

National People with Disabilities and Carer Council

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Mr Ian Holland
Secretary
Standing Committee on Community Affairs – Legislation Committee
Parliament House
Canberra ACT 2600
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Inquiry into the National Disability Insurance Scheme Bill 2012

Dear Mr Holland

Please find attached the written submission by the National People with Disabilities and Carer Council to the above Inquiry into the National Disability Insurance Scheme Bill 2012 (the Bill) addressing issues of importance to the Council.

Council appreciates the opportunity to provide a submission to the Inquiry into the Bill and would also value the opportunity to give evidence at the upcoming public hearings.

Council considers that a key goal of the National Disability Insurance Scheme (NDIS) is to bring about cultural change that then leads to structural and systems change towards advancing the participation of people with disability in Australian society. The Council therefore considers that it is essential that attention be paid to the 'culture' of the Act so that the NDIS drives real change in delivery of services and support for people with disability.

In this regard, Council's strong view is that an NDIS is not just about individual packages – it needs to empower people and communities to make changes that create greater community participation and full integration.

Alternatively, the Council is concerned that an NDIS could inadvertently end up expanding segregated services and paying for provision that should come from mainstream systems.

In this regard, Council considers that strong interface arrangements with mainstream sectors is a critical factor in the financial sustainability of the NDIS, as well as enabling people with disability to participate as fully as possible in their communities. This was described by the Productivity Commission in numerous places in their inquiry report; for example:

...regardless of the scope and size of the NDIS, it will always be just one part of a broader suite of services that are potentially relevant for people with disability. There will be....a need for mainstream services in such areas as health, housing, education, transport and employment.¹

The NDIS is a major reform under the National Disability Strategy (NDS) - the Strategy that reflects COAG's plan to improve citizenship for people with disability over a 10-year period. The NDIS should provide significant leverage for the NDS. However, there is the need to not only guard against cost shifting to the NDIS, but also ensure that all mainstream sectors relevant to the participation of people with disability in integrated life increase their capacity and offerings to people with disability in line with government NDS commitments.

I look forward to hearing from you on a suitable date for Council to address the Committee, preferably in Canberra on either 4 March or the morning of 5 March 2013.

Yours sincerely

Dr Rhonda Galbally AO

Chair

29 January 2013

¹ Page.163, Volume 1, Productivity Commission Inquiry Report: Disability Care and Support.

CONTENTS

Chapter 1- Introduction	7
Part 2 – Objects and principles	7
RECOMMENDATIONS.....	7
Section 3 – Objects of Act.....	7
Section 4 - General principles guiding actions under this Act.....	8
Section 5 - General principles guiding actions of people who may do acts or things on behalf of others.....	8
Chapter 2- Assistance for people with disability and others.....	9
Section 13 - Agency may provide coordination, strategic and referral services etc. to people with disability <i>AND</i> Section 14 - Agency may provide funding to persons or entities	9
RECOMMENDATION	10
RECOMMENDATION	11
Chapter 3 - Participants and their plans	12
Part 1 – Becoming a participant.....	12
Section 22 - Age requirements	12
RECOMMENDATIONS.....	12
Section 25 - Early Intervention requirements	13
RECOMMENDATIONS.....	13
Section 29 – When a person ceases to be a participant	14
RECOMMENDATION	14
Part 2 – Participants’ plans.....	15
Section 31 - Principles relating to plans:.....	15
RECOMMENDATION	15
Section 32 – CEO must facilitate preparation of a participant’s plan	15
RECOMMENDATIONS.....	16
Section 33 - Matters that must be included in a participant’s plan.....	16
RECOMMENDATION	17

Section 37 – When plan is in effect	17
Section 42 – Meaning of <i>managing the funding for supports</i> under a participant's plan.....	17
Section 43 – Choice for the participant in relation to plan management	17
RECOMMENDATIONS.....	18
Section 45 - Payment of NDIS amounts	18
RECOMMENDATION	19
Chapter 4 - Administration.....	20
Part 3 - Registered providers of supports.....	20
Section 70 - Registered providers of supports	20
RECOMMENDATIONS.....	21
Part 4 - Children.....	21
Section 74 – Children.....	22
RECOMMENDATIONS.....	22
Part 5 – Nominees	23
RECOMMENDATIONS.....	24
Part 6 - Review of decisions	25
RECOMMENDATIONS.....	26
RECOMMENDATIONS.....	26
RECOMMENDATION	27
Chapter 5 - Compensation payments	28
Part 1 - Requirement to take action to obtain compensation.....	28
Section 104 - CEO may require person to take action to obtain compensation.....	28
Section 105 - Consequences of failure to comply with a requirement to take action to obtain compensation.....	28
RECOMMENDATIONS.....	29
Part 3 – Recovery from compensation payers and insurers	29
Sections 109-115.....	29
RECOMMENDATION	30
Chapter 6 - NDIS Launch Transition Agency	31
Part 1 - NDIS Launch Transition Agency	31
Section 118 – Functions of the Agency.....	31
RECOMMENDATIONS.....	31

Part 2- Board of the Agency31
 Section 127 – Appointment of Board members31
 RECOMMENDATIONS.....31
 RECOMMENDATION32
Part 3 - Independent Advisory Council33
 RECOMMENDATION33

National People with Disabilities and Carer Council

Inquiry into the National Disability Insurance Scheme Bill 2012

Submission by the

National People with Disabilities and Carer Council

The National People with Disabilities and Carer Council (Council) provides advice to the Australian Government on issues affecting people with disability, their families and carers and services in Australia.

