



**National Disability Insurance Scheme Consultation Paper  
Home and Living**

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## Western Australia's Individualised Services (WAIIS)

Western Australia's Individualised Services (WAIIS) is a member-based community organisation working in partnership with people, families, service providers and government agencies to promote and advance individualised, self-directed supports and services for people living with disability, including psychosocial disability.

Since our inception in 2010, we have been thought leaders in providing comprehensive, intentional support that develops peoples' capacity to live their lives on their own terms. We hold integrity, passion and authenticity at our core. Through our extensive local, state and international networks we seek to lead, influence, innovate and inform to create meaningful and lasting change.

WAIIS provides information, resources and support about individualised supports and services that enable people to live good lives, with choice, control and self-determination. All WAIIS work is underpinned by a strong human rights framework.

Specifically, WAIIS specialises in information, support and guidance related to:

1. Creating Home – Individualised Living
2. Supported Decision Making
3. Self-management
4. Person centred Planning

## Introduction

The foundation of most modern societies is the acknowledgment of everyone's right to exercise their citizenship by leading and directing their own lives. It is essentially one of the most basic and fundamental elements of being human. This basic right matters to everyone regardless of ability, age, health or experience. The ability to decide how you want your life to be, who you want to be connected to and how you are supported are essential factors that we all understand and expect in our own lives.

Adults with intellectual and developmental disabilities are particularly vulnerable to being marginalised and socially excluded as they experience barriers to the rights and opportunities available to other citizens<sup>1</sup>. Traditional forms of providing disability accommodation may share common characteristics that include:

- use of (sometimes only) paid staff
- established routines
- ownership of the place of residence usually vested in a government or NGO service with no guarantee of continuity
- congregation of adults with disabilities in group homes and institutions, that offer no choice in choosing the people with whom they share their home.

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<sup>1</sup>World Health Organization. (2011). *World Report on Disability*. Malta: WHO Press.

With the introduction of the NDIS across Australia, it means people have the opportunity for increased choice and control over their own future and their own tailored supports and services. The NDIS is a social insurance scheme, which has a lifetime approach to support, investing in people with disability to live their life, exercise their human rights, and improve their life outcomes.

Section 3 of the National Disability Insurance Scheme Act outlines the objects of the Scheme and highlights that the Scheme gives effect, in Australia, to the United Nations Convention on the Rights of Persons with Disabilities (as well as a number of other UN Conventions). Some of the key objects of the Scheme include:

- Supporting the independence and social and economic participation of people with disability;
- Enabling people with disability to exercise choice and control in the pursuit of their goals and the planning and delivery of their supports;
- Promoting the provision of high quality and innovative supports that enable people with disability to maximise independent lifestyles and full inclusion in the community.

Highly individualised living arrangements can support people, including people who may have complex supports and / or complex communication needs, in one of the most natural and beneficially ways possible – real people connecting, supporting and sharing their lives.

When any of us, no matter who we are, need some sort of support, whether that be advice from a friend or family member, recommendations from a doctor or a professional, career guidance from a colleague, domestic support from a cleaner, our haircut by a hairdresser, we usually get that support in a way that is specific to us. It is based on who we are, what we want and need, how we communicate together, our relationship and trust, our history, our experiences, and so forth. This means that the support we get is much more likely to meet our needs, with us being able to make more informed decisions about our life and therefore better outcomes for us, because the support is individually designed around us.

When we need significant supports to assist us to live our lives, exercise our human rights, communicate and be safe, the premise of ‘design supports around me’ becomes even more critical. Unfortunately, when there are more people, in a group setting, to consider in the provision of any supports, this means a necessary compromise of the supports required by each individual. The design of supports is based and prioritised on what works for the ‘group’ as opposed to designing and prioritising supports that work for individuals. The reality for people living in group or congregate support arrangements means that there has to be compromise simply due to competing needs and the sharing of resources, if for no other reason.

Australia is a signatory to the UN Convention on the Rights of Persons with Disabilities (CRPD). The purpose of the CRPD is to ensure all people with disability have full and equal enjoyment of all human rights and to promote respect for their dignity.

Article 19 of the CRPD - Living Independently and being included in community - is about people with disabilities having the right to choose where they live and who they live with and are not obliged to live in a particular living arrangement.

<https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-19-living-independently-and-being-included-in-the-community.html>

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

WAI S endorses the NDIA's vision outlined in the Home and Living consultation paper that when the NDIA talks "about living an ordinary life with greater independence, [the NDIA] want[s] you to have the same life decisions as everyone else about where you live and how, with the same considerations as other people" and not about "living in accommodation that has been built for service delivery convenience that are invisible to the wider community".

Of significance is that the Home and Living policy is underpinned by human rights, and in its implementation, the policy facilitates people being able to exercise their rights, as opposed to limiting their rights.

WAI S in principle supports the seven themes raised in the Home and Living Consultation Paper, however we also note the critical importance of the implementation, and 'how' this will be done in partnership with, and being led by, people with disabilities and their allies.

## Changing the conversation

The NDIS was initiated, developed and intended to be implemented (as a system) by, and for, the people who it was designed to assist. The language, conversations and planning approach, was also intended to be easily accessible for all people about people living good lives, reflective of their culture and community. WAI S believes the NDIS needs to go back to this original intention and focus, which is not a 'new way of speaking about an ordinary life'.

In this context, WAI S welcomes changing the conversations from what has become known as 'system planning' back to a person centred 'whole of life planning' process, **providing** the actions and outcomes of the conversations are reflective of how the person genuinely wants to live, exploring areas of importance to the person; home, work, relationships, recreation, sport, sexuality, and so forth.

