

advocacy for **inclusion**

Submission to the Proposal for a National
Disability Insurance Scheme Quality and
Safeguarding Framework

Advocacy for Inclusion

April 2015

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 is signed onto the *ACT Human Rights Act*.

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Recommendations

Recommendation 1: Commit extra funds to expand the capacity of the National Disability Advocacy Program at least equivalent to funds provided to service providers and carer groups, ensuring that all 6 NDAP advocacy types are properly funded and made widely available.

Recommendation 2: Recognise the importance of independent advocacy (including self-advocacy) to a well-run and well managed NDIS, and as a crucial preventative and corrective mechanism at the individual and systemic levels.

Recommendation 3: Commit to a properly resourced *National Disability Strategy* and, through that, implementation of the *Convention on the Rights of Persons with Disabilities* so that independent advocacy can improve systems, rather than a form of crisis management.

Recommendation 4: Remove the onerous compliance burdens on the NDAP advocacy sector and redirect that money back into frontline advocacy.

Recommendation 5: No restrictions should be placed on who self-managing participants can employ to provide support services. The NDIA must distribute information and facilitate access to police checks, working with vulnerable people checks, and NDIA registration of the provider if the person with disability wishes, at no cost to the participant.

Recommendation 6: All 6 forms of independent, community based disability advocacy must be funded to match the demand as the primary safeguard for self-managing participants in a free market system.

Recommendation 7: A national independent statutory body for complaints, oversight and monitoring should be established and co-designed by people with disabilities. It should apply to all disability services, including all supports funded by NDIS, plus all other disability services regardless of funding source. It must also be available to people with disabilities in informal unpaid care arrangements as they choose. It must be independent from the NDIA and other services.

Recommendation 8: The statutory body must be fundamentally focused on protecting the rights, will and preferences of people with disabilities. It must be imposed on providers of support, NOT on people with disabilities.

Recommendation 9: The statutory body should have broad and authentic powers to investigate and enforce findings in regards to information and complaints received by people with disabilities, community members, and other statutory systems.

Recommendation 10: The statutory body should be extensively funded in order to meet the demand and access needs of people with disabilities. It should be allocated a fixed percentage of all other disability related spending

Recommendation 11: The statutory body must address the intersecting nature of disadvantage among people with disabilities, including factors such as age, gender, racial, cultural and linguistic status. This includes collection of data disaggregated by age, gender, racial, cultural and linguistic status, and living arrangement to understand the issues and monitor improvements in accordance with the UN CRPD.

Recommendation 12: The statutory body should include a national community visitor scheme as part of its function.

Recommendation 13: The statutory body should complement and work in collaboration with the existing legal structures, such as the police, in recognition of the extreme powerlessness faced by people with disabilities

due to societal inequalities, and their subsequent increased risk of victimisation and exploitation. It must NOT operate as a disability specific alternative to the existing justice systems.

Recommendation 14: Establish a national mandatory reporting mechanism for restrictive practices, modelled from the Restrictive Intervention Data System (RIDS) in Victoria. This must be done with a view to facilitate the elimination of restrictive practices in disability supports via robust collection of data and information, critical analysis and guidance.

Recommendation 15: In accordance with UN CRPD obligations, ensure that people with disabilities form at least half of all decision making and design bodies associated with both the *National Disability Strategy* and the NDIS, including in developing any structures associated with the Safeguards Framework, so that they are built by the people who are the experts in using them.

Introduction

Advocacy for Inclusion is a not-for-profit non-government community organisation in the Australian Capital Territory. We provide individual, self and systemic advocacy to people with disabilities to promote their human rights and inclusion in the community. We work alongside people with disabilities to help them address a range of issues in disability support arrangements, including violence and abuse, inadequate or poor quality supports, discrimination, and NDIS planning.