The Council, chaired by Dr Rhonda Galbally AO, consists of 28 members, including the Chair. Members are leaders with a diverse range of backgrounds and experience. The Council includes people with disability and their families, carers, the service sector, industry and union representatives, academics and Indigenous Australians with disability.

The formation of the Council in 2008 created a single advisory body on the inter-related issues of disability, caring and service relationships, systems and reform.

The Council is tasked with:

- Providing advice and information to the Minister and Parliamentary Secretary on issues affecting people with disability, their families and carers in Australia.
- Providing advice and information to the Minister and the Parliamentary Secretary on the implementation of the National Disability Strategy and the National Carer Strategy.
- Consulting and providing input to the design and development of key reforms to improve services and access to services for people with disability.
- Provide advice on specific matters referred to it by the Minister and Parliamentary Secretary.

Council makes the following comments on the National Disability Insurance Scheme Bill 2012.

CHAPTER 1- INTRODUCTION

PART 2 – OBJECTS AND PRINCIPLES

The Council's view is that the National Disability Insurance Scheme Bill 2012 (the Bill) needs considerable strengthening in support of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).

In particular, Council is concerned that a misunderstanding of control and choice could be reflected in the existing wording. The Bill properly gives people with disability choice over life goals and service selection. Council's concern is, however, that if services themselves are not reformed to deliver more integrated models, people will be forced to 'choose' what is available; that is to be segregated from the community, facing segregation and restrictions in all aspects of daily living.

RECOMMENDATIONS

1. Council recommends that the National Disability Insurance Scheme Bill 2012 (the Bill) needs considerable strengthening up front in support of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).
2. Council therefore recommends that the current list of "Objects of the Act" elevate the fulfilment of the UNCRPD to the primary position at the top of the list.
3. In addition, in order to ensure that all participants are afforded to same opportunity for choice and control, Council recommends that the Bill should provide participants with the opportunity to take responsibility for the reasonable risks they might wish to take, similar to all citizens.
4. Council further recommends considerable strengthening of the program goal of maximising independence and inclusion, with all necessary and reasonable supports.
5. Council recommends the following amendments under Chapter 1, Part 2 of the Bill:

SECTION 3 – OBJECTS OF ACT

S3(1): Insert after (d) "Value the decisions made by people with disability and acknowledge their right to make decisions that may involve risk in living similar to all citizens".

S3(1)(f): Amend to "promote the provision of high quality and innovative supports that enable/support people with disability to maximise independent lifestyles and maximise full inclusion in the mainstream community".

SECTION 4 - GENERAL PRINCIPLES GUIDING ACTIONS UNDER THIS ACT

S4(4): Amend to read “People with disability should be supported to exercise choice, including the ability to take reasonable risks, in the pursuit of their goals and the planning and delivery of their supports”.

S4(11): Amend by adding a new section (b) and making changes to (c) to read “Reasonable and necessary supports for people with disability should:

- a) support people with disability to pursue their goals and maximise their independence;
- b) support people with disability to live as independently as possible and to be included in the community as fully participating citizens; and
- c) develop and support the capacity of people with disability to undertake activities that enable them to participate in the mainstream community and in employment.”

SECTION 5 - GENERAL PRINCIPLES GUIDING ACTIONS OF PEOPLE WHO MAY DO ACTS OR THINGS ON BEHALF OF OTHERS

S5(a): Amend to read “People with disability will be involved in decision making processes that affect their lives and make decisions for themselves. Support to do so will be provided where necessary.”

CHAPTER 2- ASSISTANCE FOR PEOPLE WITH DISABILITY AND OTHERS

SECTION 13 - AGENCY MAY PROVIDE COORDINATION, STRATEGIC AND REFERRAL SERVICES ETC. TO PEOPLE WITH DISABILITY AND SECTION 14 - AGENCY MAY PROVIDE FUNDING TO PERSONS OR ENTITIES

Building the capacity of people with disability: the importance of disability support organisations

The Agency has indicated that people eligible for the NDIS will be allocated a Local Area Coordinator (LAC) as their point of contact with the NDIS and the community. The LAC is the voice of the Agency in the community, providing information and support to applicants and participants to access available services, both disability specific and mainstream. While LACs will provide vital assistance, in the light of the level of caseload proposed for LACs, Council considers that it would not be realistic to suggest extending this important role.

However, Council believes that the opportunities anticipated in the NDIS will only be realised if people with disability have the opportunity to build their capacity to aspire, explore pathways, plan and implement support, with the technical 'know how' associated with living ordinary lives in the community. For example, capacity building is needed to develop informal supports, locate and negotiate with potential house sharers and developing personal safeguards. Council identifies this as an essential role which has not currently been identified or assigned to a group of providers.