It also includes intentionally and genuinely discovering:

- Who I am and what makes sense for ME (and those around me)
- How I communicate
- Who is important in my life
- What is important to/for me
- My specific preferences that impact across all areas of my life
- What I have to offer – myself, others, my home, my work, my community
- Things that I struggle with, and how to support me when I am struggling

The Community Resource Unit (CRU) notes:

We appreciate that the reality for many people with disability is that they require assistance to do what they want to do with their life and that this assistance is likely to be provided by a number of people. **Ensuring that all these people are working in the same direction and that that direction is what the person actually wants is not easy and thus some formalising of the direction and a plan and the agreed steps to get there can be helpful.** This is slightly different to the general population who can usually afford to have a vague life plan in their heads and modify it as they go. They are not as dependent on others to bring the plan to life and the consequences of not having a plan are also not usually so great. **When people with disability, and the people closest to them are not setting the agenda, then others who don't know the person will set the vision of what's possible and it will be based solely on their disability needs rather than who they really are.**<sup>2</sup>

Planning, and exploration of what is possible is more likely and of greater “success” when people believe in me! If we don't have anyone looking out for us, supporting us, accepting us, challenging us, providing opportunities for us, having high expectations of us (and others around us) and GENUINELY believing in what we have to offer, then the likelihood of us having a life that is what we want and/or need is reduced and impacts on what support people provide and in what way it is provided. If people don't think I can live in my own home, it won't be explored as an option. If people aren't thinking beyond what they already know about, they will only continue to support me to explore those known options and not explore more innovative, responsive options.

Exploring 'Home' is an important part of any life planning, especially if we need support. Understanding what 'home' means to a person, is important as it is what guides any 'home and living' supports. Home is where we belong. Home is where we feel, and are, safe. Home is where we express our identity and can be ourselves. Home is where we can choose who we live with and who we spend time with and importantly, have choice and control over how we live.

WAI's role, over many years, building capacity of people, families and service providers in relation to genuine planning and exploration of home (and service design) has identified the critical importance of more than just training for all parties. It includes the need for parties/people involved to have the appropriate values, culture, approach and mindset that underpins planning and exploration of home whereby they genuinely believe in what the person offers, has higher rather than lower expectations and is willing to explore beyond what they already know. This includes a deep seated understanding and belief in the fundamental human rights of all people to “home” in the truest sense of the word.

### **Supporting you to be an informed and empowered consumer**

WAI's strongly supports Home and Living exploration and design being made available to anyone who wants to explore alternative living arrangements and people being informed and empowered throughout this process.

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<sup>2</sup> <https://thegoodlife.cru.org.au/getting-started/#getplanning>

WAI S notes the criticality of what Michael Kendrick talks about in relation to ‘life giving’:

When human beings thrive, we can properly say that there must be some active ingredient present that is fuelling such a result. Such an ingredient is “life giving”. In a similar way, we can also say that when people and their humanity are degraded and abused, they will suffer unnecessarily. Such conditions might be thought of as being oppressive of people or “life-denying”. If we are to meaningfully use the language of empowerment and liberation of people, we must seek to make choices that are “life-giving” more than they are “life-denying”. This begins with recognising that these choices always exist, and always have consequences.

In the question of the actual vision we hold about the what is possible in the lives of our fellow citizens, will rest the basis of much of what our communities will permit or enable people to do with their lives. There is no doubt that each and every one of us is shaped by our community’s view of us. We often resist the imposition of such perceptions, but we rarely are unaffected by them. What we expect of our lives is hugely influenced by what others have indicated is possible for our life. So, whether we notice it or not, the attitudes and choices being made by us collectively and individually will have some kind of shaping effect on other people’s lives. Frequently, this effect is relentlessly ongoing, significantly invisible to us, and unquestioned much of the time. We are not solely a product of our social conditioning but we are nevertheless deeply marked by it.<sup>3</sup>

WAI S highlights the specific vulnerabilities of people with disability, who are more at risk of low expectations being applied, particularly by our broader Australian society and systems. This includes people who: have complex communication access needs, have been/are incarcerated in the justice system; living out of home/under the care of the state; in hospital seeking accommodation; who identify as LGBTQI+; who are aboriginal and living in remote communities; who have aging parents with few informal supports; and people who have historically and currently live in group home/hostel style accommodation.

One of the challenges, in WAI S experience, is that many people and families (particularly people who are especially vulnerable as highlighted above) are not aware of individualised living options, and if they are aware, they are not clear it could be a real possibility for their loved one. Investment in increasing people and families awareness and understanding of individualised living options will broaden the range of options available to them and support them to be able to make more informed choices about the most appropriate living arrangement for themselves or their loved one.

Consequently, informed and empowered people and families will be an essential part of a functioning marketplace. A key principle of the NDIS is that people are the real decision makers. Over time, people and families choices will directly influence the operation of the marketplace.

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<sup>3</sup>Opening Keynote Presentation For the Congress “Crossing Boundaries” (“Over Grenzen”), Hosted By Stichting Perspectief, Wageningen, Netherlands, September 12-15, 2001. Michael Kendrick

## **Expanding support for decision making**

WAI S fully and fundamentally supports people to be able to make and implement their own decisions, and to be able to exercise their legal and human rights, which may include significant support to do so. Developing capacity of people, as decision makers, together with developing capacity of their decision supporters, and the people within the systems that support people, is critical to people being able to exercise their rights in a way that is aligned with the CRPD.

Please see **Appendix A**, joint submission by WAI S and PWDWA in response to the NDIA's Consultation Paper – Supporting you to make your own decisions (NDIS) that provides detailed information and our position in relation to support for decision making.

## **Reforming the funding model**

WAI S supports the reforming of the funding model. Currently, people who want and/or need an individualised living option, have limited options in terms of choice and control over the model of support vs adequate funding for the disability related support.

WAI S personal and professional experiences highlight gaps in the current funding model. People can be funded for individualised living supports through:

1. Daily Living Core supports (Pricing Framework applies)
2. ILO (Guidelines and costings associated)
3. SIL (rostered 1:1 support)

Whilst the intention of the Home and Living paper is deeply embedded with human rights, and empowerment for people to choose the live-in supports that work best for them, there is increasing evidence that people are being told by the NDIS that if their live-in supports are more than the cost of an ILO, they need to redesign the live-in supports to fit the guidelines, or find a group home to move into. This is in direct conflict with what the policy is intending and cannot be ignored in the collation of feedback about the Home and Living consultation paper.

The current implementation of ILO Operational Guidelines are putting some peoples individualised living arrangement at risk. Some of these arrangements have been long-standing and working for people in a way that makes sense for them.