A lack of control and choice is at the core of the issues experienced by people who come to Advocacy for Inclusion. This powerlessness poses the biggest risk to the wellbeing and safety of people with disabilities in their support arrangements, and their capacity to reach their potential and contribute to society. Maximising control and choice for people with disabilities is a key protective factor, which can be supported through:

1. Independent community based disability advocacy – all 6 forms of advocacy;
2. Independent statutory oversight body for all NDIS and disability services;
3. Mechanisms targeted at eliminating restrictive practices;
4. Genuine control and choice for people with disabilities at all levels, including the structural and policy levels.

Most importantly, control and choice cannot be achieved through regulating people with disabilities with paternalistic and controlling policies and structures. A quality and safeguarding framework should be focused on enhancing meaningful and tangible support for people with disabilities to exercise self-determination, coupled with robust accountability, transparency and monitoring systems for service providers.

1. Independent community based disability advocacy

Advocacy support by independent community based disability advocacy organisations, as funded under the National Disability Advocacy Program (NDAP), must be the primary safeguarding and capacity building mechanism in the NDIS.

The biggest risk to people with disabilities who are participants of the NDIS is powerlessness in their support arrangements, because it opens the way for power abuses. The *National Disability Strategy* recognises the significance of disability advocacy to rights protection for people with disabilities. However, disability advocacy is severely underfunded, unable to meet current demand, with the demand expected to double with the NDIS.¹ Increased funding to match the increased demand for independent community based advocacy support is vital in helping to balance out power inequities, and offering a preventative as well as corrective mechanism at individual and systemic levels.

In a context where people with disabilities face extreme socioeconomic and political inequalities, they are at heightened risk of power abuses and victimisation.² As briefly acknowledged in the consultation paper, people with disabilities have traditionally had very little market power, and they are often unable to speak up or make complaints for fear of repercussions.

Although the NDIS provides a framework for more control and choice, thereby paving the way for more equal distribution of power, people with disabilities have been conditioned to take what little they are given in a grossly underfunded and unfair support system.³ This has resulted in extreme marginalisation of people with disabilities, including forced co-habitation with other people with disabilities, institutionalisation, and

¹ 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/>

² National Cross-Disability Alliance. (2014). *Senate Standing Committee on Finance and Public Administration: Inquiry into domestic violence in Australia: Joint submission from National Cross-Disability Disabled People's Organisations*.

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

widespread but hidden use of restrictive practices, as well as outright violence, abuse and neglect. Currently, it is common for people with higher disability support needs (Tier 3 participants) to be entirely at the mercy of support providers, whose power extends to every detail of the person's day-to-day life, for example, including when, how and what they will eat.

Julia: "I'm in bed by half past 8."

Interviewer: "And what time would you like to stay up until?"

Julia: "Ten."

Interviewer: "What is the reason you don't stay up until 10 o'clock now?"

Julia: "I need two people to get me into bed and on and off the toilet. Every night at half past 7 [support provider] comes and put me on the toilet and shower and they have to leave by half past 8."

(Control and choice study individual interview participant, 2013)⁴

Advocacy for Inclusion undertook a qualitative study in 2013 with people who would likely become NDIS participants. We found that although they wanted more control over their lives, many had a great deal of difficulty conceptualising how it would work in reality, given the current constraints in their lives.⁵ They have been taught not to make choices, and not to expect to be able to make choices altogether.

Interviewer: "Do you have the option of choosing who comes to your house and when?"

Ingrid: "I don't think so. Because at our house we have 24 hour support"

Interviewer: "is that something you'd like to have more options and choice in when it comes to who comes to your house and what time?"

Ingrid: "no because it is all organised."

Interviewer: "But if you had the option of actually being involved in organising it... Would you like to be able to make those decisions?"

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

(Control and choice study individual interview participant, 2013)⁶

The current predominant negative attitudes about disability will prevail in the new system, and it will take some time before people with disabilities, their support people, and the wider community form new attitudes and habits. In particular, carers and support workers have also formed negative, limiting attitudes, because of the surrounding culture, and because of the severe lack of supports to enable people with disabilities to reach their potential and exercise their decision making capacity. For this reason, carers and support workers will continue to assume the management responsibilities in the new system, and people with disabilities will continue to face extreme powerlessness if this issue is not targeted.