The Productivity Commission Inquiry Report: *Disability Care and Support* (Productivity Commission Report) suggested that people could choose to use Disability Support Organisations (DSOs) (Box 9.2)² to:

- provide them with personal planning services over and above what they obtain from the NDIS
- help them get the best value from their self-directed funding, once that has been determined under NDIS procedures
- help them develop the skills and confidence to practically exercise choice
- provide them with information of the quality and choice of support services available from specialist and mainstream providers
- assemble 'packages' of supports from specialist and mainstream providers
- assemble 'packages' of supports from specialist and mainstream providers
- undertake administrative tasks such as record-keeping and tax returns.

² Page 416, Volume 1, Productivity Commission Inquiry Report: Disability Care and Support

RECOMMENDATION

6. Council recommends the development of DSOs as foreshadowed by the Productivity Commission to help build capacity of people with disability.

Council considers that DSO support for individuals will increase the capacity of people with disability to research, develop and implement their own plans, particularly critical in the early days of the NDIS when so few people have had any real experience in choice and control. This will reshape what people with disability seek for their support, moving people from dependent users of services to people with capacity where initiative is rewarded.

The building of capacity is critical in that it will, in turn, lead to significant service reform generated from demand for a more informed and empowered target population. DSOs are well placed to undertake this essential sector and community wide capacity building.

DSOs: Building Community Capacity and improving linkages

In addition, DSOs could take on the complementary tasks relating to facilitating community capacity building and encourage greater inclusiveness with:

- *community brokerage*: DSOs could help people with disability to find businesses, community groups or social events that match their own interests and which are able to adapt their activities (if necessary) to any particular requirements associated with the person's disability.
- *community capacity building*: DSOs could develop expertise in advising mainstream businesses and community groups about how to become more accessible to people with disability by offering advice on how to upgrade facilities and train staff, as well as how to overcome stereotypes and misconceptions about disability.
- *community awareness*: DSOs could be involved in activities that, directly or indirectly, increase awareness about disability issues and that help engage community involvement with people with disability.

The Bill anticipates the role of DSOs in supporting individuals in:

- Section 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."
- Section 4(9) "People with disability should be supported in all their dealings and communications with the Agency so that their capacity to exercise choice and control is maximised in a way that is appropriate to their circumstances and cultural needs."
- Section 13(2)(b) where the definition of *general support* is "an activity engaged in by the Agency in relation to a person".

However, Council believes that the role of the DSO needs to be more clearly stated in the legislation. This could be achieved by a specific reference in Section 13 and/or 14.

RECOMMENDATION

7. Council recommends that the community capacity building roles of DSOs as anticipated in Section 31(f) is implemented via designated provision under Section 13 and 14. This could provide the authority to fund roles in capacity building of people with disability and families, community capacity building and community awareness.

CHAPTER 3 - PARTICIPANTS AND THEIR PLANS

Council recognises that the planning process for participants in the NDIS is pivotal in the achievement of the scheme objectives. The planning process is clearly described in the Bill; however, Council has some particular concerns as outlined below.

PART 1 – BECOMING A PARTICIPANT

SECTION 22 - AGE REQUIREMENTS

To meet the age requirements for the NDIS, Section 22 (1)(a) indicates that the person must be aged under 65 years when the access request is made. The age limit will create inequity among people with disability, with access to services depending on when they acquire their disability rather than their need for support. Reducing this inequity will require substantial reform of the aged care system and improvement of the interface between the NDIS and the aged care system.

Compared with the supports envisaged under the NDIS, supports available from the aged care system:

- are more severely rationed with a relatively low average funding package;
- provide a more restricted suite of options, with key gaps including assistive technology;
- are less focused on community participation and more on personal care and in-home support; and
- entail means-tested payment of fees.

The Council believes Section 22 should be revised to allow enough flexibility to enable the NDIS to support those people over 65 with severe and profound disability whose disability care and support needs cannot be met by the aged care system and/or other community service systems. Council is aware of the significant financial risk to the NDIS should this provision be applied widely. However, Council notes that the Productivity Commission Report has already identified a small group of people who would benefit considerably if supported by the scheme but do not meet other scheme eligibility requirements (Tier 3(c))³.

RECOMMENDATIONS

8. The Council recommends that urgent reform is required to improve the provision of disability-related support services to people in the aged care system.

In particular, services that support the independence and full participation of older people - such as mobility and orientation training for people who are losing their vision and assistive technology – should be made available through aged care funding mechanisms. Improved access to such services may also potentially reduce the need of older people for intensive personal support.

³ Page 160, Volume 1, Productivity Commission Inquiry Report: Disability Care and Support.

9. The Council recommends the Bill be amended to require the NDIS to closely collaborate with health and aged care, towards co-funding arrangements, including sharing support costs and care of those whose needs cannot be met outside the NDIS.

