

Chapter 2

Rights, capacity and control

Background

National Disability Strategy

2.1 The National Disability Strategy (Strategy) is a 10 year strategy developed by COAG in conjunction with the Australian Local Government Association. It sets out the vision that people with disabilities in Australia should be to be part of '...an inclusive Australian society that enables people with disability to fulfil their potential as equal citizens.'¹

2.2 The Strategy establishes what it calls 'An inclusive agenda' that recognises the diversity of people with a disability:

The Strategy recognises that not all people with disability are alike. People with disability have specific needs, priorities and perspectives based on their personal circumstances, including the type and level of support required, education, sex, age, sexuality, and ethnic or cultural background. Some experience multiple disadvantages. Sex, race and age can significantly impact on the experience of disability.²

2.3 The Strategy also explicitly adopts³ the principles set out in Article 3 of the UNCRPD and promotes their use as a key tool in addressing disadvantage for people with disabilities:

The Strategy will help ensure that the principles underpinning the [UNCRPD] are incorporated into policies and programs affecting people with disability, their families and carers. The [UNCRPD] is unique in that it is both a human rights instrument and a development instrument which aims to redress the social disadvantage of people with disability.⁴

2.4 It was during the development of the Strategy that the government asked the Productivity Commission to undertake its inquiry into a national disability 'long-term

1 *National Disability Strategy 2010–2020*, agreement of the Council of Australian Governments dated 13 February 2011, www.fahcsia.gov.au/sites/default/files/documents/05_2012/national_disability_strategy_2010_2020.pdf (accessed 27 January 2013), p. 8.

2 *National Disability Strategy 2010–2020*, agreement of the Council of Australian Governments dated 13 February 2011, www.fahcsia.gov.au/sites/default/files/documents/05_2012/national_disability_strategy_2010_2020.pdf (accessed 27 January 2013), p. 14.

3 *National Disability Strategy 2010–2020*, agreement of the Council of Australian Governments dated 13 February 2011, www.fahcsia.gov.au/sites/default/files/documents/05_2012/national_disability_strategy_2010_2020.pdf (accessed 27 January 2013), p. 22.

4 *National Disability Strategy 2010–2020*, agreement of the Council of Australian Governments dated 13 February 2011, www.fahcsia.gov.au/sites/default/files/documents/05_2012/national_disability_strategy_2010_2020.pdf (accessed 27 January 2013), p. 16.

care and support scheme, including consideration of a national disability insurance scheme'.⁵

2.5 As discussed in chapter one, the Productivity Commission report identified a number of failings in the current provision of disability services and funding models. The purpose therefore of the NDIS is to alleviate this disadvantage by creating a scheme that:

- will take an insurance approach that shares the costs of disability services and supports across the community;
- will fund reasonable and necessary services and supports directly related to an eligible person's individual ongoing disability support needs; and
- will enable people with disability to exercise more choice and control in their lives, through a person-centred, self-directed approach, with individualised funding.⁶

Applying a rights-based approach

2.6 A key theme in a significant number of the 1600 submissions that the committee received was whether the bill delivered on the policy intention of safeguarding and advancing the rights of people with disability. Many submissions identified a fundamental tension between the rights-based and entitlement-based language of the bill's objects and the UNCRPD on the one hand, and a range of processes in the bill on the other. Examples include the agency CEO's discretion in decision making, such as in assessing against the eligibility criteria, and the requirement that they "approve" of plans, restrictions over holidays etc.

UN Convention on the rights of People with Disabilities

2.7 The Bill includes reference to the UNCRPD in the objects of the bill. Paragraph 3(1)(h) states that the objects of the Act are to:

- (h) give effect to certain obligations that Australia has as a party to the Convention on the Rights of Persons with Disabilities.⁷

2.8 The Explanatory Memorandum (EM) expands on paragraph 3(1)(h) by setting out the specific Articles in the UNCRPD that the Bill will engage with. The EM also cites the International Covenants on Economic, Social and Cultural Rights; and Civil and Political Rights:

The legislation will engage the following rights:

5 *National Disability Strategy 2010–2020*, agreement of the Council of Australian Governments dated 13 February 2011, www.fahcsia.gov.au/sites/default/files/documents/05_2012/national_disability_strategy_2010_2020.pdf (accessed 27 January 2013), p. 20.

6 NDIS Bill, Explanatory Memorandum, p. 1.

7 NDIS Bill, paragraph 3(1)(h).

- The rights of people with disabilities in the *Convention on the Rights of Persons with Disabilities* (CRPD), especially Articles 3, 4, 7, 8, 12, 19, 20, 21, 22, 26, 28, 30, 31;
- The rights of children in the *Convention on the Rights of the Child*, especially Articles 12 and 23;
- Article 10 of the *International Covenant on Economic, Social and Cultural Rights*; and
- Article 17 of the *International Covenant on Civil and Political Rights*.