In conflict with the Home and Living consultation paper, peoples' experience have included:

- Significant reductions in funded supports without explanation or opportunity to discuss
- Being asked for significant evidence as to why they cannot share their home with other people
- Consequent pressure to consider other living options, including group living models, even when evidence indicates group living may not be suitable or sustainable
- People not being able to move out of group homes and institutions (justice and/or health)

This is due to the strict interpretation of the guidelines and the NDIA's heavy focus on "scheme sustainability". Greater flexibility is required in the interpretation of the ILO guidelines (as was originally intended), to maximise the potential of individualised living arrangements. The NDIS Act 2013, s34, states that 'reasonable and necessary' includes that 'the support represents value for money in that the costs of the support are reasonable, relative to both the benefits achieved and the cost of alternative support'. WAIIS strongly believes through the experiences of people, that the 'benefits' achieved for people being forced to move out of their own home, into group living arrangements are not on par, and whilst some individual living arrangements may be funded higher than the current guidelines suggest, or cost more than living in a group home, the benefits, both socially and economically to people and our society, absolutely represent value for money. It is therefore critical that the NDIS, in its deliberations, has an appropriate and real understanding (not merely academic or presumptive) of what these benefits and outcomes actually are when making value for money decisions.

This GAP in the funding system 'not designed or costed within ILO guidelines', but still an individualised living arrangement, needs to be addressed in any funding model reform related to Home and Living.

WAIIS understands the need for a robust, and sustainable NDIS. However, scheme sustainability **cannot** be at the expense of people being safe from abuse and neglect, feel and be safe in their own home, and to be economically and socially participating in their community.

With any reform of the funding model, the NDIS must be fully informed about and take into consideration the complexities of the legalities that impact specifically on individualised living arrangements. These include:

- Constraints of the Federal Modern SCHADS Award
- Changes to the WA industrial relations legislative system to remove the exclusion of people providing a domestic service in a private home
- Lack of clarity and currency of ATO rulings and determinations in relation to non-taxable payments to hosts
- Work Health and Safety implications.

### **Improving choice and control through flexible budgets**

WAIIS fully endorses the ability for people to have flexibility with their budget. This would be the ultimate realisation of people having choice and control. However, flexibility is great, only if budgets are actually fundamentally flexible in implementation, and are adequately funded to be flexible with in the first place. Flexibility with a fundamentally inadequate budget will not support people to thrive with the supports they can put in place and, instead, forces people to "do the best they can" (merely survive) and, as is stated in the NDIS Act 2013, s4, not able to access the support and services required to:

- pursue their goals and maximise their independence; and
- live independently and to be included in the community as fully participating citizens; and
- develop and support their capacity to undertake activities that enable them to participate in the community and in employment.

## **Assisting implementation and maintenance**

Since the introduction of the NDIS, there has been a great need for investing in the training, development and support for people and their families/allies in accessing, understanding and navigating the NDIS. This investment is also required for staff who are in roles that are supporting people and their families in the NDIS. This includes planners, LACs, Partners, Community Connectors and others in the community who engage with people regularly.

The unfortunate reality of the investment in staff in those roles, to date, is that it has been sporadic, disjointed and inconsistent, as it has been left to the relevant agency employing them to determine ie LAC partners, NDIA, etc.

Any proposal for professional development, ongoing education and training cannot be more of the same. And anything that is to be offered needs to incorporate values based recruitment, cultural competency, person centred/recovery focused approaches, etc.

## **Engaging the market and driving innovation**

WAI S understands the importance of market stewardship and the need to drive the market in order for people and their families to access the most appropriate services. It is important to highlight that if the intent is an individualised, market-based schemes that extends choice and control to people with disability, this is only achievable if the market operates effectively to this end.

The type of evidence that governments tend to draw on in market stewardship is typically limited to inputs and outputs and has less insight into the outcomes services do or do not achieve. While this is a typical approach to market stewardship, we argue it is problematic and that a greater focus on outcomes is critical and necessary and should include the account of the lived experience of people with disability.

With the lived experience evidence of people with disability included, market stewardship will be better able to take account of outcomes as they play out in the lives of those using the market and, ultimately, achieve greater choice and control for people with disability.<sup>4</sup>

The lived experience of people with disability should also be central to any investment in building the capacity of service provider. Such investment should provide information, guidance and support required for providers to improve business and investment decisions, facilitate targeted expansion, and/or offer people a new individualised living service.

Fundamentally, engaging the market and driving innovation requires investment in the development in the capacity of people and families themselves as well as providers.

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<sup>4</sup> Meltzer, A., Dickinson, H., Malbon, E. and Carey, G. (2021) Why is lived experience important for market stewardship? A proposed framework for why and how lived experience should be included in stewarding disability markets, Evidence & Policy, vol xx, no xx, 1–13, DOI: 10.1332/174426421X16142714946996

## APPENDIX A

### PWdWA & WAIIS submission - NDIA Consultation Paper – Supporting you to make your own decisions (NDIS)

#### Introduction

People's access to adequate, appropriate, responsive and individualised supports funded under the NDIS to support them to live a good life is an extremely important aspect of both PWdWA's and WAIIS's work at both a systemic and individual level. Support for decision making has consistently been an area of our work where policy and practice of the NDIS can and should improve.

We recognise the development and implementation of the proposed policy as an expression of the NDIS Act's commitment to strengthening the upholding of the human rights of people with disability. This is a step towards upholding the Australian government's obligation to 'take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.'<sup>5</sup>

WAIIS and PWdWA acknowledge and concur with the issues identified by the NDIA in the consultation paper. We are grateful for the opportunity to highlight additional issues experienced through our work, and to provide feedback on the NDIS Proposed Support for Decision Making Policy (the proposed policy).

The recommendations made in this submission are based on the experiences of people with disability, their families and carers as well as advocates and advisors who provide information and support to people. They are underpinned by the provisions in the UNCRPD, and best-practice models of supported decision making.

#### Summary of Recommendations

We have made a number of recommendations we strongly encourage the NDIA to adopt. In implementing these recommendations the NDIA must ensure adequate funding and resources are allocated to ensure their success.