SECTION 25 - EARLY INTERVENTION REQUIREMENTS

The early intervention requirements acknowledge the importance of investing to maximise function and reduce a person's future need for supports. However, Section 25(c) needs a minor but important adjustment. It states:

- (c) the CEO is satisfied that the provision of early intervention supports for the person is likely to:
 - (i) mitigate, alleviate or prevent the deterioration of the functional capacity of the person to undertake communication, social interaction, learning, mobility, self-care or self-management;

This clause fails to reflect the situation of young children who may not yet have developed functional capacity in those areas and need therapy to develop that capacity.

Mitigating Perverse Incentive

Under the proposed arrangements outlined in the Bill, there would be a perverse incentive for people with degenerative conditions who were approaching 65 years to exaggerate their functional incapacity in order to gain access to the NDIS.

As one example, under its early intervention provisions (Section 25), the NDIS could allow access for people who have a diagnosis of a listed degenerative condition (such as motor neurone disease, multiple sclerosis or post-polio syndrome), even if at age 65 they do not yet need formal support services. If the NDIS Launch Transition Agency (the Agency) accepted that people with these conditions are likely to deteriorate in coming years (to a point where they would require services) they could be deemed a participant, but have planning for support suspended.

RECOMMENDATIONS

10. Council recommends Section 25 (c)(i) should be amended to include the phrase: "or build the functional capacity of the person".
11. Consistent with the UNCRPD, Council recommends that Section 25 allows for people with a diagnosis of a listed degenerative condition to join the NDIS through early intervention provisions and that therefore, no age limit is placed on becoming a participant for people with a listed degenerative condition.

However, recognising the financial impact of this proposed amendment on the NDIS, Council recommends the compromise that a time limit apply to the plan suspension (such as, the participant would need to be receiving supports by the age of 70 or they would cease to be a participant).

SECTION 29 – WHEN A PERSON CEASES TO BE A PARTICIPANT

Young people in Nursing Homes

Section 29(1)(b) states that a person ceases to be a participant in the NDIS launch when “the person is aged at least 65 years and has entered a residential care service, or is being provided with community care, on a permanent basis”.

As the Younger People In Residential Aged Care (YPIRAC) initiative shows, many people age beyond notional age cut off points while they wait for a response. The fact that the NDIS is set for full operation in 2018 will mean that many people eligible for the scheme and living in aged care homes or in receipt of aged care supports now, may well have aged beyond 65 waiting for the scheme to become operational.

All people aged under 65 years and currently living in residential aged care or receiving community aged care services should have access to NDIS-funded supports.

If, because of a lack of appropriate alternative options, they remain living in residential care beyond the age of 65, they should be eligible to continue in the NDIS and receive additional supports. In particular, the person should at least be able to retain the use of any NDIS-funded assistive technology.

The Council is aware that such a provision may necessitate other provisions for shared funding arrangements for the total support of a participant and is supportive of the NDIS part funding a participant’s total support needs in such cases.

RECOMMENDATION

12. In relation to Section 29 (1)(b), Council recommends that individuals under 65 years of age (including those using aged care services, whether residential care or community care services) retain scheme eligibility if they age beyond 65 years and that this be provided as an exception in this section.

PART 2 – PARTICIPANTS’ PLANS

SECTION 31 - PRINCIPLES RELATING TO PLANS:

Council considers that efforts to build or sustain capacity of families and carers should be applicable at all times. It is important that the plan provides the context for the provision of services relevant to the stated goals and aspirations of the participant.

RECOMMENDATION

13. Council recommends the following amendments under Part 2, Division 1, Section 31 of the Bill:

S31(d): amend to read “Strengthen and build capacity of families and carers to support participants”.

S31(k): amend to ensure that the plan coordination includes “community services” as well as disability services and to ensure accountability for the delivery of those mainstream services to meet the individual’s plan.

SECTION 32 – CEO MUST FACILITATE PREPARATION OF A PARTICIPANT’S PLAN

Distinguishing between high-level planning by the Agency with the need for independent day-to-day planning to be undertaken by DSOs

Council believes that the high-level role designated for the Agency in planning for assessment, e.g. to move out of the family home, to get a job, is not the same as the need to assist participants with the detail of ongoing planning.

Specifically, the Council is aware that the Agency will act as both a plan manager and fund holder for an individual (Chapter 3, Divisions 2 & 3). The Council recognises that this is important because the Agency has responsibility for the financial viability of the NDIS and hence must be mindful of the level of funding of each participant.

However, Council believes that people with disability need to also have support from external planners in order to ensure that all information and consideration is included in the high level planning session with the Agency. In addition, external planners would help to identify changing needs that can in turn be brought to the attention of the Agency.

The ultimate decision as to what to fund is the Agency’s, but Council considers that the best decision would be reached if there is the opportunity for additional information to be brought to the planning sessions to assist in decisions about what is reasonable and necessary to assist the person with disability to live the fullest life in the community.

Developing this role for DSOs in external day-to-day planning would be an effective way of assisting participants to undertake detailed planning before and after (in response to changing needs) the high-level planning and assessments with the Agency. In addition, many DSOs will become designated plan managers.

Many participants will need considerable support from day-to-day DSO planners to be ready to develop their goals in a formal way with the Agency. Engagement in the minutiae of independent planning may take months or years. The onus should be on the Agency to provide support via DSO's necessary for this process.