2.9 Pam Spelling from Independent Advocacy Townsville spoke to the committee from the perspective of an individual with a significant vision impairment as well as from an advocacy viewpoint. She contended that the concept of choice of control has to be stronger in the bill by explicitly citing the principles of the UNCRPD as the principles that underpin the legislation:

...the United Nations Convention on the Rights of Persons with Disabilities is somewhat absent in the bill framework in mentioning the rights of people with disabilities under the UNCRPD...I think that is a really critical part of the NDIS bill given that it is something that is going to include many people with disabilities more than ever before in terms of some level of support. It should be enshrined in a rights model. That is really so the rights of people with disabilities are promoted and protected within the bill.

The bill infers some of the rights in terms of people being able to have individual choice and control, but I think it needs to be strengthened by being quite explicit in using the UNCRPD.⁸

2.10 Ken Wade, Queensland Advocacy Incorporated, welcomed the inclusion of the UNCRPD in the objectives of the bill but commented that the wording is too broad:

...to its great credit, the bill has acknowledged the Convention on the Rights of Persons with Disabilities, and...it states that one of the objects is to put into effect certain obligations that the government has under the CRPD, but that leaves quite a wide range for interpretation of what those obligations are going to be.⁹

2.11 The Law Council emphasised the importance of the having clear direction on the face of the bill of Australia's obligations under various human rights instruments:

Human rights and fundamental freedoms have certain connotations, which basically the Law Council would seek to have enshrined in the legislation. We think it is very important that there be a link back to the convention and that that link be included in the objects of the legislation so that it is clear to

8 Ms Spelling, Independent Advocacy Townsville, *Proof Committee Hansard*, 29 January 2013, p. 23.

9 Mr Wade, Queensland Advocacy Incorporated, *Proof Committee Hansard*, 30 January 2013, p. 16.

anyone interpreting the legislation that the government has in mind Australia's obligations under the convention in designing the legislation.¹⁰

2.12 Carolyn Frohmader from Women with Disabilities Australia (WWDA) also wanted a stronger statement within the objects and principles of the bill that would underpin the rights-based approach of the legislation. Ms Frohmader also questioned why the object of the bill that does cite the UNCRPD does not embrace all of the rights contained within the UNCRPD:

We are also really concerned about some of the language in the bill around the idea that it is predicated on human rights principles and a human rights framework. But setting out from the outset that one of the objectives is it would give effect to certain obligations under the CRPD seems to be like saying you can have a little bit of human rights. Either it does or it does not. I do not understand why that is in there given that the CRPD enables the progressive realisation of rights, so there is no reason that it cannot be there in its entirety.

2.13 Heidi Forrest, who gave evidence to the committee in Newcastle, went further by recommending that the bill explicitly states which Articles within the UNCRPD should be adopted in the legislation. Her submission provided a detailed recommendation for amendment to the bill:

That the NDIS legislation more comprehensively adopts the principles expressed in the *Convention on the Rights of Persons with Disabilities* (CRPD), particularly Article 8 Awareness Raising; Article 12 Equality Before the Law; Article 19 Living Independently in the Community; Article 20 Personal Mobility and Article 26 Habilitation and Rehabilitation.¹¹

2.14 DANA were also strong advocates of explicitly including the commitment to meeting Australia's obligations under the UNCRPD in the objects of the Bill. They suggested adopting the language of the Human Rights and Anti-Discrimination Bill 2012 which states as one of its objects:

“3(1)(b) in conjunction with other laws, to give effect to Australia’s obligations under human rights instruments ...(See subsections (2)...”

“3(2) The **human rights instruments** are the following, as amended and in force for Australia from time to time:

... the Convention on the Rights of Persons with Disabilities done at New York on 13 December 2006 ([2008] ATS 12).”¹²

2.15 AFDO agreed that human rights were not sufficiently enshrined in the legislation:

At present, the legislation does not provide for an approach centred on the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD), let alone other human rights covenants which are relevant to the

10 Mr Parmeter, Law Council of Australia, *Proof Committee Hansard*, 5 March 2013, p. 12.

11 Ms Forrest, *Submission 495*, p. 2.

12 *Human Rights and Anti-Discrimination Bill 2012, Exposure Draft Legislation*. s(3)(1)(b).

rights based participation of citizens. If the legislation is to be interpreted well by a range of people for years to come, it must enshrine these rights more explicitly.¹³

2.16 However the Disability Discrimination Commissioner, Graeme Innes, and his colleague, Dr Helen Potts were of the view that the general reference to the UNCRPD in the bill, with particular Articles specified in the EM would be sufficient:

Dr Potts: My understanding of it is, it is in the statement of compatibility as well, when you look at that. The way it is written it says, 'The legislation will engage the following rights', and then it refers to the CRPD and the Convention on the Rights of the Child and the International Covenant on Economics, Social and Cultural Rights, but when it is speaking of the CRPD it says:

The rights of people with disabilities in the Convention on the Rights of Persons with Disabilities (CRPD), especially Articles ...

so it is not exhaustive.

