

advocacy for **inclusion**

Submission into the Implementation,
Performance and Governance of the National
Disability Insurance Scheme in the ACT

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 is a non-for-profit Disabled People's Organisation (DPO) community organisation in the Australian Capital Territory (ACT), Australia. We provide individual and systemic advocacy services to people with disabilities to promote their human rights and inclusion in the community. 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 is signed onto the *ACT Human Rights Act*.

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Executive Summary – the NDIS in the ACT

Advocacy for Inclusion receive no funding from the ACT Government to provide advocacy support to Canberra's most marginalised population, unlike other specialist organisations and information services in the ACT.

Advocacy support by independent community-based disability advocacy organisations, like Advocacy for Inclusion, as funded under the Department of Social Services (DSS) and the National Disability Advocacy Program (NDAP), must remain the primary safeguarding and capacity building mechanism in the NDIS. Advocacy for Inclusion has been provided funding to support people with disabilities who seek an external review of NDIA decisions through the Administrative Appeals Tribunal (AAT), which is an important mechanism to ensure that decisions are fair and robust.

As an organisation, it remains imperative that Advocacy for Inclusion continue to remind the ACT Government and the NDIA of the choice and control within a human rights framework, underpinned by the *UN Convention on the Rights of Persons with Disabilities* (UNCRPD)¹ and the National Disability Strategy.²

The continued risks of people with disabilities who are participants of the NDIS are powerlessness in their support arrangements, because it opens the way for power abuses. Although the NDIS has promised a framework for more control and choice, with the illusion of paving the way for more equal distribution of power, people with disabilities remain conditioned to take what little they are given in a grossly underfunded and unfair support system.³ The *National Disability Strategy* recognises the significance of disability advocacy to rights protection for people with disabilities. However, disability advocacy is severely underfunded and uncertain past June 2020, despite increase in advocacy funding invested by the Commonwealth Government in 2017⁴ and this may become an increased issued in the ACT.

The role of Advocacy for Inclusion as an advocacy organisation is to raise the voices of people with disabilities – their rights, will and preferences – both at the individual level and at the systemic level. Advocacy is a crucial feedback mechanism to enable the NDIS to achieve its intended outcomes, both for individuals and for the system, particularly in enabling people to speak up when they are otherwise afraid or simply not being listened to.

Key Recommendation: The ACT Government to consider funding advocacy at a territory level to match the increased demand for independent community-based advocacy support is vital leading up to 2020.

¹ With focus on *Article 12(5)* where people with disabilities have the right to 'live in the community, with choices equal to others' (emphasis added) and 'freedom of expression and opinion, through the communication of their choice'

² National Disability Strategy (2010-2020), *Outcome 4: Area for Future Action*

'Adopt sustainable funding models and service approaches that give information, choice and control (emphasis added), social participation and relationships, to be supported in government policy and program design'

³ Productivity Commission. (2011). Disability Care and Support. Report no. 54, Canberra

⁴ The Hon. Jane Prentice and the Hon. Christian Porter, Media Release (2017), *\$5.3 million invested in advocacy services for Australians with disability*, 14th December 2017

Key Concerns

Combinations of environmental and attitudinal barriers have led to people with disabilities being effectively excluded from participating equitably in the ACT community. As a result of discrimination and social exclusion, the invisibility of persons with disabilities at all levels of society and the lack of positive responses becomes a driving factor as to why people with disabilities cannot actively participate on an equal basis in areas of social and economic life.

Without representative advocacy organisations like Advocacy for Inclusion, the ACT Government will not systematically hear the opinions and priorities of people with disabilities when it comes to issues of people with disabilities and high levels of imprisonment, high rates of child removal from parents with disabilities, guardianship, violence and abuse prevention and response for women with disabilities, problematic housing such as institutional and congregate living arrangements.

We provide expert advice on all these issues. Many of the issues we advocate for are out of the scope of the NDIS and require individual advocacy.

