no certainty of access to appropriate supports”⁵⁵. As a result, people with disabilities have become passive service recipients, unaccustomed to a system where they can negotiate with providers, or able to complain and go elsewhere if a service is not performing to their satisfaction.

Because support services are vital to the survival and wellbeing of people with disabilities they are not positioned to easily complain and negotiate with service providers without fear of repercussions. In Advocacy for Inclusion’s experience and according to our research, people with disabilities are concerned about damaging their relationship with a service provider or being seen as a ‘difficult client’⁵⁶. Independent advocacy services are crucial for supporting people with disabilities to pursue complaints about the disability support system, and for operating as active service users in a market based scheme such as the NDIS.

⁵⁰ DANA. (2013). *Submission to Australian Government Community Consultation 2013-14 Budget*.

⁵¹ *National Disability Strategy 2010-2020*. Evidence Base. (p. 7)

⁵² Productivity Commission. (2011). *Disability Care and Support*. Report no. 54, Canberra

⁵³ DANA. (2013). *Submission to Australian Government Community Consultation 2013-14 Budget*.

⁵⁴ Productivity Commission. (2011). *Disability care and support: Key points*. Retrieved from <http://www.pc.gov.au/projects/inquiry/disability-support/report/key-points>

⁵⁵ Productivity Commission. (2011). As above

⁵⁶ Advocacy for Inclusion. (2013). “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*. <http://www.advocacyforinclusion.org/index.php/publications-home/decision-making>

DANA explains that:

*Independent advocacy is a key design feature of all disability service systems. It will ultimately not be possible for service systems to appropriately target their services without advocacy support and representation being available to those most in need of services. Nor will it be possible for service systems to ensure comprehensive quality assurance and improvement processes are in place without the feedback loops created by individual and systemic advocacy practice.*⁵⁷

A portion of NDIS funding must be allocated towards independent advocacy in the ACT to address existing demand and to meet expected demand. This should be administered separately to minimise conflicts of interest. DANA asserts that federally, independent disability advocacy funding should be at least 1.3 per cent of the National Disability Agreement and NDIS expenditure. Advocacy for Inclusion recommends that this must also apply at the ACT level.

Recommendation 14: The ACT to allocate 1.3% of NDIS funding pool towards independent advocacy, administered separately to ensure independence.

Recommendation 15: When the NDIS becomes streamlined into a federal program, the ACT should advocate within COAG that this funding system for independent advocacy be transferred to the federal system, and administered separately from the NDIA.

⁵⁷ DANA. (2013). *Submission to Australian Government Community Consultation 2013-14 Budget*.

5. Meaningfully include people with disabilities in all aspects of the community

People with disabilities cannot operate as active citizens when they are shut out and denied participation in the community. In the ACT policies and practices segregate and exclude people with disabilities from the community. According to Article 19 of the *Convention on the Rights of Persons with Disabilities*, Australia and the ACT must take effective measures to facilitate full participation by people with disabilities in all aspects of the community. The ACT must actively move away from supporting segregated models towards supporting people with disabilities as active citizens, who are included and valued in the community.

The ACT Government is committed to the *National Disability Strategy* (NDS). The NDS is based on the social model of disability, which emphasises that the person's disability is not the cause of exclusion, rather social attitudes, practices and structures are significant factors that create barriers to a person's full participation in the community. The ACT's policies and programs are among the key barriers for people with disabilities to enjoying active Australian citizenship. People with disabilities are excluded from the community, often for their whole lives. For some people, a typical day rarely involves interaction with the world outside disability specific environments.

Figure 5: Case study

Marie attended a special school for her whole childhood and she caught the special bus with other children with disabilities. As an adult she lives in disability supported accommodation, where she lives with other adults with disabilities, whom she did not choose as co-tenants. She leaves home usually only to attend a segregated day service or her sheltered workshop, where she works and does activities with other people with disabilities. When she occasionally goes out into the 'mainstream' community for dinner her support workers interact with wait staff and community members on her behalf.