Further to the need for the scheme to facilitate participant's community engagement, Council believes that Section 32 not only needs to require the Agency to facilitate the preparation of the participant's plan, but also to facilitate its implementation. This would result in an improved focus on locating the participant's plan in the context of a life beyond disability services, and capitalising on the community-building imperative of the scheme.

RECOMMENDATIONS

14. Council recommends that DSOs undertake the function of detailed, on-going, day-to-day planning and that the Agency should maintain the high level-planning role. Day-to-day planning should be delegated to organisations that are independent of the Agency and of service providers. This could be achieved by the addition of a new Section 32(3) indicating "The CEO may provide assistance to enable people with disability to prepare a plan".
15. Council recommends that Section 32 not only needs to require the NDIS to facilitate the preparation of the participant's plan, but also to facilitate its implementation. This would result in an improved focus on locating the participant's plan in the context of a life beyond disability services, and capitalising on the community-building imperative of the scheme.

SECTION 33 - MATTERS THAT MUST BE INCLUDED IN A PARTICIPANT'S PLAN

Council supports a goal based planning methodology, as it is essential that participant plans are developed specifically around the needs, aspirations and choices of individuals, their families and networks.

However, Section 33 attempts to oblige the Agency to include the goals and aspirations of the participant in a very formal way. This section could be reworded to make clearer that the obligation is on the scheme and not necessarily on the individual.

As outlined above in Section 32, Council reiterates that the Agency should only undertake planning at the high level associated with the acceptance of goals and the determination of funds to implement those goals.

Section 33(6) also states that:

To the extent that the funding for supports under a participant's plan is managed by the Agency, the plan must provide that the supports are to be provided only by a registered provider of supports.

This interfaces with Section 70 regarding levels of risk when determining if safeguards are needed and/or a registered provider (for a particular class of supports) should be used.

RECOMMENDATION

16. Council recommends that Section 33(6) be amended to require that when a plan is managed by the Agency or by a plan management provider, a 'registered provider' will be required for certain classes of support. This would ensure that the Agency or plan management provider uses only registered providers for some types of services or support while allowing generic services to be sourced more broadly. *See more information under Section 70.*

SECTION 37 – WHEN PLAN IS IN EFFECT

Under Section 37(2) Council is concerned that a plan cannot be varied but needs to be replaced when a variation is approved. Council is concerned that this appears to be overly rigid given that life can be unpredictable. Council believes that it is important that there is capacity provided in the legislation or the NDIS rules around participant plans to allow flexibility and variation to occur with Agency approval.

Council is also concerned that there needs to be clear recognition of the degree to which participants can alter service delivery as the plan is being implemented. This flexibility is at the very core of the notion of individualised services and plans, so provision needs to be made for variation within the plan.

SECTION 42 – MEANING OF *MANAGING THE FUNDING FOR SUPPORTS UNDER A PARTICIPANT'S PLAN*

SECTION 43 – CHOICE FOR THE PARTICIPANT IN RELATION TO PLAN MANAGEMENT

The Bill seeks to provide authentic choice and control to participants, assisted in this aspiration by Section 42(2)(a) that enables participants to manage their own funds or have their plan nominee do so on their behalf (Section 42(2)(b)).

People who are able to manage their own plan are then authorised to do so under Section 43(1)(a) but those who need assistance are required to use a registered plan management service or the Agency.

Council believes that the function of plan management should also be available for plan nominees. Through the many self-managed options available to people with disability in NSW, many family members currently manage the supports of their family member in a most capable manner and should be enabled to do the same under the NDIS.

Section 42(2) and Section 43 also enable registered service providers to be appointed as plan management providers for participants they also provide services to. Council is concerned that the lack of separation of plan management and service provision gives rise to a conflict of interest and the risk of participants being captured by support providers who may give advice to stay with their current offering of segregated services, which in turn would mitigate against services reforming and developing new service offerings that support people with disability to participate as fully as possible in the mainstream community.

This risk needs to be carefully managed to ensure that the choices open to participants are not, in practice, limited to their current service provider and current segregated service offerings.

Reforming the disability sector and the disability provider market is a key reform objective of the NDIS. Allowing service providers to combine plan management and service delivery could undermine this reform imperative.

It is therefore important that, wherever possible, participants have the option of an independent plan manager and that a plan manager is required always to disclose in a comprehensive and accessible way its interests, including its financial interests, to the participant.

Council recognises that in some circumstances, the Agency will need to engage in market development to ensure that participants have access to an independent plan manager.

In this regard, Council believes that it is the responsibility of the Agency to locate the plan management provider for a participant anywhere in Australia, with as far as is possible, the separation of the planning and service provision as a central tenet of the scheme design.

In particular, Council understands that the paucity of services in rural and regional Australia may require a different approach to the recommended separation of plan management from service delivery.

In addition, Council recognises that some participants, regardless of their location, may want the organisation that provides them with support also to manage their plan. The Agency should, however, have the power to deny a participant that choice if it believes that the organisation will exert influence over the participant that is contrary to the objects and principles of the Act.

While it is the preference of Council that the functions of plan management and service provision are separated, it is recognised that in the early stages of scheme rollout, the lack of independent plan management services makes this a challenge.