...

Mr Innes: I do not think that is a concern. As Helen says, it makes special reference to those articles, but includes the whole convention, so I do not think that is a problem.¹⁴

Committee View

2.17 Ensuring rights-based language in the primary legislation reflective of a rights-based approach to the NDIS is of huge significance for many stakeholders in the disability field. While the bill may be implemented within the context of the UNCRPD and give effect to obligations contained therein, the committee supports the removal of the conditional language of the current object (h) in clause 3 of the Bill. The views of a wide range of submitters would be accommodated by taking the same approach in the current bill as the government is taking in the Human Rights and Anti-Discrimination Bill 2012. The committee considered the suggestion by DANA and supported by many others, to refer to not only to the UNCRPD, but also the other Convention and Covenants specified in the EM. However it also drew some comfort from the view of the Disability Discrimination Commissioner that the current position is sufficient. On balance the committee were of the view that the language should be strengthened to coalesce with the Strategy's commitment to using the CPRD as 'a human rights instrument and a development instrument which aims to redress the social disadvantage of people with disability' as discussed in paragraph 2.3 above.

13 Australian Federation of Disability Organisations, *Submission 514*, p. 3.

14 Mr Innes, Disability Discrimination Commissioner and Dr Potts, Disability Rights Unit, Australian Human Rights Commission, *Proof Committee Hansard*, 1 February 2013, p. 34.

Recommendation 1

2.18 The committee recommends that the conditional language of s3(1)(h) of the Bill be revised to more strongly reflect Australia's international human rights obligations such as those in relation to:

- civil, political, economic, social and cultural rights;
- the prevention of racial discrimination or torture; and
- people with disability, women, and children.

Choice, Control and Capacity

The presumption of Capacity

2.19 The presumption of capacity of individuals with disabilities is a key issue for many stakeholders. Clause 4(8) of the bill states that:

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

2.20 Clause 5 of the bill outlines the intention that if actions are required to be undertaken by others on behalf of a person with a disability, this should be done in accordance with the general principles set out in clause 4. A further set of principles, the first of which is paragraph 5(a)—'people with disability should be involved in decision making processes that affect them, and where possible make decisions for themselves'¹⁵—will also guide actions.

2.21 The statement in subclause 4(8) makes reference to people with disability being 'equal partners in decisions that will affect their lives', whereas many submitters argued that a person with a disability should be the principal decision-maker for their own lives where possible (not merely an 'equal partner' with others).¹⁶

2.22 A number of submitters such as the Victorian Government and a range of disability organisations such as COTA Australia,¹⁷ Cerebral Palsy League of Queensland,¹⁸ and Queensland Alliance for Mental Health Incorporated did not think that the bill in its present form clearly demonstrated that 'participants have their own decision-making capacity',¹⁹ and should be strengthened by including an explicit statement that a person with disability should be presumed to have the capacity to make decisions.

15 NDIS Bill, paragraph 5(a).

16 See Pegg, Mallett or Hardaker, *Proof Committee Hansard*, 22 February 2013.

17 COTA Australia, *Submission 617*, p. 3.

18 Cerebral Palsy League of Queensland, *Submission 641*, p. 3.

19 Cathy O'Toole, Queensland Alliance for Mental Health Incorporated, *Proof Committee Hansard*, Wednesday 30 January 2013, p. 12.

2.23 The Victorian Government suggested that this be addressed by adding a new sub-clause to clause 5 to this effect, as well as making other amendments to the parts of clause 5 in order to strengthen the focus on the preferences and decisions of people with disability.²⁰ The rationale for these amendments is that the principles currently espoused in the bill do not make it clear that people should be supported in their decision making to the fullest extent possible in the first instance before any options for substitute decision making are explored.

2.24 Queensland Alliance for Mental Health Incorporated was of the view that 'with the correct support, it is possible for people to make decisions, where, on the surface, it may appear they may not have the capacity'. To ensure this they suggested the bill explicitly reflect the intent of the UNCRPD Articles 3 and 12:

...the bill needs to clearly demonstrate the assumption that participants have their own decision-making capacity. It is important that the bill closely reflects the intent of the United Nations Convention on the Rights of Persons with Disabilities, specifically the following articles. Article 3, general principle (a):

Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons;

And article 12 (3):

States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.