Listening to consumers, watching the NDIS trends in the ACT and collaborating with others, the key gaps and concerns that we have seen in our work are concerning:

- The lack of choice and control experienced by people with disabilities. Not having sufficient support, including pre-planning support to exercise choice and control, to understand the scope of supports, to feel confident in asking for supports or know what is available to even consider what a choice may be.
- People with disabilities being placed on long waiting lists to access services. When provided a plan with funding, if they don't access the funds or the service, the supports have been removed from the plan due to lack of support coordination. The lack of accessibility of mainstream services and supports also means that even with specialist disability supports funded by the NDIS, people have still not able to receive all the support they need to exercise community participation.
- The continued inaccessibility of information and planning processes, the lack of time to adequately confer and work through what is required, the lack of time to consider equal access for people with different communication needs, being provided phone numbers only to access services without further assistance, and the control of plans by planners, LACs and service providers.⁵
- Concern and confusion that independent advocacy and representation support will be changed or included into the role of Local Area Coordinators (LACs). This will further remove choice and control of individuals when 'shutting out' advocacy organisations.
- Lack of skills of planners and LACs, including lack of skill and knowledge in people with disabilities, disability types and why particular supports are 'reasonable and necessary' without question.

Fundamentally, the NDIA should be focused on increasing meaningful and tangible support for people with disabilities to exercise self-determination, tied with vigorous accountability, transparency and monitoring systems.

Alongside the NDIA, independent advocacy and representative organisations, like Advocacy for Inclusion, of people with disability need to continue to play a critical interconnecting role in progressing the human rights of people with disability and supporting Australia's international human rights obligations under the UN *Convention on the Rights of Persons with Disabilities* (CRPD).

Recommendation 1: Advocacy organisations and functions to remain separate from the NDIA to allow choice and control and increased frontline observations to allow a continued voice on informing, changing and implementing policy outcomes in the ACT and disability community service space.

⁵ Also noted in ACTCOSS (2017) *Choice and Control: Strengthening the human rights, power and inclusion for people with disabilities*, p. 12

Advocacy Models Matter

Disability advocacy services like Advocacy for Inclusion operate to enable and support people with disabilities in the ACT to safeguard their rights and overcome barriers that impact their ability to fully participate in the community.

Advocacy supports people to make sure that their rights are promoted and valued, to participate in the decisions that affect their lives, particularly around access to services and support, and to be actively involved in their communities. Such support enables people with disabilities to actively participate in the decision-making processes that safeguard and advance their human rights, wellbeing and individual interests.

Advocacy for Inclusion plays a crucial role in the ACT by providing 3 types of advocacy:

1. **Individual advocacy:** intensive one on one support with people with disabilities to raise and resolve service issues. The NDIS is a system that will allow people with disabilities to consider support arrangements that they have never been able to consider in the current inflexible service system. Individual advocacy will and must play a major role in supporting people to express their wishes in a new system, especially those most isolated and marginalised. This includes through planning processes and also after plans are implemented if issues arise.
2. **Self-advocacy** supports and trains people with disabilities to speak up on their own behalf, through learning about their rights and how to navigate the system. This can be done in an ongoing group setting, where people with disabilities access concrete learning experiences about speaking up and exercising self-determination.⁶
3. **Systemic advocacy** identifies themes in issues raised by people with disabilities through direct individual and self-advocacy support, and seeks to introduce and influence long-term changes to ensure that the rights of people with disabilities are attained and upheld to positively affect the quality of their lives. Through systemic advocacy, positive changes to legislation, policy and service practices and work towards raising and promoting community awareness and education of disability issues.

Recommendation 2: People with disabilities need continued access to advocacy support, in the form of the three types of advocacy that Advocacy for Inclusion provides. This supports individuals to prevent and resolve support issues and provides feedback systemically to improve the NDIS broadly.

The Current NDIS Climate

Advocacy for Inclusion is concerned with the changes occurring in NSW where the State will no longer provide funding for their independent advocacy and representation roles as this funding will be provided to the Commonwealth for the NDIS. It has created a paradoxical situation and must be avoided by the ACT Government taking a similar action.

The loss of advocacy groups in NSW will leave significant gaps in representation for people with disabilities, where frontline support is available to provide information and independent advocacy. Although the ACT only has two⁷ disability support advocacy organisations, the presence of Advocacy for Inclusion has been predominant in ensuring people with disabilities continue to be heard and supported through individual advocacy, self-advocacy facilitation and training and systemic advocacy work.

We act as an 'early warning system' to prevent and respond to limitation and systemic failures of people with disabilities in the ACT. The independent representation and advocacy respond and identifies the failures and gaps in the mainstream support system, particularly in highly vulnerable areas such as the criminal justice system,

⁶ Advocacy for Inclusion. (2014). *As above*.