RECOMMENDATIONS

17. Council recommends that Section 43(1) include the additional provision of enabling a plan nominee, where requested by a participant, to manage the participant's plan.
18. Council recommends that where possible plan management is separate from service provision to avoid conflict of interest situations.
19. Council recommends that a practical solution to the development of independent plan management capacity in Australia is to focus on defining this as part of the role of DSO's as a matter of priority.

SECTION 45 - PAYMENT OF NDIS AMOUNTS

While the notion of individual plans and resources requires the individual to have control over resources, Council believes that other payment arrangements may be more viable than simply transferring cash amounts into nominated bank accounts. With the variety of financial and e-commerce products available, this section may be limiting as to the options available to both the participant, plan management provider or the scheme itself.

It is feasible that a participant could have full control of their plan and its implementation, but the NDIS makes the transactions with providers via the use of a swipe card or e-invoices. This type of system is in place with private health insurers and other compensation schemes. Optimal control and choice is still possible for participants with a number of purchasing options.

Bulk purchasing and pricing

The decentralisation of service purchasing has many advantages for scheme participants and provides a degree of financial certainty for the scheme, but does compromise the scheme's ability to take advantage of bulk purchasing opportunities for assistive technology and consumables, undertake comprehensive pricing negotiations with provider bodies or to implement a range of provider management activities.

RECOMMENDATION

20. Council recommends that the legislation or the Rules to the legislation provide the capacity to enable investigation of bulk purchasing schemes, similar to PBS cost plus pricing.

CHAPTER 4 - ADMINISTRATION

PART 3 - REGISTERED PROVIDERS OF SUPPORTS

SECTION 70 - REGISTERED PROVIDERS OF SUPPORTS

Section 70 empowers the Agency to approve a person or entity as a registered provider of supports. The criteria for registration will be prescribed in the NDIS Rules and may specify that the person or entity is a registered provider of supports in respect of “a class of supports” or “a class of person”.

There are four areas of risk that should be considered when determining if safeguards are needed and/or a registered provider (for a particular class of supports) should be used:

- *participant-related*: e.g. vulnerable participants whose disability or circumstances puts them at increased risk of abuse, neglect or exploitation.
- *service-related*: e.g. supports that require specialist skills or involve personal contact with participants, such as personal support, positive behaviour support, high medical support needs or specialised therapies.
- *cost-related*: e.g. significantly expensive items such as some equipment or extensive staffing requirements.
- *market readiness or maturity*: this is a transition risk where prior to providers or participants developing a sophisticated understanding of how to market to, or wield, consumer power there is a risk of exploitation of market weaknesses to the detriment of participants.

The level of regulation should reflect the level of risk and higher safeguards should operate for more vulnerable individuals and situations (as noted in the four risk factors above). This could occur through stipulating (in the NDIS Rules) the broad categories of support or client circumstances where registered providers must be used.

Regulation by the Agency should, at a minimum:

- ensure that appropriate safety screening and monitoring of personal support workers is undertaken.
- ensure support workers are appropriately skilled for the support they provide.
- require registered providers to be accredited as complying with the Disability Service Standards.
- require that registered plan management or provider organisations manage support staff in circumstances where the employment arrangements are complex and/or where the participant has insufficient knowledge or capacity to manage the duties of an employer (developing this capacity could be built into a participant’s plan).
- require at a minimum that any provider being engaged with NDIS funds has public liability insurance.

Participants should have choice of the person or entity that will manage their plan as well as choice of support providers. As long as plan management providers that are independent of service providers are available, a participant should be free to choose a registered service provider to manage their plan.

Council believes that not every support available under the NDIS should necessarily be provided by a registered provider of supports (for instance, the Agency could agree to make some provision for transport, gardening or cleaning which could be sourced from generic providers). However, support that is personal or highly-skilled (such as personal care, community participation, complex behaviour support and early intervention therapies) should be sourced from registered providers of supports. See Section 33(6) for recommendation related to this issue.

RECOMMENDATIONS

21. Council strongly recommends that the NDIS legislation and Rules should take a risk-management approach rather than a risk-averse approach.
22. Based on the areas of risk that should be considered when determining if safeguards are needed and/or a registered provider is needed as outlined above, Council recommends that as soon as possible a comprehensive review is undertaken to ensure that the skills required for the range of supports available are not in effect stipulated as barriers to entry, rather than genuinely necessary for the particular task.

PART 4 - CHILDREN

The NDIS needs to be respectful of the life of children in families, recognising that it involves much more than just the disability supports they receive. The notion of control, choice and decision making for children is essentially different from that which is understood for adults. Decisions are made in the context of the child living in a family and their situations are constantly changing with developmental stages and general family life. At different ages and stages children's capacity to determine their best interests and to articulate their needs and wishes will change and the NDIS will need to recognise this without intervening unreasonably in family life.

At all times however it is essential that children are given opportunities to actively participate in decision making processes, to voice their views and preferences and for these to be a primary consideration for key decisions and plans, however best communicated. This will be important in the preparation of the participant statement required by Section 33(1) and will be highly subject to change. Council believes that greater practical clarity is required about how these will be developed and utilised for children and young people.