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

⁴ 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>

⁵ Advocacy for Inclusion. (2013). As above.

⁶ Advocacy for Inclusion. (2013). As above.

(Unpaid carer of a control and choice study individual interview participant, 2013)⁷

Major cultural change and capacity building among people with disabilities and their support people is needed, and it must be provided over the long-term. Short lived training sessions will not be adequate to address these issues, nor are they accessible or appropriate for the learning needs of many Tier 3 participants. 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, other people continue to exert power over the person's life.

In our direct individual advocacy experience in NDIS planning processes with consumers, support providers existing in the person's life have come to the person with disability with a prepared contract to be signed, stipulating how they will receive services under the new regime. It is only because an individual advocate was present during the process that the person with disability was supported to effectively negotiate these contracts, rather than simply sign them and accept what was on offer (as they always have in the past in the previous system). Our long-term self-advocacy program has also assisted people with disabilities to become familiar with the NDIS processes, consider their support needs, identify their goals and rights, and be prepared for NDIS planning before it occurs.⁸

Through this, advocacy support is both preventative and corrective. Safeguarding and capacity building needs to take the form of advocacy support by independent community based disability advocacy organisations, as funded under the National Disability Advocacy Program (NDAP). The role of disability advocacy organisations is to raise the voices of people with disabilities – their rights, will and preferences – both at the individual level and at the systemic level. The numbers of people with disabilities receiving paid supports was expected to double with the NDIS roll out.⁹ 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.

Independent disability advocacy organisations play a crucial role in this by providing 6 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.¹⁰
3. **Systemic advocacy** identifies themes in issues raised by people with disabilities through direct individual and self-advocacy support, and feeds this back to government and non-government systems and structures (for example, through this submission). Advocacy organisations, as independent bodies, need to be funded to collect information about the experiences of people with disabilities out on the

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 Advocacy for Inclusion. (2014). *Enhanced self-advocacy group project report.* Retrieved from http://www.advocacyforinclusion.org/publications/Reports/Enhanced_Self-Advocacy_Group_Report_FINAL.docx

⁹ Productivity Commission. (2011). *Disability Care and Support.* Report no. 54, Canberra

¹⁰ Advocacy for Inclusion. (2014). *As above.*

fringes, who otherwise are forgotten and silenced, and undertake direct consultation in ways that are accessible and meaningful to them.

4. **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.
5. **Family advocacy** supports families to advocate the wishes and rights of a person with disability.
6. **Citizen advocacy** matches a person with disability with a volunteer who provides long-term advocacy support, in a more organic unpaid arrangement.

Recommendation 1: Commit extra funds to expand the capacity of the National Disability Advocacy Program at least equivalent to funds provided to service providers and carer groups, ensuring that all 6 NDAP advocacy types are properly funded and made widely available.

Recommendation 2: Recognise the importance of independent advocacy (including self-advocacy) to a well-run and well managed NDIS, and as a crucial preventative and corrective mechanism at the individual and systemic levels.

Recommendation 3: Commit to a properly resourced *National Disability Strategy* and, through that, implementation of the *Convention on the Rights of Persons with Disabilities* so that independent advocacy is can improve systems, rather than a form of crisis management.

Compliance burdens

The Department of Social Services has changed our external quality systems 3 times in the past 5 years, yet it cannot provide certainty about our funding. We have an extremely onerous compliance system of external annual audits. We are forced to spend thousands of dollars each year from our unindexed funding on auditors, which for Advocacy for Inclusion equated to 6 weeks pay for a front line Individual Advocate this year. However, there is no funding support to keep up with the increasing demand for disability advocacy at this time of great change and reform.¹¹ This is a significant barrier to efficient and effective use of advocacy funding.

Recommendation 4: Remove the onerous compliance burdens on the NDAP advocacy sector and redirect that money back into frontline advocacy.