#### Recommendation 1

Amend the *NDIS Act 2013* to ensure that all people with disabilities have the right to enjoy legal capacity on equal basis with others, including the right to exercise choice and control

#### Recommendation 2

Strengthen the human rights basis of the proposed policy to ensure its goal and outcome is supporting people with disabilities to enact their human rights including the unqualified right to exercise legal capacity to make decisions

#### Recommendation 3

Provide clear definitions of the terms *individual decision making capacity* and *decision making capability*

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<sup>5</sup> United Nations CRPD Article 12

**Recommendation 4**

NDIA works with people with disability, their decision supporters and people who are responsible for medically assessing capacity to determine what the process to assess and record decision making capacity should look like. This should include acknowledgement that capacity may fluctuate along with the need for support for decision making.

**Recommendation 5**

Robust internal policies and guidelines must be implemented so that NDIA and Partner staff do not recommend or make applications for Guardianship and/or Administration Orders unless clear evidence and rationale are available, including that it is a last resort. In this regard, mental capacity is not a sufficient rationale for recommending an application.

**Recommendation 6**

We recommend the NDIS proposed policy provides for the five elements of support in the WAiS Decision Making Possibilities (DMP) practice framework, to decision makers and their network of decision supporters.

We recommend that information about each of the elements of the DMP supported decision making model be developed in accessible formats to assist decision makers.

**Recommendation 7**

The proposed policy needs to separate the concept of capacity from good, rational decision making or it risks perpetuating actions and policies which restrict the rights of people with disabilities to make their own decisions.

**Recommendation 8**

NDIA must ensure that persons, including those with appointed decision-makers, are always involved in decision making using a capacity building approach. This includes coming to the required agreements with state-based substitute-decision making authorities to ensure this occurs.

**Recommendation 9**

Replace the current nominee arrangements to allow participants to nominate decision supporters. This should include clear guidelines around the role, responsibilities and duties of decision supporters.

Participants should have the sole authority to appoint or revoke a decision making supporter, with the ability to specify the limitations of that support, retaining ultimate decision making authority. Third party decisions should only be made where a person's will and preferences cannot be determined even after significant efforts (including through the provision of support). The best interpretation of will and preferences should form the basis of decisions that need to be made.

**Recommendation 10**

The NDIA should clearly define the concepts of conflict of interest, bias and undue influence and develop policies and guidelines to manage these issues based on best practice, including the use of independent facilitation.

**Recommendation 11**

The NDIA must commit to co-designing guidelines for funding reasonable and necessary supported

decision making within a person's plan not only to ensure those who need it receive it, but also so that NDIA decision making is transparent and consistent.

### **Recommendation 12**

Amend the Goal of the proposed policy to:

Support people with disabilities to enact their human rights including exercising the legal capacity to make decisions

Enable people with disabilities to build capability to direct their own lives, with the right support to do so

### **Recommendation 13**

Amend the Roles and Responsibilities in Appendix B to “Rights and Responsibilities”. This would better reflect a rights based approach and give more weight to the statements e.g. Rights of the Participants, Responsibilities of the NDIA

### **Human Rights as Policy Foundations**

Human rights must be central to any policy decisions or directions undertaken by the NDIA. This is enshrined in the foundations of the NDIS Act 2013 which states the Act will give effect to Australia’s obligations under the Convention on the Rights of Persons with Disabilities (UNCRPD)<sup>6</sup>. The consultation paper briefly touches on human rights and legislative considerations but we believe not enough emphasis is placed on ensuring outcomes of the proposed policy promote the human rights of people with a disability.

The consultation notes the specific guiding principles in the Act relevant to decision making:

- People with disability should be supported to exercise choice, including in relation to taking reasonable risks, in the pursuit of their goals and the planning and delivery of their supports. (Section 4(4))
- People with disability have the same right as other members of Australian society to be able to determine their own best interests, including the right to exercise choice and control, and to engage as equal partners in decisions that will affect their lives, to the full extent of their capacity. (Section 4(8))
- People with disability should be involved in decision making processes that affect them, and where possible make decisions for themselves (Section 5(a))

These principles however, must always be considered under the broader context of the UNCRPD. In the case of the proposed policy we believe it is critical that the NDIA consider how the policy contributes more broadly towards Australia’s obligations under Article 5 and Article 12 of the UNCRPD:

- Article 5 Non Discrimination: to remove a person’s right on the basis of a disability is to discriminate against them on the basis of that disability
- Article 12 Equal Recognition before the Law: grants people with a disability inalienable rights to legal capacity on an equal basis with others.

Article 12 does not require a person to have mental capacity in order to have legal capacity and

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<sup>6</sup> NDIS Act 2013, Part 2, 3(1)(a,c,e)

asserts that these are two distinct concepts under the UNCRPD. Under Article 12 a person's mental capacity cannot be used as a means to deny legal capacity. From this perspective, supported decision making is about legally recognising the support offered, not by just legitimising the role of the supporter, but by formally acknowledging that the support offered changes the person's capacity. This is because supported decision making redefines capacity as interdependent.<sup>7</sup>

The right of people who don't use words or speech in typical ways for their age and culture to make decisions has often been assumed to be non-existent<sup>8</sup>. A supported decision making approach starts from an assumption that the building blocks of decision making capability can be established with and around a decision maker.

The United Nations Committee on the Rights of Persons with Disabilities (CRPD) calls for substitute decision making regimes (that amount to discrimination on the basis of disability) to be replaced with supported decision making. To this end, the CRPD states that support with decision making must be made available to everyone and that the government has the responsibility for facilitating the creation and availability of this support in the community.

We acknowledge the NDIS sits within the broader legal and political landscape where issues around legal capacity, mental capacity and supported decision making are playing out. There is currently no consistent approach within Australia to legal capacity. Many States and Territories still have best interest substitute-decision making systems in place which are at clear odds with the intent of Article 12.<sup>9</sup> Additionally, government support for people with disabilities goes beyond just the NDIS. There is an expectation that all levels of government (federal, state, and local) provide services that are accessible to people with disability, consistent with a human rights commitment. All these jurisdictions need a legal supported decision making framework, for example, to assist people with disability to make decisions related to health, justice, education, or engagement with local government.