Plans for children in the NDIS context need to be, by definition, flexible and able to incorporate change. The requirement to have a brand new plan in the case of a variation (Section 37(2)) appears to be excessively bureaucratic. A degree of authority needs to be given to parents (as plan managers) or external plan managers to implement minor variations and service substitutions without having to replace the plan itself.

SECTION 74 – CHILDREN

Council is concerned that Section 74(1)(b) gives the CEO unreasonable power in regard to the choices and operations of families. It is essential that such a power, if it is to remain, is consistent with, and does not override or contradict, State/Territory Child Protection or Forensic care systems.

Council believes that such a power is only used in rare circumstances that are clearly prescribed in the legislation as it risks imposing profound negative impacts on a family, if a parent or parents with no protective concerns was not able to manage their child's plan or their services. In cases where services are provided in the family home, it is critical that parents/families have strong input into the management of that service to ensure it has a good fit with the life of the family.

Council believes the power in this section in the NDIS is in place as a safeguard for the NDIS funds, rather than for the effective provision of services for the child. If there are no protective or forensic concerns, then there would need to be exceptional services that would see a parent being overridden in their role of managing their child's plan (the decision to hold funds notwithstanding).

It is Council's view that in most cases differences about choices, options or service delivery should be able to be managed through skilled planning and other scheme processes, where judgement can be applied to resolving differences and making constructive decisions. In cases where planners/providers have concerns about the safety of the child, then a referral to the relevant State/Territory authorities may be made. There are already decision-making processes in place for medical decisions for a child and some of these rely on opinions of a medical practitioner and/or a court order. In the case of healthcare decisions, there are professional ethics and protocols that exist within the medical profession that are closely governed that come into play, and court processes are similarly rigorous. These may well apply for some decisions confronting participants under the age of 18, but these are different from decisions in regard to disability services.

RECOMMENDATIONS

23. Council recommends Part 4 - Children should be better framed with principles that demonstrate values around families, as well as the developing capacity of children. Council also recommends that the section be retitled to: "Children and young people."
24. Council recommends that Section 74(5a) needs clarification. As a child under 18 is not able to sign contracts, there is a concern about waiving a right to have a responsible adult (other than the CEO) to sign off on a participant plan. If there are concerns about disagreements about choices and decisions that arise within families, it is the responsibility of the NDIS planning mechanisms to work through the dilemmas methodically and come to a reasoned and informed decision that is in the best interest of the child and has the support of the parents.

If there are no protective concerns with the parents, it is unreasonable for the NDIS to have the power to override the parents of a child without strong justifiable cause.

25. Council recommends that if Section 74(5a) is aimed at ensuring that the developing capacity of young people needs to be recognised in planning, then this needs to be included as a specific principle in Section 31, *Principles relating to plans* that relates to participants under the age of 18. Council further believes that this capacity should naturally be recognised and encouraged. Council believes that this should be done in a way that ensures that it does not marginalise the families of the participant, particularly where no concerns about parenting exist.
26. Section 74(6) states that the *NDIS rules MAY prescribe criteria to which the CEO is to have regard in deciding* on such action. If this clause is to remain, then Council strongly recommends that the criteria must be spelt out in the legislation itself.
27. Council strongly recommends the inclusion of criteria that need to be met for the CEO to activate this provision.

PART 5 – NOMINEES

Council is concerned that the section on nominees does not detail under what circumstances the CEO can appoint nominees. Council believes that nominees should only be appointed where there is clear evidence that a participant has been shown not to have decision-making capacity. This would be defined by State and Territory Guardianship, Child Protection and Forensic orders.

This evidence should include an analysis of what decision-making supports have been enlisted to assist the participant to achieve the capacity to make their own decisions as well as an analysis of why these supports have not been successful in achieving this outcome.

First and foremost as stated above, the Council recommends that the planning process should support decision-making by all participants to the maximum of their capacity and ability. In this regard as has been previously outlined, the Council recommends that DSO's provide assistance for people to develop and strengthen their planning skills.

Council does however recognise that some participants will need different mechanisms and assisted decision making. In this regard Council believes that the emphasis should be supporting participants' decision making in the context of their plans and that the appointment of nominees should be a last resort option.

As far as the provision for nominees is as a safeguard for NDIS funds, then Council would encourage Government to look carefully at the balance between control and choice for the participant and the degree of control over the participant reserved by the Agency contained in Part 5.

Imposing a nominee is a serious decision that can have significant impact on the autonomy of the participant and any action by the Agency to limit people's decision-making ability needs to be clearly justified according to clearly defined principles.

RECOMMENDATIONS

28. In regards to the concerns above, Council recommends that the legislation needs to detail the criteria that the CEO would have to satisfy in order to be able to initiate the appointment of a nominee.

This could be detailed under Section 86, *Appointment of plan nominee* that could contain greater specificity as to the criteria that can be used by the NDIS Agency CEO to appoint a plan nominee that takes account of Council recommendation about differentiating between risk adversity and risk mitigation.