Safeguards for self-managing participants

In regards to the specific question raised in the consultation paper – what if any quality and safeguard protection should apply for these people – we recommend *Option 1: Building the capacity of participants to manage their own risks* (p. 59). This option maximises the ability for people with disabilities to employ people they know and trust to provide their supports, including within their natural networks. All 6 forms of advocacy must be funded within this model to support people to consider their options, navigate the system, know their

¹¹ Advocacy for Inclusion. (2015). *Submission to the impact on service quality, efficiency and sustainability of recent Commonwealth community service tendering processes by the Department of Social Services*. http://www.advocacyforinclusion.org/publications/Position_Papers/Senate_Inquiry_into_community_sector_funding_March2015.docx

rights, and raise and have resolved issues if they arise. In addition, as mentioned in *Option 1*, the NDIA must facilitate access to police checks, working with vulnerable people checks and registration of the provider with the NDIA if the person with disability prefers.

A screening agency should be set up as outlined in *Option 3* to enable participants to easily access working with vulnerable persons checks for their providers should they choose, and also for people accessing supports through NDIA registered agencies.

Recommendation 5: No restrictions should be placed on who self-managing participants can employ to provide support services. The NDIA must distribute information and facilitate access to police checks, working with vulnerable people checks, and NDIA registration of the provider if the person with disability wishes, at no cost to the participant.

Recommendation 6: All 6 forms of independent, community based disability advocacy must be funded to match the demand as the primary safeguard for self-managing participants in a free market system.

2. Independent statutory complaints and oversight body

A national statutory complaints and oversight body must be established (alongside compulsory internal standards and complaints handling for NDIA registered providers), independent from the NDIA (as suggested in *Option 3b: Disability complaints office*), to help balance out power inequalities and enhance accountability and transparency among service providers. This mechanism must be co-designed by people with disabilities.

It is well established in the research literature that when people are isolated, with a lack of outside scrutiny, they are at higher risk of victimisation and exploitation.¹² This coupled with the extreme powerlessness that people with disabilities can face in disability support arrangements creates a breeding ground for violence, abuse and neglect. There seems to be a lack of appreciation in the consultation paper for the role independent oversight and monitoring plays as a preventative measure, rather than simply a corrective measure.

This complaints and oversight mechanism should apply to all disability services, regardless of whether they are funded by the NDIS, and consistently across all jurisdictions. It must also be available to people with disabilities in informal unpaid arrangements if the person with disability chooses, as currently applies in the ACT Official Visitor Scheme. It should have broad powers to investigate and enforce findings in regards to complaints, provider misconduct, violence, abuse and neglect against people with disabilities, which addresses the intersecting nature of these issues with other factors such as age, gender, racial, cultural and linguistic status.¹³

As noted in the consultation paper, allegations of criminal activity against a person with disability should be reported and investigated by the police. Criminal activity in disability support arrangements is often perceived and dealt with as a service issue, and is kept out of the criminal justice system.¹⁴ This encourages a high tolerance for crimes against people with disabilities in disability service settings.^{15 16 17} A statutory complaints

¹² Marsland, D., Oakes, P. White, C. (2007). Abuse in care? The identification of early indicators of the abuse of people with learning difficulties in residential settings. *The Journal of Adult Protection*, 9(4), 6-20

¹³ National Cross-Disability Alliance. (2014). *Senate Standing Committee on Finance and Public Administration: Inquiry into domestic violence in Australia: Joint submission from National Cross-Disability Disabled People's Organisations*.

¹⁴ National Cross-Disability Alliance. (2014). *As above*.

¹⁵ Hollomotz, A. (2011). *Learning difficulties and sexual vulnerability: A social approach*. London: Jessica Kingsley Publishers.

¹⁶ Jenkins, R. Davies, R., & Northway, R. (2007). Zero tolerance of abuse of people with intellectual disabilities: Implications for nursing. *Journal of Clinical Nursing*, 17, 3041-3049.