⁷ The other service being ADACAS, that provide individual and systemic advocacy, but not self-advocacy training.

child protection, guardianship orders and institutional living arrangements – issues which fundamentally lie outside the NDIS.

The other concern, should the NDIA shut advocacy organisations out, is the people who need advocacy the most won't be able to access it. Relying on individual's capacity to privately pay for advocacy via their NDIS plan is likely to render it unobtainable to the most marginalised and vulnerable in the ACT community⁸. When asked what your "reasonable and necessary" requirements are it will be almost impossible to predict how much individual advocacy you may need. This kind of support is often unexpected and unlikely to be 'budgeted for'.

During a major point of change with the NDIS continue to form and develop, there remains people in the ACT community who neither have very little knowledge of the NDIS nor will be eligible for a funded package under the NDIS – these people require individual, self-advocacy and systemic advocacy support.

The core function of Advocacy for Inclusion is to provide unbiased, accurate and verified information for people with disabilities as a measure of inclusion. Should the ACT Government consider the option of removing or limiting advocacy services for people with disabilities, with the belief that the NDIS is a fix-it solution, the impact will dire for people with disabilities who are highly marginalised and require individual advocacy support.

Recommendation 3: The ACT Government need to ensure that the frontline information and advocacy supports provided for people with disabilities remain available alongside the NDIA and other government bodies.

Recommendation 4: The 'early warning system' role of independent advocacy and representation is recognised and sufficiently resourced through the ACT Government and the NDIA.

The NDIS is not everything

It is recognised that under the NDIS, people with disabilities can access supports that encourage and assist individuals to achieve to maintain their rights and achieve equity of access and participation in the community. However, the impression that the NDIS should control every mainstream aspect of people with disabilities is concerning.

The need for advocacy will become more acute as people with disability experience increased choice and control under the NDIS. Since 2013, major cultural change and capacity building among people with disabilities and their support people have varied⁹, with choice and control needing to be placed at the priority of the mission of the NDIS, just as promised when the NDIS was in early development. In 2016, it was found one third of NDIS participants were exercising choice and control, whereas 15% were exercising less choice and control. Those who experienced a decrease also had less supports received in funding and were unable to navigate services.¹⁰

These are the people who unable to articulate their support needs, come from a background of high vulnerability and marginalisation and require individual advocacy support. People with disabilities need long-term support to build self-advocacy skills, and they also need independent individual advocacy support in the highly likely instance that regardless of their self-advocacy skills.¹¹

There remains concern how much choice and control are provided to NDIS participants, that are not the prompting of disability service providers.^{12 13} Originally, the NDIS promised to provide as much choice and

⁸ Productivity Commission (2011), *Disability Care and Support: Productivity Commission Inquiry Report*

⁹ Mavromaras, K., Moskos, M., and Mahuteau, S. (2016) *Evaluation of the NDIS: Intermediate Report* by the National Institute of Labor Studies, Flinders University

¹⁰ *Ibid*, p.xiii

¹¹ Advocacy for Inclusion, *Ask Me. I Make my Own Decisions: Report on the findings of a study into the experience of choice and control of people with disabilities in the ACT.*

¹² ACTCOSS (2017) *Choice and Control: Strengthening human rights, power and inclusion for people with disability*, p. 16-17

¹³ Productivity Commission (2011), *Disability Care and Support: Productivity Commission Inquiry Report*, p.2

control for the person with disabilities¹⁴, and what requirements an individual may need to have ‘reasonable and necessary’ supports in their daily lives. As the NDIA becomes increasingly more bureaucratic and increase in power are provided to disability service providers, the message of ‘choice and control’ is becoming less certain among people with disabilities who feel choice and control are lacking.

The assumption the NDIS will be everything an individual will need for their needs is not correct and will not be correct. At present, what may seem ‘reasonable and necessary’ is not always delivered when it should be. The choice and control to access a service may be funded and put in place, yet the individual is placed on a long waiting list that often requires advocacy support or intervention to make space or find an alternative program.

Recommendation 5: Review and amend NDIA operations, policies and processes so people with disabilities can exercise increased power, informed choice and control in their own lives and community participation.

That Accountability and Transparency Thing

In our advocacy work we have observed several concerning transparency and accountability issues, particularly between agencies and people with disabilities. This is particularly evident with the NDIA (Agency) not communicating with advocacy organisation, service providers, people with disabilities and their families in a transparent and fair manner.