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<sup>7</sup> Bach, M., & Kerzner, L. (2010). *A new paradigm for protecting autonomy and the right to legal capacity* (Report prepared for the Law Commission of Ontario) Retrieved from <http://www.lco-cdo.org/en/disabilities-call-for-papers-bach-kerzner>

Browning, M., Bigby, C., & Douglas, J. (2014). Supported decision-making: Understanding how its conceptual link to legal capacity is influencing the development of practice. *Research and Practice in Intellectual and Developmental Disabilities, 1*(1), 34-45. doi:10.1080/23297018.2014.902726

Series, L. (2015). Relationships, autonomy and legal capacity: Mental capacity and support paradigms. *International Journal of Law and Psychiatry, 40*(1), 80-91. doi:10.1016/j.ijlp.2015.04.010

Watson, J. (2016a). The right to supported decision-making for people rarely heard (Doctoral dissertation). Retrieved from [https://www.researchgate.net/profile/Joanne\\_Watson/publication/258997358\\_Thesis\\_The\\_right\\_to\\_supported\\_decision-making\\_for\\_people\\_rarely\\_heard/links/5751420a08ae17e65ec149cf.pdf](https://www.researchgate.net/profile/Joanne_Watson/publication/258997358_Thesis_The_right_to_supported_decision-making_for_people_rarely_heard/links/5751420a08ae17e65ec149cf.pdf)

<sup>8</sup> Bach, M., & Kerzner, L. (2010). *A new paradigm for protecting autonomy and the right to legal capacity* (Report prepared for the Law Commission of Ontario) Retrieved from <http://www.lco-cdo.org/en/disabilities-call-for-papers-bach-kerzner>

<sup>9</sup> The Committee on the Rights of Persons with Disabilities, *General Comment No. 1; Article 12: equal recognition before the law*, 11<sup>th</sup> sess, UN Doc CRPD/C/GC/1/, 19 May 2014, [27].

A society-wide cultural change is needed to embed a supported decision making approach to upholding the right of people with disability to have a say in the decisions that impact their life. There is currently an opportunity to learn from other countries, such as Austria, which have developed a whole-of-government approach to supported decision making. The NDIS can set the precedent within Australia by developing a best practice approach to supported decision making which mainstream government services, funded human services and the private sector could adopt and adapt to strengthen the extent to which the UNCRPD Article 12 is upheld in this country. More broadly this means reviewing the NDIS Act 2013 to remove qualifiers of legal capacity that currently exist in the legislation.<sup>10</sup>

### **Recommendation 1**

**Amend the *NDIS Act 2013* to ensure that all people with disabilities have the right to enjoy legal capacity on equal basis with others, including the right to exercise choice and control**

### **Recommendation 2**

**Strengthen the human rights basis of the proposed policy to ensure its goal and outcome is supporting people with disabilities to enact their human rights including the unqualified right to exercise legal capacity to make decisions**

### **Individual Capacity vs Decision Making Capability**

Individual decision making capacity has been the basis for justifying informal and formal substitute decision making arrangements. However, decision making capability is the basis for supported decision making. It's vital that all decision supporters and decision makers understand the difference.

There is no uniform definition or standard for capacity in legislation.<sup>11</sup> How capacity is defined in law has meant people with intellectual and other cognitive disabilities have had to demonstrate their autonomous, rational capacity to understand and appreciate the consequences of decisions. Decision-making capability is an alternative way of viewing capacity based on: ability + supports and accommodations<sup>12</sup>. Decision making capability is a feature of the person and their supporters, which can be increased through the group knowing the person and applying a supported decision making model.

With the right support and accommodations, a person's decision making capability can be increased through exploring, making and implementing decisions. An example of an accommodation is having time for a supported decision making process. People with CCAN may need significant time to receive information about a decision, weigh up the decision and communicate the decision to people who can interpret their communication. The NDIS and other support systems need to allow the time needed.

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<sup>11</sup> ALRC report *Equality, Capacity and Disability in Commonwealth Laws* (ALRC report 124). [alrc 124 whole pdf file.pdf](#)

<sup>12</sup> Bach, M., & Kerzner, L. (2010). *A new paradigm for protecting autonomy and the right to legal capacity* (Report prepared for the Law Commission of Ontario) Retrieved from <http://www.lco-cdo.org/en/disabilities-call-for-papers-bach-kerzner>

NDIA has also provided limited information on how they plan to assess and record a person's individual decision making capacity including where they sit on the decision making continuum outlined in Appendix B. There is no information on how this assessment will actually be used in practice, including in the appointment of nominees.

### **Recommendation 3**

**Provide clear definitions of the terms *individual decision making capacity* and *decision making capability***

### **Recommendation 4**

**NDIA works with people with disability, their decision supporters and people who are responsible for medically assessing capacity to determine what the process to assess and record decision making capacity should look like. This should include acknowledgement that capacity may fluctuate along with the need for support for decision making.**

### **Additional issues relevant to Supported Decision Making**

WAI S and PWDWA would like to take this opportunity to highlight how policies and directions within the NDIA are leading to the appointment of substitute decision makers in Western Australia. This issue was not specifically raised within the consultation paper but must be recognised and addressed.

Western Australia operates under a substitute decision making model where a guardian and/or administrator is granted the legal right to make decisions on another person's behalf based on their perceived best interest. It is a system at odds with the UNCRPD, which strips a person of their right to make decisions about their own life, and to have their will and preferences respected.

WAI S and PWDWA have experienced a disturbing trend around the application for guardianship orders involving NDIA staff and support providers. This includes guardianship orders being recommended by NDIA staff or Support Coordinators as a matter of routine for people with intellectual, cognitive or psychosocial disability who have limited family support. Parents/family members who play a significant role in supporting the decisions of their loved one are also being strongly encouraged to apply for guardianship. Additionally, support providers in WA are known to seek guardianship orders with the intent of keeping people safe and managing conflict. It is rare for the person with a disability to be consulted when an application is made. The application process often leads to long-lasting trauma which for many is compounded by having their legal right to make decisions removed.