...Incorporation of these articles will ensure that substitute decision making is used only as a last resort.²¹

2.25 Queensland Advocacy Incorporated suggested that the NDIS mandate that guardianship arrangements in relation to decision-making be amended to ensure that a person has a role in their own decision making. Nick Collyer from the organisation cited arrangements in Canada and some states in the United States as a possible model:

Currently we do not have supported decision-making in any jurisdiction in Australia, but it is there in Canada and in some states of the United States, I understand. It is a new way of approaching guardianship. You may know that, under our current guardianship systems, we have a combination of best-interest decision-making and substitute decision-making. The problem with that is that there is no onus on the guardian—or the public advocate, as it may be in Victoria, for example—to ensure that the person has a role in their own decision-making. Supported decision-making is a specific mechanism—an agreement, essentially, that is set up between a support person and the person with a cognitive or intellectual disability or a mental health issue which ensures that that person has a role in all decisions about their life. We think that supported decision-making is the way to go and we

20 Victorian Government, *Submission 608*, Appendix A, p. i.

21 Ms O'Toole, Queensland Alliance for Mental Health Incorporated, *Proof Committee Hansard*, 30 January 2013, p. 12.

think that the NDIS bill should explicitly mandate supported decision-making.²²

2.26 AFDO contributed on what they perceive is a general lack of assumption of capacity in the legislation. In their submission they cite clause 4(4) 'People with disability should be supported to exercise choice and control in the pursuit of their goals and the planning and delivery of their supports' and argued that the language of 'supporting people' was indicative of a presumption that capacity would be lacking:

This general principle speaks to a much broader problem with the underlying assumptions of this legislation: namely, it talks about 'supporting' people with disability to have choice and control over goals, rather than assuming that capacity for choice and control is inherent and acting accordingly.²³

2.27 The submission continued on to highlight what it saw as inadequate provisions for ensuring that the person with the disability is at the centre of the decision making for their own lives:

At present the draft NDIS legislation works on the basis that there may be circumstances where taking over control and choice for the person is appropriate, rather than enabling the person with assistance. Whether or not the term 'support' is meant to imply a collaborative relationship has become irrelevant, because the goal of that support is fundamentally different.²⁴

Committee View

2.28 The committee agrees with the concerns expressed by a number of submitters that the objects and principles of the bill do not presume capacity. In particular the Victorian government's suggested amendments to clause 5 would help ensure that capacity is presumed, and that the first position of the scheme would be to support individuals to make decisions themselves. If this was not possible, and had been objectively assessed as being not possible, then substitute decision making processes would be invoked.

Recommendation 2

2.29 The committee recommends that clause 4 of the bill be amended to explicitly state that it is presumed that people have the capacity to make their own decisions unless objectively assessed otherwise.

22 Mr Collyer, Queensland Advocacy Incorporated, *Proof Committee Hansard*, 30 January 2013, p. 16.

23 Australian Federation of Disability Organisations, *Submission 514*, p. 5.

24 Australian Federation of Disability Organisations, *Submission 514*, p. 5.

Recommendation 3

2.30 The committee recommends that clause 5(a) of the bill be amended to read:

- (a) **people with disability should participate actively in decisions that affect their lives, and be supported where necessary to enable this to occur.**

Choice and Control

2.31 While the prospect of increased choice and control for persons with disabilities was universally welcomed by those who submitted and contributed to the inquiry, some potential challenges were also discussed. Duncan Brown from the TIPACL highlighted potentially unforeseen consequences for people with intellectual disabilities and their carers of this greater control:

The NDIS will obviously generate positive changes and foster increased choice and control for people with disabilities. This will be a challenge for people with intellectual disability who have difficulties in understanding those choices and expressing those opinions. People with intellectual disability—who are the majority of users of disability services, by the way—often rely on proxy decision makers. If those proxy decision makers themselves have difficulties in comprehending and decision making, or where they have no proxy decision makers, people with intellectual disability can be severely disadvantaged in self-directed, individualised funding systems in comparison to other people with disabilities.²⁵

2.32 The MS Society in Western Australia made a general point that the legislation has a general tone of mistrust and emphasised that people with disabilities are not accessing the system out of choice, but because they have a disability through no fault of their own:

Where power is concerned, I think that in many respects the general tone of the legislation smacks of mistrust and punitive action. I would just like to make the statement that we are not talking about people who are choosing not to work, who may be choosing to surf every day and to find every benefit they can find within the system. We are talking about people who, through no fault of their own, have a disability that has already impacted severely on their quality of life.²⁶

2.33 The ACT Disability Aged and Carer Advocacy Service (ADACAS) agreed that the legislation strikes the wrong tone and creates a potential scenario where the individual is not an equal partner in the relationship with the transition agency:

It is disappointing that at present the tenor of the bill focuses on managing risk and describes the participants as submissive to the agency in all of their

25 Mr Brown, Townsville Independence Program for Adult Community Living Inc., *Proof Committee Hansard*, 29 January 2013, p. 39.