Current programs operating in the ACT that segregate people with disabilities include:

Disability Employment Enterprises. A modern term for "sheltered workshops." They are workplaces where people with disabilities are segregated from the community. In this way, the contribution made by people with disabilities to the community is rendered invisible. People with disabilities must be supported to secure and sustain employment in the community, as active and visible contributors to community life.⁵⁸

Special schools. Where children with disabilities are segregated from other children to receive education. This sets them up for a life of exclusion from the community. Young people with disabilities must be given the supports they need to access education alongside children without disabilities.⁵⁹

Disability specific accommodation. Includes combined accommodation and community based residential support such as group homes. These homes are directed by the service provider and operate as a 'workplace', where people with disabilities are passive service recipients rather than active citizens with control and ownership over their own homes. These are segregated simulations of the larger congregate style accommodation they take as their precedents. The ACT Government has recently committed to building two homes specifically to provide supported accommodation to 5 adults with disabilities in each home.⁶⁰ People are being forced to live in these arrangements only because it provides them with the support they need.

⁵⁸ Article 27 UN Convention on the Rights of Persons with Disabilities (CRPD)

⁵⁹ Article 24 CRPD

⁶⁰ ACT Government. (2012). *Request for costing of election commitment*. www.treasury.act.gov.au/electioncostings/documents/Labor/Requests/LAB083%20-%20Community%20Supported%20Disability%20Housing.pdf

The ACT Government is obliged under CRPD Article 19 and the *Disability Services Act 1991*, to develop accommodation options that afford people with disabilities the same range of choices enjoyed by the general community. Further, the Committee on the Rights of Persons with Disabilities states:

*The Committee recommends that the State [Australia] party takes immediate action to make sure that persons with disabilities are given a free choice of where they want to live and with whom and be able to receive the necessary supports regardless of the place of residence.*⁶¹

Combined support and accommodation models do not resemble “the conditions of everyday life enjoyed in the general community.”⁶² The Australian Bureau of Statistics reports that only 10% of the population live in a household of 5 or more persons.⁶³ If the general population mostly chooses not to live with 4 or more other adults, then why would people with disabilities be any more likely to choose such an arrangement? There is an expectation that these are the sorts of environments people with disabilities ought to be living in. This expectation must change.⁶⁴

Inaccessible public infrastructure and resources. This includes transport, community services, private housing and businesses such as restaurants, which are often physically inaccessible for people with disabilities. People with disabilities are barred from jury duty in the ACT Supreme Court because it is not physically accessible. People with disabilities must be present to engage in the community and exercise their rights and responsibilities as citizens.⁶⁵

The ACT must actively move away from supporting segregated models towards supporting them as active citizens, who are included and valued in the community. This includes improving the inclusiveness of mainstream programs and policies, as well as phasing out systems that segregate. An example of this has already been demonstrated by the ACT Government through the closure of a respite facility which congregates people with disabilities together in order to receive supports. Advocacy for Inclusion encourages the ACT Government to continue with this progress by diverting funding towards meaningful community based alternatives.

Recommendation 16: The ACT to actively phase out systems and facilities that segregate people with disabilities from the community and increase supports and resources to support people with disabilities to live, work and be educated in the community as active citizens. This should be done by halting further funding to segregated systems and instead divert it to supports and resources for inclusion, as well as improving the inclusiveness of mainstream policies and programs.

⁶¹ Committee on the Rights of Persons with Disabilities. (4 October 2013). *Concluding observations on the initial report of Australia, adopted by the Committee at its tenth session (2–13 September 2013)* (Para. 42).

⁶² ACT *Disability Services Act 1991*

⁶³ ABS. (2012). Population: Households and families. *1301.0 Year Book Australia*. Retrieved from www.abs.gov.au/ausstats/abs@.nsf/Lookup/by%20Subject/1301.0~2012~Main%20Features~Households%20and%20families~56

⁶⁴ Article 19 CRPD

⁶⁵ Article 19 CRPD

Chronic problems caused by passive citizenship – Address the key pressure points

The key pressure points which create the need for advocacy are the areas of life where people with disabilities are most passive and devalued. Their lack of active participation minimises their contribution to the community and allows problems to develop and thrive. When people are respected and supported to operate as active citizens they have far greater capacity to engage in preventing or resolving their own problems. Instead, responses to our consumers are paternalistic and targeted at pushing people with disabilities into further passivity, for example by putting them under a guardianship order, by taking their children away, or by putting them into an institutional setting where they are falsely assumed to be 'safer'. Key areas for disability advocacy demand in the ACT include:

1. Equal recognition before the law (CRPD Article 12)

People with disabilities are denied the right to make their own decisions and exercise their legal capacity. They are not trusted to make decisions about their own lives and become passive spectators as others make decisions and operate on their behalf. When people with disabilities do not make decisions about their own lives, others can place them into arrangements that are unsuitable and unsustainable. This eventually leads to crisis, when the person is unable to cope with a lack of control and choice any longer. Crisis manifests in a range of ways including self-harm, harming others, becoming involved in the criminal justice system, being assaulted by a co-tenant they did not choose, or homelessness.