In many of these cases there has been no consideration of the role Support for Decision Making could have played. In some cases NDIA staff have specifically stated if a person requires a high level of support to make decisions then someone else should be making those decisions for them. Although the NDIA is not responsible for each State's and Territories approach to legal capacity, they cannot ignore the intersection between the NDIS and other systems. Without a human rights approach, which acts to minimise the occurrence of substitute decision making, the NDIS risks creating situations where people's human rights are taken away.

## **Recommendation 5**

**Robust internal policies and guidelines must be implemented so that NDIA and Partner staff do not recommend or make applications for Guardianship and/or Administration Orders unless clear evidence and rationale are available, including that it is a last resort. In this regard, mental capacity is not a sufficient rationale for recommending an application.**

### **Feedback on Proposed Policy**

#### **Fundamentals of effective supported decision making<sup>13</sup>**

The proposed policy needs to be informed by greater depth of practice knowledge of supported decision making. We describe below some important elements that need to be provisioned in the proposed policy.

A supported decision making process starts with the decision maker identifying who they want to invite to be their decision supporters. We generally choose with whom we will speak to about what topics when we need to make a decision. We choose a few people, perhaps on the basis of trusted relationship, and history or expectation of their respect and belief in us. This would be no different for people with disability. Decision supporters are led by the person to develop a better, shared understanding of the decision maker and how they want to live and self-direct their life.

Decision supporters need to understand, agree with, commit to and implement the spirit of the UNCRPD and supported decision making principles. They need to understand decision making capability and their part in building it with a decision maker. Their role is to help the person explore, clarify and communicate their will and preferences in relation to a specific decision opportunity<sup>14</sup>. For people with CCAN, supporter responses involve acknowledging, interpreting and acting on the person's expressions of preference<sup>15</sup> as the building blocks of their decision making<sup>16</sup>. Building decision making capability starts before an NDIS plan is developed. An NDIS plan should be informed by a genuine person centred planning process with a decision maker and their supporters.

This is the foundation to understanding and acting on their expressions of will and preferences as the building blocks of their decision making. This planning process also highlights upcoming decision making opportunities. As these opportunities are explored, a decision maker may want to make changes to their NDIS plan. Decision supporters are well placed to assist them to do this.

People need to have information in a range of accessible formats including plain language, easy read and multimedia formats. People with disabilities need to be involved in the development,

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<sup>13</sup> Questions 1, 3, 7, 9

<sup>14</sup> Browning, M. (2018). Developing an understanding of supported decision-making practice in Canada: The experiences of people with intellectual disabilities and their supporters (Doctoral dissertation). La Trobe University, Melbourne, Australia.

<sup>15</sup> Watson, J., Wilson, E. & Hagliassis, N. (2017). Supporting end of life decision making: Case studies of relational closeness in supported decision making for people with severe or profound intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, 30, 1022–1034. doi:10.1111/jar.12393

<sup>16</sup> Watson, J., Voss, H. & Bloomer, M.J. (2019). Placing the preferences of people with profound intellectual and multiple disabilities at the center of end-of-life decision making through storytelling. *Research and Practice for Persons with Severe Disabilities*, 44(4), 267-269. Doi:10.1177/1540796919879701

production and testing of these resources. Decision makers may also need specific support that's consistent with their informal or formal communication system to understand information. The broad support needs of people with disability to make and communicate decisions are also more likely to be met if we start by addressing the support needs of people with complex communication access needs (CCAN).

In some settings people are not supported to have input to decisions which impact on them, including their support or treatment, unless they use spoken or written words to provide consent for advocacy support. The requirement for consent in this way also restricts the opportunity to bring together or get input from people who know them and their communication to support their decision making. Support systems need to validate the range of ways a person communicates their preferences and decisions in the context of decision supporters who know them.

We agree that there are different cultural needs that need to be considered for decision makers. A supported decision making process which starts with the person being supported to identify and invite their preferred decision supporters will go some way to meeting their cultural needs in the context of building decision making capability. The role of the NDIS is to respond to cultural needs whilst also upholding the person's right to exercise their legal capacity as a decision maker.

Support for decision making is a long term investment and strategy for people, families, communities and across government. The NDIS must adequately invest in building the capacity of people and their supports through their funding with a long term outlook.

### **Proposed SDM Practice Framework**

A robust supported decision making framework can help to ensure the quality of the process. The proposed framework presents as a very linear process for supported decision making. However, decision making does not always follow a linear process. The examples given in the paper are very straightforward decisions with no complexity, for example where a person has limited decision supporters, or requires communication support, or the decision carries a level of risk. The approach appears to try and systematise everything into simple boxes when in reality decision making in real life doesn't fit a box e.g. life/stages/impact.

WA's Individualised Services is currently managing an ILC-funded supported decision making project. The Decision Making Possibilities (DMP) Practice Framework is based on research and learning from a previous WAiS supported decision making project. It consists of five key elements of support to a decision maker and their network:

1. Network establishment and support through facilitation
2. Communication support
3. Knowledge of the person and genuine person centred planning
4. Education and training on human rights, social model of disability and supported decision making; and
5. A supported decision making model of practice.

Each of these elements work together to build the capability of people and their network of decision supporters to make decisions and determine their own lives.



Decision Making Possibilities applies the following model of supported decision making.



**Recommendation 6**

**We recommend the NDIS proposed policy provides for the five elements of support in the WAIS Decision Making Possibilities (DMP) practice framework, to decision makers and their network of decision supporters.**

**We recommend that information about each of the elements of the DMP supported decision making model be developed in accessible formats to assist decision makers.**

**Independent/Rational/Good Decision Making<sup>17</sup>**

We are concerned that particularly in the period of transitioning to adulthood, a paternalistic approach will be perpetuated by the NDIS, expressed through expectation of holding people with

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<sup>17</sup> Questions 1, 3

disability to a higher standard than the general community in terms of being perceived as making rational decisions. The consultation paper suggests that when trying to make decisions a person *must* weigh the positives and negatives and *needs* to think about what might happen in the future. In the general population, people's capacity is not correlated with independent, rational or 'good' decisions. Most people will make irrational decisions in their life, or decisions where they are not sure of the consequences. Experiencing those consequences is part of learning.