¹⁷ Strand, M. L., Benzein, E., & Saveman, B. (2004). Violence in the care of adult persons with intellectual disabilities. *Journal of Clinical Nursing*, 13, 506-514.

body must not reinforce this by operating as a disability specific alternative to the criminal justice system. Rather, it must complement and work alongside the existing criminal justice system, offering additional supports, reporting and investigation mechanisms in acknowledgement of the extreme powerlessness, barriers to accessing help and justice, and high risk faced by people with disabilities in disability specific arrangements.

For example, if a person with disability reports a crime by an individual support worker to the police, the police should undertake their usual response to that report, as well as have the capacity to forward a report or information to the statutory body, which might then decide to conduct a broader investigation into the practices of that provider.

A streamlined national community visitor scheme should be delivered by the statutory body. The purpose of this body should NOT be to operate as an adult protection system imposed on people with disabilities, which can further disempower and discourage people with disabilities from seeking or accepting help. It must be based on the protection of individual's rights and expressed wishes. It must be properly funded and resourced, easy to access and readily available to people with disabilities. While it should not have the capacity to impose on people with disabilities, it should have authentic statutory powers to investigate with or without service provider consent.

Critically, this oversight body should collect data disaggregated by age, gender, disability status, place of residence and cultural background, as per international obligations and recommendations from the UN treaty monitoring bodies.¹⁸ This is critical in understanding the issues occurring for people with disabilities in their support arrangements, developing policies and legislation that enable people with disabilities to access basic human rights, and in monitoring progress.

Recommendation 7: A national independent statutory body for complaints, oversight and monitoring should be established and co-designed by people with disabilities. It should apply to all disability services, including all supports funded by NDIS, plus all other disability services regardless of funding source. It must also be available to people with disabilities in informal unpaid care arrangements as they choose. It must be independent from the NDIA and other services.

Recommendation 8: The statutory body must be fundamentally focused on protecting the rights, will and preferences of people with disabilities. It must be imposed on providers of support, NOT on people with disabilities.

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¹⁸ UN Committee on the Rights of Persons with Disabilities. (2013). *Concluding observations on the initial report of Australia*. http://tbinternet.ohchr.org/_layouts/treatybodyexternal/Download.aspx?symbolno=CRPD%2fC%2fAUS%2fCO%2f1&Lang=en

Recommendation 12: The statutory body should include a national community visitor scheme as part of its function.

Recommendation 13: The statutory body should complement and work in collaboration with the existing legal structures, such as the police, in recognition of the extreme powerlessness faced by people with disabilities due to societal inequalities, and their subsequent increased risk of victimisation and exploitation. It must NOT operate as a disability specific alternative to the existing justice systems.

Difference between NDAP funded advocacy and a statutory body

It is important to note that an independent statutory complaints body meets different needs to that met by independent community based disability advocacy. Community based disability advocacy (as provided under NDAP) is less formal and does not have statutory powers attached to it.

These advocacy organisations provide the types of advocacy support that can be engaged before complaints arise as well as in respond to issues. For example, a person with disability supported by an Individual Advocate through the NDIS planning process, to ensure the person's wishes are heard and respected and to help avoid problems arising in the delivery of support after the plan is made. Self-advocacy programs also offer capacity building by supporting people with disabilities to identify their rights and goals in group settings, along with follow up group based support as needed.¹⁹

3. Eliminating restrictive practices

We recommend a national mandatory reporting approach, modelled from the Restrictive Intervention Data System (RIDS) in Victoria (as outlined in the consultation paper), with an aim to eventually eliminating restrictive practices.

As identified in the consultation paper, restrictive practices are a significant and serious concern facing people with disabilities receiving disability supports. These practices are largely hidden, fundamental violations of human rights, operating inside and outside behaviour management protocols established by providers. Yet there is very little in the way of accountability and oversight in the use of these practices.

The current *National Framework for Reducing and Eliminating the Use of Restrictive Practices in the Disability Service Sector* has a number of major weaknesses, including that it is not enforceable and therefore does nothing to improve accountability or transparency. It fails to use the social model of disability to conceptualise “challenging behaviours” and restrictive practices. Restrictive practices are said to be used in response to challenging behaviours, where there is a risk of harm to the person with disability, to other people, or to property. Using the social model, challenging behaviours can be understood as adaptive behaviours to maladaptive environments; legitimate expressions of protest or unmet need.²⁰ Furthermore, restrictive practices are also used in the absence of challenging behaviours.