2. Respect for home and family (CRPD Article 23)

A large number of Advocacy for Inclusion's consumers are parents with disabilities, who have had their children removed or are at risk of having their children removed. Parents with disabilities are assumed to be incapable and are subject to scrutiny far beyond that experienced by parents without disabilities. Child protection case conferences are held about families without the parents in the room, because of an assumption that professionals and family members know better than the person with disability. The parent with disability is not valued and respected as an active citizen, who can found a family and make decisions about their own family life. As a result, their parenting needs are not heard or supported, and interventions are imposed upon them.

There is a high rate of child removal from parents with learning difficulties,^{66 67} causing ongoing trauma for parents and their children, and preventable demands on the frequently overstretched out-of-home care system. The ACT should progress its current work to reduce the rates of children in out-of-home care⁶⁸ by supporting people with disabilities as valued parents, as is beginning to be demonstrated in other jurisdictions.⁶⁹ Advocacy for Inclusion has raised this issue repeatedly in budget submissions since 2009 and the issue remains unaddressed.

Recommendation 17: The ACT to progress its current work to reduce the rates of children in out-of-home care by developing policies that promote and support people with disabilities as valued parents, particularly parents with learning difficulties.

3. Freedom from exploitation, violence and abuse (CRPD Article 16)

The *National Disability Strategy* recognises that people with disabilities experience high levels of violence compared to the general community. One quarter of Advocacy for Inclusion cases relate to violence in disability group homes and over 30 per cent of all cases relate to sexual violence or exploitation. Many researchers assert that this heightened risk comes from the devalued status of people with disabilities in the community, where they are taught to be passive and compliant, and their concerns about violence

⁶⁶ Llewellyn, G., McConnell, D. & Ferronato, L. (2003). Prevalence and outcomes for parents with disabilities and their children in an Australian court sample. *Child Abuse & Neglect*, 27(3), 235-251. doi: 10.1016/S0145-2134(03)00004-8

⁶⁷ Booth, T., & Booth, W. (2004). Findings from a court study of care proceedings involving parents with intellectual disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, 1(3-4), 179-181. doi: 10.1111/j.1741-1130.2004.04032.x

⁶⁸ See ABC News <http://www.abc.net.au/news/2013-09-05/fewer-children-in-act-out-of-home-care/4936692>

⁶⁹ See for example the CORRE program funded by NSW Government, ADHC:

http://www.washhouse.org.au/index.php?option=com_content&task=view&id=11&Itemid=18

disbelieved and trivialised.^{70 71 72} Domestic Violence law in the ACT does not recognise the living arrangements of many people with disabilities, such as supported accommodation, excluding them from the same protections afforded to people without disabilities. In contrast, when people are valued and their concerns taken seriously including in the eyes of the law, violence can be better addressed and prevented. Our colleagues in NSW have reported the benefits of recognising disability specific accommodation in their Domestic Violence Law, including better resourcing of support programs to address violence against people with disabilities, and improved community awareness and response.

Recommendation 18: Urgently amend the *Domestic Violence and Protection Orders Act 2008 (ACT)* to incorporate the NSW definition of household⁷³, which extends to disability specific living arrangements. This must be done to provide equality before the law for people with disabilities who experience violence and abuse in their homes, and enable better community recognition and response.⁷⁴

4. The rights of women and girls with disabilities (CRPD Article 6)

Women with disabilities are especially passive in the community as they face intersectional disadvantage. They have lower employment rates than men with disabilities⁷⁵, are subjected to higher rates of violence⁷⁶, experience higher rates of poverty, have less access to appropriate supports⁷⁷, and face increased barriers to securing leadership representative roles. They are also less likely to be appointed as leaders and representatives as evidenced by the ACT NDIS Expert Panel.

5. Living independently and being included in the community (CRPD Article 19)

People with disabilities are shut out from the community. They are marginalised and denied access to the same benefits and resources afforded to other Australian citizens, such as education and employment opportunities. They are denied the right to choose where and with whom they live, which can spiral into other social problems such as domestic violence. So long as this continues they are unable to fully participate as active citizens.

People with disabilities need to be respected as equals before the law, be supported to exercise control and choice in their lives, be meaningfully engaged in leadership and representative roles, have access to adequate independent advocacy, and be included in community life. These are measures that promote the active citizenship of people with disabilities, and support them to become engaged as active participants and contributors at the personal and community level.