The issues that we have seen in our NDIS Appeals functions have largely come down to the lack of transparency of inexperienced planners and LACs and NDIA call-center staff towards NDIS participants and those looking to enter the NDIS – issues that can fixed quickly if transparency and accountability on NDIA’s side was present. Our advocates in both the individual and self-advocacy space has acted in assisting the individuals outside their scope of work when they too face a lack of communication and transparency when sourcing information.

Advocacy for Inclusion is not funded to provide planning support or assistance in gaining NDIS plans, yet we find that we are continuously being asked to assist, particularly when working with vulnerable individuals who need extra support to gain information to understand the NDIS. This is where the community become confused and the perceptions that independent advocacy and representation will be replaced or subsumed into the role of LACs. The role of LACs is to assist people with disabilities to link to mainstream service, whilst independent advocacy and representation assists when the system fails, and gaps are present. Systemic advocacy from the frontline is evidently needed when solutions and recommendations are to be found to address system failures. This must not be blurred and need to stay as is to ensure voices and concerns are heard,

The provision of advocacy support represents a much less costly response and removes the marginalisation and discrimination inherent in the ACT. The ACT Government and the NDIA need frontline advocacy organisations to recognise its obligation to support people with disabilities in a variety of complex support settings. This is evidently needed for people with disabilities caught in the justice system, guardianship and the child protection systems where the NDIA won’t provide frontline advocacy support, to effectively turn existing resources to provide early intervention and ongoing supports.

Case study

Advocacy for Inclusion has been working with Mandy, a mother with cognitive disability who has had two children removed from her care.

Mandy used an advocate to assist her in liaising with CYPS and NDIA for support services to be established for herself, and her children. Both CYPS and NDIA had refused to collaborate with each other, and there had been a number of changes in caseworkers in CYPS, fracturing communication further.

With six months, the advocate worked with Mandy to ensure that she was supported to be an equal participant in proceedings involving her with both CYPS and NDIA. The advocate assisted in communication, navigating

¹⁴ Australian Government (2013) *National Disability Insurance Scheme Act 2013*, p. 4

available services and processes, ensuring support for attendance at case meetings, and providing referral to appropriate services. The advocate worked alongside Mandy, and was guided by her expressed wishes, and assisted in achieving her desired outcomes. With the assistance of an advocate, Mandy is confident in liaising with both organisations to gain support mechanisms.

Mandy is currently working through a plan for the restoration of one of her children now that she can rely on support services covered by the NDIS. One year ago she was facing 18 year final orders.

Since the availability of the NDIS is the ACT, Advocacy for Inclusion has pushed for protocols to be developed to ensure Child Protection Services engages directly with the NDIS whenever supports are required for a parent with disability to maintain custody of their children.

The case study indicates that accountability and transparency is rarely called on by all parties involved in a single individual's matter and often regularly fails to engage. Advocacy for Inclusion has now intervened in numerous cases to bring the two agencies together so that custody can be retained, or in some cases restoration can be worked towards. Advocacy organisations work collaboratively with the NDIA and other agency bodies to ensure support is put in place to ensure transparency and accountability is upheld.

Conclusion

To be heard and voices raised, systemic advocacy is about collaborating to make systems work better for people with disability generally. Individuals can't drive this kind of work and shouldn't have to pay for it. People with disabilities who are already isolated, marginalised and vulnerable in the ACT community need good quality information and advocacy support to allow them to access services to assist them in their daily lives.

The biggest risk to the success of the NDIS in the ACT is continued powerlessness and lack of choice and control in a constant changing system – where there is imbalance of power for people with disabilities. The NDIS originally provided a framework for increased control and choice and this needs to continue as the key focus of the Scheme. However, a significant amount of support and work is needed to ensure that this translates to practice in a context where people with disabilities have traditionally had very little market power – and this can be supported with increasing the value of advocacy organisations in the ACT.

Advocacy organisations need to remain funded outside of the powers of the NDIA because people with disability who are ineligible for individual support packages under the NDIS will also require advocacy services. It is unfair to cut the remaining people off from advocacy services as without individual funding their need for advocacy may be greater.

Advocacy is a crucial component of making society an accessible place for people with disability to lead meaningful lives, but it only works if it is accessible to people who need it, when they need it. This is not an area that the NDIA nor disability service providers should control.

Importantly, people with disabilities must continue to be engaged as designers and co-designers in all NDIS and disability related systems, to enable real self-determination for people with disabilities – as originally intended.