Decision supporters often demonstrate their bias towards keeping a person safe. We note that keeping a person safe is not the explicit goal of supported decision making. People should be free to take risks. However, the goal of building decision making capability should include exploring the question of what will it take for the person to be the safest they can be whilst taking risks.

### **Recommendation 7**

**The proposed policy needs to separate the concept of capacity from good, rational decision making or it risks perpetuating actions and policies which restrict the rights of people with disabilities to make their own decisions.**

### **Role of informal and formal decision makers<sup>18</sup>**

Knowing a person is important to being able to assist them with making decisions. Knowing a person's history and life story correlates with intimate or very close relationships<sup>19</sup>. This level of knowledge in supporters makes them more likely to be responsive to that person, in terms of acknowledging, interpreting and acting on their expressions of preference.

Effective decision supporters have a range of beliefs, attitudes, knowledge and skills. Willingness to be in the role is a necessary but basic starting point. Decision supporters should be effective communication partners who are attuned and acknowledge, interpret and act, or facilitate action, on the person's communication. Decision supporters need attitudes of belief and expectation of building decision making capability. Decision supporter relationships should be characterised by equality, respect and trust.

Supported decision making research has pointed to the importance of decision makers and their supporters receiving education and training on a range of topics including the right of people with disability to make decisions<sup>20</sup>, their right to enjoy legal capacity on an equal basis with others<sup>21</sup>, the

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<sup>18</sup> Questions 2, 5, 6

<sup>19</sup> Watson, J. (2016a). The right to supported decision-making for people rarely heard (Doctoral dissertation). Retrieved from [https://www.researchgate.net/profile/Joanne\\_Watson/publication/258997358\\_Thesis\\_The\\_right\\_to\\_supported\\_decision-making\\_for\\_people\\_rarely\\_heard/links/5751420a08ae17e65ec149cf.pdf](https://www.researchgate.net/profile/Joanne_Watson/publication/258997358_Thesis_The_right_to_supported_decision-making_for_people_rarely_heard/links/5751420a08ae17e65ec149cf.pdf)

<sup>20</sup> Burgen, B. (2016). Reflections on the Victorian Office of the Public Advocate supported decision-making pilot project. *Research and Practice in Intellectual and Developmental Disabilities*, 3(2), 165-181. doi:10.1080/23297018.2016.1199969

<sup>21</sup> Harding, R., & Taşciouğlu, E. (2018). Supported decision-making from theory to practice: Implementing the right to enjoy legal capacity. *Societies*, 8(2), 25-39. doi:10.3390/soc8020025

aim and principles of supported decision making<sup>22</sup>, understanding the process of decision making support<sup>23</sup> and developing practical strategies in how to provide decision support<sup>24</sup>.

Supported decision making practice evidence suggests that a formalised network facilitator role helps to ensure independence and sustainability of the process. Ideally, independent facilitation of supported decision making is in the context of a group of decision supporters.

There are limitations to the suggested formal supports in the proposed policy. The stakeholders identified should be part of the process but not driving it or leading the decision maker. Formal decision makers within the NDIS often don't know the person, carry inherent bias from working within the system and may have a conflict of interest in terms of the decisions being made.

In relation to proposed NDIS changes to the appointment of nominees, NDIS staff, nominee applicants, supporters and decision makers need to:

- know that a legally appointed substitute decision maker is a last resort and when one is appointed, this should NOT mean the person is no longer involved in a decision making process.
- recognise that appropriate supports can reduce, or eliminate the need for substitute decision makers
- understand that decision making capacity is person-, support-, decision- and circumstance-specific
- offer ongoing support for decision making on the assumption that the person can learn and develop capacity as a decision maker.

The suggestion that advocacy, peer support or circle of supports can be relied on for supported decision making is unworkable on several counts:

- Advocacy services are already unable to meet the demand for their service
- Advocacy services are issues based, time-limited supports that are accessed when a person is facing a specific problem. Knowledge of a person's will and preferences is limited to the specific circumstance they are engaged around
- Whilst it is true that these supports may indirectly help to build decision making capability, this is not their reason for being. Without explicit clarity about using a supported decision making approach and relevant education, it's likely that people will not understand their roles or the process, and the potency of the approach will be diminished.

These models of support must be acknowledged, respected and given the required scope to support someone to exercise their legal capacity but cannot be expected to meet the need for

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<sup>22</sup> James, K., & Watts, L. (2014). Understanding the lived experiences of supported decision-making in Canada: Legal capacity, decision-making and guardianship (Report commissioned by the Law Commission of Ontario). Retrieved from <https://www.lco-cdo.org/wp-content/uploads/2014/03/capacity-guardianship-commissioned-paper-ccel.pdf>

<sup>23</sup> Browning, M. (2018). Developing an understanding of supported decision-making practice in Canada: The experiences of people with intellectual disabilities and their supporters (Doctoral dissertation). La Trobe University, Melbourne, Australia.

<sup>24</sup> Bigby, C., Whiteside, M., & Douglas, J. (2017a). Providing support for decision making to adults with intellectual disabilities: Perspectives of family members and workers in disability support services. *Journal of Intellectual and Developmental Disabilities*, 1-14. doi:10.3109/13668250.2017.1378873

decision making support. They must also be appropriately funded to ensure their availability to everyone who needs them.

We know that some people with a disability do not have people in their lives to help them work with the NDIS or to help them to develop and use their NDIS plan. For people who are isolated, there may be value in offering the opportunity and support to bring together potential decision supporters who are interested to build a relationship with the person, learn their communication, support their decision making and facilitate their connection with long term decision supporters. A relevant example is contained in the IAC Support for decision making in the NDIS, July 2019 discussion paper.

*A participant who lives in a boarding house or group home and is isolated from family and friends could identify decision making as a goal in their plan, could be allocated reasonable and necessary capacity building support to build relationships and support decision making and be supported to become a member of a peer network.*

The need for a values-based, supported decision making process is especially important for people whose decision support needs are complex. Formal decision supporters tend to apply black and white rules to these contexts which err towards taking away a person's right to choose. It can take a facilitated, skilful and knowledgeable group of decision supporters who know the person and who are committed to supporting both their rights and their wellbeing to navigate an effective supported decision making process.