In short, people with disabilities have a right to be a part of designing the policies and programs which will address their exclusion from the community. They cannot be active citizens unless they are in the room, as equals, and supported to be so.

Recommendation 1: Improving the inclusion of people with disabilities as active Australian citizens in all aspects of the community must be the driving principle behind all ACT public policy, including disability specific and mainstream policy.

⁷⁰ Fitzsimons, N. M. (2009). *Combating violence and abuse of people with disabilities: A call to action*. Maryland, USA: Paul H. Brookes Publishing Co.

⁷¹ Hollomotz, A. (2011). *Learning difficulties and sexual vulnerability: A social approach*. London: Jessica Kingsley Publishers.

⁷² Sobsey, D. (1994). *Violence and abuse in the lives of people with disabilities: The end of silent acceptance?* USA, Maryland: Paul H. Brookes Publishing Co.

⁷³ *NSW Crimes (Domestic and Personal Violence) Act 2007*, Section 5.

⁷⁴ As previously recommended in Advocacy for Inclusion's *Submission to ACT Budget Consultation 2013 - 14*

⁷⁵ Australian Bureau of Statistics. (2006). *Labour force characteristics of people with a disability. Year Book Australia 2006*.

⁷⁶ Australian Human Rights Commission. (2012). *Independent interim report on CEDAW: Report to the committee on the elimination of all forms of discrimination against women*. http://www2.ohchr.org/english/bodies/cedaw/docs/followup/ngos/AHRC_Australia.pdf

⁷⁷ WWDA. (20). *Gender and disability: An overview of the status of women with disabilities in Australia*. <http://www.wwda.org.au/snapshot.htm>

The current lack of disaggregated data collected and made publicly available about people with disabilities further pushes them into passivity. For example, the ACT Civil and Administrative Tribunal (ACAT) does not collect data about the age, gender, cultural background, and the type and duration of guardianship orders. Care and Protection Services in the ACT does not collect data about whether or not their service users have disabilities. A number of studies indicate that parents with disabilities are grossly overrepresented in the child protection system,^{78 79} yet they are invisible in child protection data. Without data, appropriate policies and programs cannot be developed to address and prevent social issues. In particular, areas of intersectional disadvantage, such as that experienced by women and girls with disabilities, cannot be analysed and targeted.

If government remains unaware of the scale of the problem for parents with disabilities, it will continue to allow their children to be removed, and will also fail to consider that parents with disabilities should be members of policy setting reference groups to address child protection issues.