26 Mr Stafford, MS Society Western Australia, *Proof Committee Hansard*, 18 February 2013, p. 8.

interactions with it, rather than as equal partners in the creation of systems that enable them to live free and fulfilling lives.²⁷

2.34 Carers Queensland expressed concerns that the legislation offers no assurance that carers will benefit from the increase of choice and control directed at people with disabilities:

...the NDIS draft legislation marginalises our concerns and our contribution in determining service delivery options and assigning claim management responsibility and specialist interventions that will support and assist carers to effectively manage changed or deteriorating health or functionality. This marginalisation reinforces to carers the perception that control is outside of our sphere of influence—that is, carers can and will do the grunt work whilst practitioners, albeit well-meaning, make decisions with limited regard to our aspirations, thoughts and experiences.²⁸

2.35 Julie Guilfoile provided the committee an example of how her son, Eamon has had choice and control taken from his life since he moved into residential care. Ms Guilfoile's evidence illustrated how restrictions on care, be they through staffing issues or through organisational priorities of the care provider, remove the element of control for Eamon. In this specific case, Eamon is unable to socialise with his sibling due to this being unsupported by his service provider:

The other thing I will try and finish quickly is the sibling relationship. It is probably the most significant of Eamon's life span. His brother and sister will outlive us and their relationship with their brother is very important to all of them. Eamon allows his little sister to do things that he does not let anybody else do. He adores her. It is not possible for a staff member to take Eamon out with his sister. I am not sure why. That is seen to be unreasonable.²⁹

2.36 Ms Leanne Annette, a client of ADACAS who has cerebral palsy and resides in an aged-care home, succinctly described the lack of control she has in relation to her own care needs:

My needs have to fit in with the care rather than the care having to fit in with my needs.³⁰

2.37 Carers Victoria also suggested that choice and control should be extended to the families of people with disabilities, commenting that the bill does not include any reference to families and what their role should or could be:

While the draft legislation recognises the autonomy and independence of individual adults with a disability and their right to choice and control,

27 Mrs May, ACT Disability Aged and Carer Advocacy Service, *Proof Committee Hansard*, 4 March 2013, p. 11.

28 Ms Walbank, Carers Queensland, *Proof Committee Hansard*, 30 January 2013, p. 3.

29 Ms Guilfoile, Private Capacity, *Proof Committee Hansard*, 18 February 2013, p. 26.

30 Ms Annette, Client, ACT Disability Aged and Carer Advocacy Service, *Proof Committee Hansard*, 4 March 2013, p. 12.

which we thoroughly support, it does not set a framework to accommodate what is reasonable and necessary for families to provide; nor does it set a framework, which probably needs to be elaborated in the rules, to be inclusive of considering the support services needed by both the person with a disability and their family. We think the legislation should promote the option of joint or family plans rather than masking family needs in a participant plan where that is a couple or family's preference and where families need direct support to sustain their caring role.³¹

2.38 Monica McGhie from People with Disabilities Western Australia gave compelling evidence to the committee through a poem she wrote to illustrate how the notion of choice and control over her decisions, activities, and risk taking is played out in her everyday life:

I have no legs, so I get a wheelchair,
 I love my wheelchair, it moulds to my shape
 It can change and adjust as I grow and develop
 It goes in the direction I choose
 It travels at my varying pace
 It follows my lead
 It is quick to respond
 I pick the destination and choose all the routes
 We have been on one-way streets, gone through red lights and arrived at dead ends
 This has helped me to grow and learn and become a better driver
 I have no arms, so I get a support provider
 I love my wheelchair
 It never tells me to eat my veggies, wear a hat, muzzle my dog, go to bed,
 not use my credit card, stop smoking and ask my friends to leave
 and it never refuses to pour me another drink.
 It never says, 'No, that's not in your best interest.'
 'I cannot be your friend because you are a client.'
 'I am going on holidays and there is no one to cover.'
 'My duty of care trumps'
 'You have a choice'
 'So that won't be happening.'
 'My manager says no.'
 and it never, ever tells me off.
 I love my wheelchair.³²

2.39 Dr Taleporos expressed concerns from a Victorian perspective that the NDIS might represent a backward step if it limited the choices of individuals:

I do not know if the committee is aware, but in Victoria people with disabilities have a right to choose whatever service that they need as long as it fits within their plan and their goals. I am concerned that the way the