It also lacks critical analysis of the subjective nature of “last resort” as a concept, and the challenges in applying this concept in practice, particularly when staff are inexperienced and lack supervision. In short, this framework is grossly inadequate, lacks robust exploration of the issues surrounding restrictive practices and how they might be eliminated, and clear guidance for support providers.

¹⁹ Advocacy for Inclusion. (2014). *Enhanced self-advocacy group project report*. Retrieved from http://www.advocacyforinclusion.org/publications/Reports/Enhanced_Self-Advocacy_Group_Report_FINAL.docx

²⁰ Ramcharan, P. (2009). *A view from people with disabilities and family carers: A final research report to the Office of the Senior Practitioner*. Retrieved from http://www.dhs.vic.gov.au/__data/assets/pdf_file/0008/608588/osp_experiencesofrestrictivepractices_pdf_0509.pdf

As rightly noted in the consultation paper, with appropriate supports restrictive practices can be eliminated. The NDIS provides access to these appropriate supports, with increased funding and consumer control. However, there needs to be a nationally consistent approach to monitoring and regulating these practices particularly while old practices continue in the new system until cultural change is achieved.

Recommendation 14: Establish a national mandatory reporting mechanism for restrictive practices, modelled from the Restrictive Intervention Data System (RIDS) in Victoria. This must be done with a view to facilitate the elimination of restrictive practices in disability supports via robust collection of data and information, critical analysis and guidance.

4. Genuine control and choice at all levels

Self-determination is a key protective factor for all people. The NDIS has initiated the process for people with disabilities to gain more control over their supports at the individual level. However, what is lacking is meaningful engagement of people with disabilities at the structural and leadership level of the NDIS. People with disabilities need to have real influence over high level policy decisions, including the development of a safeguards framework.

The *National Disability Strategy 2010-2020* 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 Convention on the Rights of Persons with Disabilities states:

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.²¹

Despite this, there is an underrepresentation of people with disabilities at the policy level of the NDIS. In order to achieve self-determination, people with disabilities must represent themselves and be part of solving their own problems. A safeguarding framework must ensure that people with disabilities form at least half of all decision making and design bodies associated with both the *National Disability Strategy* and the NDIS so that they are built by the people who are the experts in using them. This measure has the additional benefit of recognising the leadership and decision making capacity of people with disabilities rather than continuing to structure systems which question and deny this ability, which will over time assist with adjusting prejudicial community attitudes.

Recommendation 15: In accordance with UN CRPD obligations, ensure that people with disabilities form at least half of all decision making and design bodies associated with both the *National Disability Strategy* and the NDIS, including in developing any structures associated with the Safeguards Framework, so that they are built by the people who are the experts in using them.

²¹ Article 4.3, UN Convention on the Rights of Persons with Disabilities <http://www.un.org/disabilities/default.asp?navid=14&pid=150>

Conclusion

A quality and safeguards framework should be focused on enhancing meaningful and tangible support for people with disabilities to exercise self-determination at all levels of the NDIS, coupled with robust accountability, transparency and monitoring systems for service providers.

The biggest risk to the safety and wellbeing of people with disabilities in the NDIS is continued powerlessness in a new system – where there is imbalance of power, there exists increased risk of abuse. The NDIS provides a framework for increased control and choice. 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.

To address this, people with disabilities need access to advocacy support, in the form of all six types of NDAP advocacy. This supports individuals to prevent and resolve support issues, and provides feedback systemically to improve the NDIS broadly. To achieve this, the NDAP funding must be significantly increased to match demand.

An independent statutory complaints body and a mandatory reporting system for the elimination of restrictive practices must be established for all disability services nationally. This is essential to create robust transparency and accountability processes, and to address the extreme powerlessness often faced by people with disabilities in support arrangements.

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