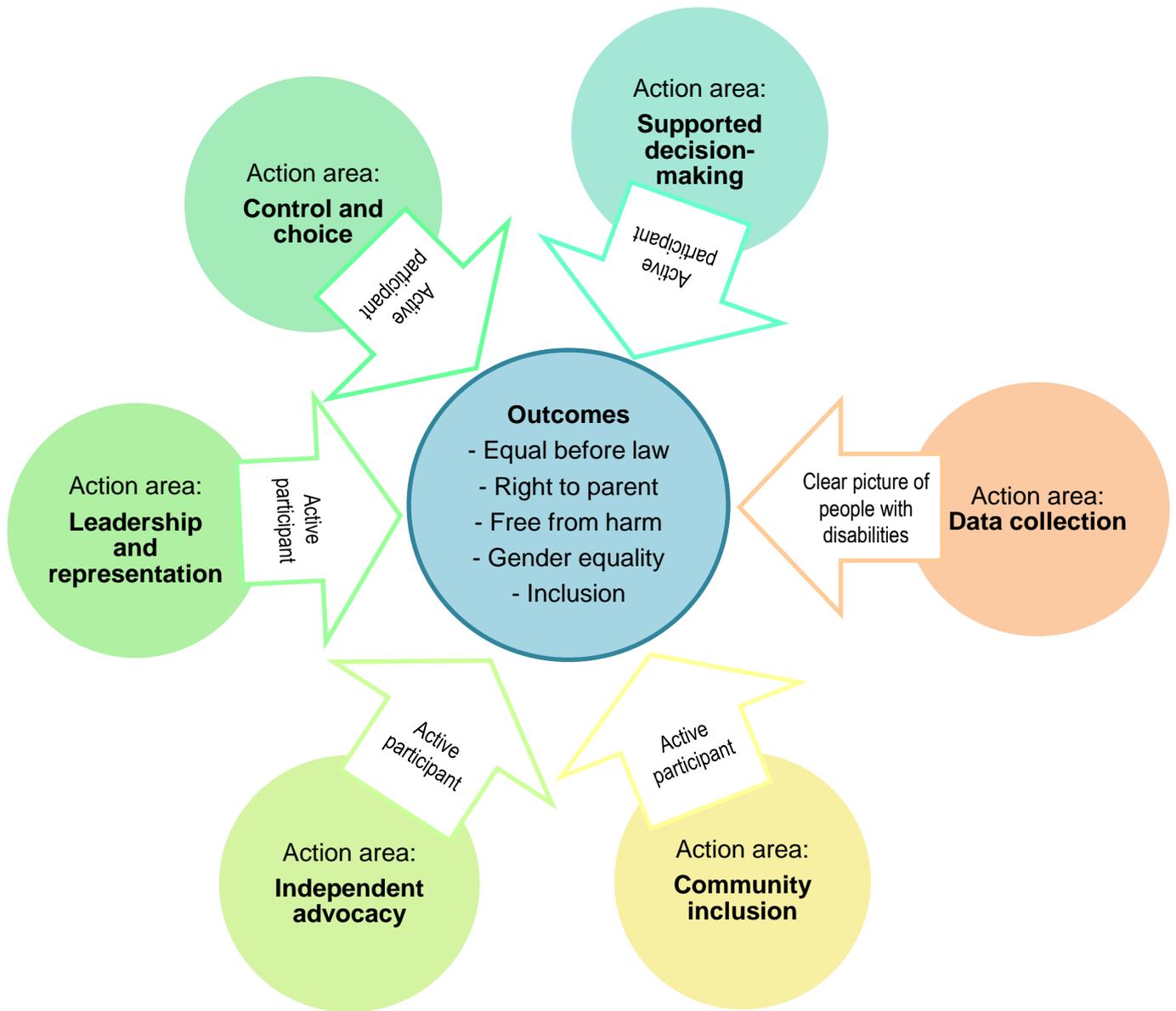
The UN Committee on the Rights of Persons with Disabilities has now recommended that Australia develops nationally consistent measures for data collection and public reporting of disaggregated data across the full range of UN CRPD obligations, and that all data be disaggregated by age, gender, presence of disability, place of residence and cultural background. Accordingly, and in collaboration with the Federal Government, the ACT must establish data collection measures to gain a clear picture about people with disabilities to inform mainstream and disability specific policies and programs.

Recommendation 19: In collaboration with the Federal Government, the ACT to develop mechanisms for data collection about people with disabilities across the full range of UN CRPD obligations. Data must be disaggregated by age, gender, presence of disability, place of residence and cultural background, as recommended by the UN CRPD concluding observations.

⁷⁸ Llewellyn, G., McConnell, D. & Ferronato, L. (2003). Prevalence and outcomes for parents with disabilities and their children in an Australian court sample. *Child Abuse & Neglect*, 27(3), 235-251. doi: 10.1016/S0145-2134(03)00004-8

⁷⁹ Booth, T., & Booth, W. (2004). Findings from a court study of care proceedings involving parents with intellectual disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, 1(3-4), 179-181. doi: 10.1111/j.1741-1130.2004.04032.x

Figure 6: Active citizenship for people with disabilities: Areas for ACT Government action and the expected outcomes



Conclusion

People with disabilities can exercise their rights as active citizens when they have access to basic human rights and freedoms. They can enjoy their entitlement to vote, sit on a jury, and run for Parliament when:

1. Their decisions are legally and socially recognised and valued;
2. They have control and choice over their own lives;
3. They are co-designers as representatives and leaders;
4. They have back up from independent advocacy organisations;
5. The community is accessible and inclusive.

These are measures that will promote the active citizenship of people with disabilities, and support them to become engaged as active participants and contributors at the personal and community level. People with disabilities have a right to be a part of designing the policies and programs which will address their exclusion from the community. They cannot be active citizens unless they are in the room, as equals, and supported to be so.

The rollout of the NDIS will lead to more people with disabilities having their support needs met. It will provide the opportunity for them to take control and make real choices in their lives. This should be the vehicle that moves people with disabilities into greater independence, and therefore, into the active citizen space. However, people with disabilities will be prevented from taking this opportunity if exclusionary attitudes and practices persist. The system will get bigger but poor practices that make people with disabilities dependent and passive citizens will remain. Now is a pivotal time to build people with disabilities as active citizens, so that the benefits of the NDIS can be maximised.