31 Ms Pierce, Carers Victoria, *Proof Committee Hansard*, 20 February 2013, p. 38.

32 Miss McGhie, People with Disabilities Western Australia, *Proof Committee Hansard*, 18 February 2013, p. 39.

legislation has been drafted will be a backward step for Victorians, who currently have a lot more choice...They are able to employ their support workers directly. There are rules which they have to comply with – WorkCover and all the sorts of obligations that all employers have. That is available in Victoria. I want to see the freedom of choice that is available in Victoria extended across the country through the NDIS.³³

2.40 The concept of more choice and control for individuals with disabilities also presents challenges for disability service providers. The committee heard from providers about the challenges they faced in managing such a transformational change in how services are delivered and funded. Brett Edwards from Cootharinga in North Queensland explained the task ahead for his organisation:

Some of the key concerns and, I guess, opportunities and challenges for those individuals we support would be around self-direction, choice and control. The individuals we support have limited capacity to make some of those key decisions, so needing to support them and their families around a shift to self-direction we see is a fairly significant challenge. Looking also around the viability of those services currently, as we move towards individuals having more choice and control, a large portion of those individuals are in arrangements that are locked into block funding. An area is ensuring that we have viability around maintaining those supports for individuals but also enabling choice and control so that people can actually move as their lifestyles change, as their relationships change, as their needs change—so that we can accommodate that.³⁴

2.41 Peggy Campbell from Community Connection Inc., in Townsville also emphasised the scale of the task ahead for service providers:

In order for more traditional services to make the transition to an NDIS model of service, it will take a paradigm shift. Traditional services hold all of the power. They offer a service and the individual with a disability has to leave their life to get support. For example, a centre might have a spot available where that person can go from Monday to Friday, 9 am to 5 pm, and hang out with a whole heap of other people because that is the most cost-effective way to provide support, yet that person may want to go out and have everyday opportunities like everybody else and not go to a centre. They might have other interests that are not being satisfied if they go to the centre.³⁵

2.42 The potential tension between choice and control and the long term sustainability of a NDIS was an issue that was raised by the Association for Children with a Disability. They saw the balance being achieved through the Productivity Commission's idea of the Disability Service Organisation (DSO), which could provide

33 Dr Teleporos, Youth Disability Advocacy Service, *Committee Hansard*, 21 February 2013, pp. 38–39.

34 Mr Edwards, Cootharinga, *Proof Committee Hansard*, 29 January 2013, p. 10.

35 Ms Campbell, Community Connection Inc., *Proof Committee Hansard*, 29 January 2013, pp. 35–36.

the cost efficiencies required by having a whole-of-life focus on an individual, with the National Disability Insurance Agency (NDIA) provided the central source of funding:

The keys to NDIS's success is balancing the right to choice and control with efficient management. ACD proposes that a robust and effective link between the NDIA and direct service delivery must be the development of what the Productivity Commission called 'disability service organisations' on the one hand and a centralised fund management system that will achieve cost efficiencies.³⁶

Committee View

2.43 The committee became aware firsthand of the limitations some people with a disability can experience when their lives are regulated by those providing care. During a recent hearing as part of another inquiry the committee were unable to hear from four witnesses with disabilities because a single staff member of their residential care provider had called in sick and so they were unable to manage their transport requirements. It was a frustrating experience for everyone, illustrating what the committee heard many times throughout its inquiry.

2.44 The concept of choice and control is a welcome aspiration of the legislation but the committee is of a similar view to many of the submitters that this intent is not always backed up by the detail as expressed in a number of the bill's provisions. The specific clauses where the committee thinks the bill has not achieved an appropriate balance will be discussed in the following chapters.

The 'dignity of risk'

2.45 Another matter repeatedly raised during the inquiry, related to the concept of choice and control, was the right of individuals with disabilities to take risks, and occasionally make mistakes like everyone else in society. Ms Epstein-Frisch from Family Advocacy emphasised to the committee that it was important that participants were allowed to take the same risks as other members of the community:

Part of the issue is risk—that is the significant worry that people have—and who is taking that risk. If you have, within a definition of high-risk clients and high-risk services, provision for people to show that they can take responsibility themselves for those risks that should be enabled. Yes, there should be safeguards and regulations in services that potentially pose a risk to individuals and for clients that are very vulnerable, but there should be avenues that you can still show reasons that you do not need to avail yourself of those anticipated safeguards.³⁷

2.46 Similarly, Independent Advocacy Townsville argued that:

I guess it is about even when that choice may at time put people at risk – and I do not mean huge risk or huge harm. I think there needs to be more