#### **Recommendation 8**

**NDIA must ensure that persons, including those with appointed decision-makers, are always involved in decision making using a capacity building approach. This includes coming to the required agreements with state-based substitute-decision making authorities to ensure this occurs.**

#### **Recommendation 9**

**Replace the current nominee arrangements to allow people to nominate decision supporters. This should include clear guidelines around the role, responsibilities and duties of decision supporters.**

**People should have the sole authority to appoint or revoke a decision making supporter, with the ability to specify the limitations of that support, retaining ultimate decision making authority. Third party decisions should only be made where a person's will and preferences cannot be determined even after significant efforts (including through the provision of support). The best interpretation of will and preferences should form the basis of decisions that need to be made.**

#### **Conflict of interest, bias and undue influence<sup>25</sup>**

The NDIS has an obligation to implement the proposed policy such that it 'ensures that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law. Such safeguards shall ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the

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<sup>25</sup> Questions 10, 11

person's circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body. The safeguards shall be proportional to the degree to which such measures affect the person's rights and interests.' (Article 12 UNCRPD)

The proposed policy and its implementation needs to clarify and educate people about the related concepts of conflict of interest, bias and undue influence. If these are not properly understood and managed by people involved in supported decision making there is a risk to the person's human rights in that their decision may not be heard and upheld, or they may be placed at non-consensual risk.

The three may be managed differently, for example, a decision supporter who has a paid role in the person's life may need to withdraw from a specific decision making process due to conflict of interest. Bias is a broader concept. Every decision supporter brings bias to the process so they can never be entirely neutral. Their own values, experiences, goals, priorities and preferences can influence the support they provide. But the intention they have when providing support, and the strategies they take to mitigate the impact of their biases, such as trying to be as neutral as possible, non-judgmental and minimising their influence are very important.

In order for bias to be effectively managed it must become conscious and shared, otherwise it can manifest as undue influence on the decision maker's process. Independent facilitation of the process can assist with minimising the impact of bias and undue influence on a decision maker. It should also ensure the person feels safe in the process of making a decision.

Undue influence can manifest as a range of decision supporter tones of engagement, for example a patronising, cloying tone which leads a decision maker to want to please others with their decision, or a paternalistic, controlling tone which leads a decision maker to not want to distress or anger others with their decision. Undue influence may occur when the decision being made has the potential to negatively impact on a decision supporter.

Inherently NDIA and support staff have a level of undue influence due to the uneven power dynamics they hold. There is also a conflict of interest as they are both facilitating support for the person but responsible to others for how that support is provided.

A group of people who know the person and are committed to building their decision making capability can protect the person from the negative impacts of conflict of interest, bias and undue influence.

### **Recommendation 10**

**The NDIA should clearly define the concepts of conflict of interest, bias and undue influence and develop policies and guidelines to manage these issues based on best practice, including the use of independent facilitation.**

### **Funding SDM for individuals vs increasing sector and supporter capabilities<sup>26</sup>**

We are concerned that people are not supported to have a breadth of experiences which then lead to decision opportunities. This is especially relevant for people who are isolated or who have lived in institutional settings. Genuine person centred planning leads to a broader range of experiences and choices which is an essential basis for a person to exercise their legal capacity. This element of support is currently missing and not funded for many people. The NDIS needs to offer funding for the support elements which contribute to building decision making capability which is a long term investment (see Decision Making Possibilities Practice Framework). We are concerned about the NDIS perpetuating broader low societal expectations about people's adult lives and the extent to which they will include typical experiences such as contribution, work and creating a home, by not fully supporting people to exercise their legal capacity to direct their lives.

We are concerned that the proposed policy does not include a clear commitment to providing NDIS funding for people to build decision making capability. Individualised funded support must be made available if the stated goals are to be achieved.

The NDIS investment in training, education, and support related to supported decision making, including genuine person centred planning and communication is missing for most people. It's important that all stakeholders are educated about how people typically make decisions and for this knowledge to be applied in a supported decision making context. However, the supported decision making context for people with disability needs more intention and structure than is typical for the broader community. Without education, intention and structure, the risk is that decision supporters won't understand their role, and the quality of the process and outcome is reduced.

We are concerned about the proposed policy assumption that capability will be built and therefore support for decision making funding will reduce over time. The NDIA cannot take an approach that an investment will reduce or remove the ongoing cost of support for decision making for all participants. The elements and practice of effective decision making support may be developed over time so that the decision maker's capability is more responsive in a shorter time frame. However, capability may only be built with the right formal and/or informal support in place and in many cases the need for support with decision making will fluctuate, for example, for people with episodic psychosocial disability. Practice evidence indicates that without external facilitation, networks and circles of support tend to fragment in a two-to-three year timeframe. Therefore, the default approach must be to provide maintenance support for decision making capability as needed.

Sitting alongside this is the intersection between the NDIS and other mainstream services where a person may require support for decision making in order to exercise their legal right to make decisions. The consultation paper does not address the need for people to receive support for decision making outside of just their NDIS plans and supports. For example, this may include medical treatment decisions or financial decisions. It is not clear if the NDIA has considered how these supports will interact. It has the potential to leave substantial gaps in the decision making support that people may need across the whole breadth of their lives.

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<sup>26</sup> Questions 1, 4, 8

### **Recommendation 11**

**The NDIA must commit to co-designing guidelines for funding reasonable and necessary supported decision making within a person's plan not only to ensure those who need it receive it, but also so that NDIA decision making is transparent and consistent.**

### **Other feedback**

We believe the proposed Key Principles and Goals in the proposed policy could be stronger. The current statements are too passive and do not place enough emphasis on human rights outcomes.

### **Recommendation 12**

**Amend the Goal of the proposed policy to:**

**Support people with disabilities to enact their human rights including exercising the legal capacity to make decisions**

**Enable people with disabilities to build capability to direct their own lives, with the right support to do so**

### **Recommendation 13**

**Amend the Roles and Responsibilities in Appendix B to “Rights and Responsibilities”. This would better reflect a rights based approach and give more weight to the statements e.g. Rights of the Participants, Responsibilities of the NDIA**