36 Mrs McGarry, Association for Children with a Disability, *Proof Committee Hansard*, 20 February 2013, pp. 18-19.

37 Ms Epstein-Frisch, Family Advocacy, *Proof Committee Hansard*, 31 January 2013, p. 47.

about people being able to make decisions and make mistakes, just like everyone else in the community. I think the bill needs to elaborate on the fact that people with disabilities can and do make decisions and, even if that means at times making mistakes, people with diminished decision-making ability also need to be able to make mistakes.³⁸

2.47 The committee heard that the underlying presumption should be that participants are capable of making the right choices for their own situation:

In the rules [discussion paper] I notice that it is 'should' dignity of risk underlie this whole thing about who can negotiate a plan and manage their plan. Absolutely, the default needs to be that we start from a point that people can do this. All we need to do then is consider with people what support can make that happen. Some will need none; some will need a lot; some will need something on a whole continuum in between. It has to be underpinned with a level of dignity of risk that says people have the right to do this.³⁹

2.48 It was put to the committee that the benefits of being able to make mistakes tend to outweigh the negatives of the mistakes themselves:

I think that there is often a concern that we need to make sure that bad things do not happen, but the real world is what it is. We know that people with disabilities want to live in the real world. We do not want to live in a world that is made up of hundreds of thousands of rules that prevent us from taking any risks. Sometimes risk leads to good outcomes and sometimes it lead to bad things happening – but we feel that the benefits definitely outweigh the risks.⁴⁰

2.49 The department responded to the committee that the intention is not to 'constrain' people by risk averse decision making:

The Department recognises that a decision to deny a participant's request that they manage all or a part of the supports in their plan needs to be handled with care in order to fulfil the objective that the Scheme enable people with disability to exercise choice and control in the pursuit of their goals and the planning and delivery of their supports. In most cases this decision will be based on Section 44(2)(a), and that section provides that the threshold 'unreasonable risk to the participant' has to be crossed before the CEO can decide that a participant cannot manage all or part of the supports in their plan. The NDIS rules made pursuant to Section 44(3) have been designed also to ensure that this decision is only made after a rigorous risk assessment process that includes consideration of other safeguards that can be built around the participant. The Department is confident that the

38 Ms Spelling, Independent Advocacy Townsville, *Proof Committee Hansard*, 29 January 2013, p. 24.

39 Ms Pearman, Western Australia Individualised Services, *Proof Committee Hansard*, 18 February 2013, p. 44.

40 Dr Teleporos, Youth Disability Advocacy Service, *Proof Committee Hansard*, 21 February 2013, p. 39.

operation of this section will, in practice, ensure that people with disability are not constrained by risk averse decision making, and that decisions to limit the control and choice for a participant in relation to the management of their plan are only made when there is an unreasonable risk to the participant that cannot be addressed through other measures.⁴¹

2.50 There is an ongoing tension however between the desire for people to be free to make mistakes, and the importance of ensuring quality of care as more providers enter the market. The Queensland Alliance for Mental Health argued for the necessity of appropriate regulation:

But the bill needs to demonstrate that providing people choice of service will not compromise the quality of these services. Quality and risk management systems will need to be in place, we think, to ensure that people can enjoy the opportunity of choice, regardless of what option is chose, and also to be confident that they will continue to receive quality services.⁴²

Committee View

2.51 The committee agrees with the majority of submitters who promoted the idea of risk being managed by individuals wherever possible. This should flow from assessments of the capacity of people to manage their own affairs, based on objective assessments of their abilities. While accepting the assurances from the department that the risk assessment will include the 'consideration of other safeguards that can be built around the participant' that will still allow them to manage their own affairs, the committee is of the view this should be included in the general principles of the bill to ensure it underpins these processes.

2.52 The committee is supportive of the risk being managed by the individual where the individual has been assessed as being able to control their own funds. Being free to make mistakes requires that people are able to employ the people they wish to provide the services they need. The 'quality and risk management' assurances when risks are managed by the individual are the same that operate for the rest of the community: the importance of a business's reputation, the requirement to adhere to occupational health and safety legislation, and compliance with relevant industry and government guidelines and regulations.

Recommendation 4

2.53 The committee recommends that subclause 4(4) of the bill be amended to read:

(4) People with disability should be supported to exercise choice and control and manage the associated risk in the pursuit of their goals and the planning and delivery of their supports.

41 FaHCSIA, *Proof Committee Hansard*, 5 March 2013, p. 35.

42 Mr Nelson, Queensland Alliance for Mental Health Inc., *Proof Committee Hansard*, 30 January 2013, p. 14.

Accessibility

2.54 Several witnesses noted the language in several clauses, such as 7(2), that referred to things being done orally and/or in writing, and queried whether this kind of language was the most appropriate way to prescribe communication, given the diverse communication needs of people with disability.⁴³

2.55 The Federation of Ethnic Communities' Councils of Australia (FECCA) suggested that Clause 7(2) be amended to refer to modes of communication rather than oral and writing:

An explanation given under subsection (1) must be given **in more than one format accessible to the participant** ~~both orally and in writing~~ if reasonably practicable.⁴⁴

2.56 The Bolshy Divas pointed out to the committee that there appeared to be very little material produced that provided information on the various aspects of the bill in an easy-to-understand format:

One of the things that we were particularly concerned about with the legislation—and we understand that all legislation is pretty inaccessible in its language—was that there appeared to be very little attempt to produce information about the legislation in language that the average person can understand. There was an easy English overview, but there was so little in that that it was hard to find anything to comment on. It was left up to people with disability and their families to themselves produce some plain-language information about the legislation.⁴⁵

2.57 Independent Advocacy Townsville also remarked on the importance of appropriate communication in underpinning accessibility for individuals with disabilities:

Things like choice and control that people with disabilities need to exercise at all levels of accessing the NDIS are really important. It goes right down to the language that is used in the bill. It concerns us that 'best interests' is used in the bill when most of us in society do not make decisions based on best interests. It is about our interests. It sounds like semantics, but that is really important in talking about people with disabilities being able to exercise their right to choose.⁴⁶

2.58 Heidi Forrest suggested that the general principles of the bill should include something similar to the Victorian Disability Commissioner's recommendations:

[We] would also like to see the inclusion of a few other General Principles that were recommended in the submission to the Senate Inquiry from the Victorian Disability Services Commissioner:

43 FECCA, *Submission 551*, pp. 5–6.

44 FECCA, *Submission 551*, p. 6.

45 Ms Softly, Bolshy Divas, *Proof Committee Hansard*, 18 February 2013, p. 33.

46 Ms Spelling, Independent Advocacy Townsville, *Proof Committee Hansard*, 29 February 2013, p. 23.

- a. People with disability have the right to access information and communicate in a manner appropriate to their communication and cultural needs.⁴⁷

2.59 The National Ethnic Disability Alliance (NEDA) submitted that there should be a commitment in the Objects of the Act that recognises the barriers faced by people from both Aboriginal and Torres Strait Islands communities and people from culturally and linguistically diverse (CALD) backgrounds, and ensures equitable access for those people:

NEDA recommends for the Bill to acknowledge the additional barriers that people from NESB/CALD communities with disability may face. *NEDA further supports a comment from its member organisation, AMPARO Advocacy to include the following point to this section:*

- (i) Ensure equitable access to the NDIS by people with disability who may experience additional barriers, including Aboriginal and Torres Strait Islanders and people from culturally and linguistically diverse backgrounds.⁴⁸

2.60 NEDA also pointed out that there are often cultural issues around gender that can add to discrimination, particularly against women, and that this should be guarded against in the bill, particularly in relation to clause 5 where the principles guiding actions on behalf of another person are set out:

...refer to 5 (a), in consideration of gender and cultural roles, and the limits that are placed by the law in which “a person with disability can be involved in decision making processes ‘*where possible*’ it is crucial to understand that gender may affect women from NESB/CALD backgrounds with disabilities due to traditional expectations of gender roles in which they are often at risk of exploitation and negligent treatment from their male counterparts; and men may manipulate their power in making the decisions for women from NESB/CALD backgrounds with disabilities.

2.61 NEDA recommended the inclusion of 'gender' to paragraph 5(d) to offer some protection.

Committee View

2.62 The committee agrees that the range of communication needs should be recognised, and it believes subclause 7(1), which is an overarching requirement for all communication relating to the legislation, addresses this. That clause requires all significant information to be provided 'to the maximum extent possible to the person in the language, mode of communication, and terms which that person is most likely to understand'.

2.63 The committee agrees with NEDA's suggestion that gender should be considered in a cultural context as part of the principles that guide the actions of people representing others.

47 Ms Forrest, *Submission 495*, p. 4.

48 National Ethnic Disability Alliance, *Submission 614*, p. 3.

2.64 The committee was supportive of the suggestion by the Bolshy Divas that there should be more information available in a format that is easily understood by those it is intended to affect. While the committee does not think it practical to translate legislation itself into Easy English it believes there is significant scope for the provision of various associated documents and explanatory material in such a format.

Recommendation 5

2.65 The committee recommends that clause 5(d) be amended to read:

- (d) the cultural and linguistic circumstances and gender of people with disability should be taken into account.**

Recommendation 6

2.66 The committee recommends that all explanatory material associated with the operation of the NDIS Scheme be provided in an easy-to-understand format such as Easy English.