29. Council recommends that nominees should not be appointed on the basis that participants' decisions are deemed to impose a potential risk to themselves where the nature and extent of the risk is deemed reasonable risk for people without a disability.

For example, the decision to leave the family home to live independently could be viewed as risky, but with the provision of a skilled planning process that can work with the range of issues constructively, such risk can be mitigated.

30. Council recommends that the Agency should be required to report annually on how many nominees have been appointed and the circumstances for doing so.

31. Council recommends that if there opportunities for electronic payment options should be developed and available for services. This could enable the same levels of control and choice by the participant as having the cash in their bank account but could ensure less onerous control powers for the NDIS.

Nominees and People with Psychosocial Disability

On the whole, people with psychosocial disability will have the capacity to make their own decisions despite cognitive impairments as long as there is a pathway back if mistakes are made. If the person has appropriate supports and confidence in the process then they should be supported to make their own decisions. If not, then they ought to be offered supported decision-making.

However, there are some circumstances where substituted decision-making may be necessary. In these circumstances it would be important for a carer or a significant person in the individual's life situation to have some input to decision-making. The functional disability assessment index/measure may be useful in assessing the person's relationship to their environment and determining decision-making functionality for these individuals.

If there are circumstances where supported decision-making is not able to be implemented, the proposed process for appointing nominees should be adhered to as outlined above.

PART 6 - REVIEW OF DECISIONS

The Council recognises that the Bill contains provisions for timely internal review and an avenue of appeal to the Administrative Appeals Tribunal (AAT). The Bill presently states, “Applications may be made to the Administrative Appeals Tribunal (AAT) for review of a decision made by a reviewer under Section 100(6).

Council supports the inclusion of external review in the legislation as it is important from a rights perspective to provide access to legal redress for serious disputes. Council does, however, have strong concerns about the lack of reference in the Bill to a specialist, inquisitorial review panel.

Experience in NSW demonstrates the need for specialist inquisitorial panels. The introduction of the *Disability Services Act* in NSW in 1994 was accompanied by complementary legislation to provide for complaints, appeals and monitoring of services. The Community Services Commission (CSC) and the Complaints Services Appeals Tribunal (CSAT) so established were pivotal in significant reform in services for people with disability. In a process of streamlining government services, the CSC was rolled into the NSW Ombudsman and the CSAT into the generic Administrative Decisions Tribunal. The generalist review and appeals bodies are much less responsive to the issues faced by people with disability and hence are much less effective as mechanisms for systemic reform for better lives for people with disability.

Council believes that the scale of the NDIS and the particular lifetime relationship the scheme has with its participants requires that an independent panel with inquisitorial processes be established. This is particularly important given that people with disability have not had a transparent and accountable review process with current disability funding programs, and this one needs to be accessible and effective.

Council believes that only when disputes cannot be resolved through this first independent level of appeal should an approach to the AAT be indicated. The AAT is, of necessity, a legalistic tribunal where people are more likely to have favourable outcomes with legal representation. Although applicants can have lay support to assist in the AAT process, the Agency is likely to routinely have legal representatives on its side, making it compelling for appellants to acquire legal representation if they not to be disadvantaged in their application.

Council is concerned that if the AAT is the only level of external, independent review, that large numbers of participants (many of whom will be on low incomes) will need to apply for legal aid services in their State or Territory. With access to Legal Aid becoming more difficult because of funding constraints, it is likely that this will act as a serious limiter for participants’ full access to an independent review process.

Council is cognisant of the excellent track record of the AAT in utilising ADR. However, Council is concerned that while ADR achieves a mediated outcome, it does not necessarily achieve a just and fair outcome and is therefore not a substitute for an independent hearing of an appeal.

The Launch of the NDIS (and the evaluation of new processes) lends itself to the trialling of a specialised review mechanism; hence Council is of the view that it is essential to have it in the legislation to signal the intention to have a highly accessible, two-stage independent appeals process.

RECOMMENDATIONS

32. Council recommends that a first independent level of appeal be established that is non-legal, free and accessible, utilising an inquisitorial (rather than adversarial) approach to dealing with disputes that cannot be settled through the internal review mechanism/s. Given that the NDIS is a lifetime support scheme, it is essential that dispute resolution processes be constructive and non-adversarial processes.
33. The Council recommends that the legislation be amended to include establishment of a tailored inquisitorial tribunal to facilitate address of review decisions that are contested by scheme participants.

Addition of National Public Advocate

Council notes the absence in the Bill of an effective external and independent monitoring presence to be established. Further, Council considers that the most effective approach operating at state level resides with the respective Public Advocates; especially those empowered to undertake systems level investigation, reporting and advocacy.

RECOMMENDATIONS

34. Council proposes that an Office of the National Public Advocate be established along the following lines to promote and protect the rights of people with disability, especially those with decision-making impairments by:
 - a. monitoring the operations of the Act.
 - b. promoting the development of the ability and capacity of people with disability to act independently especially with a focus on the minimisation of restrictions on their rights in services provided under the Act.
 - c. conducting systems advocacy related to rights protection, community integration and access to the services and opportunities available for all citizens.
 - d. investigating concerns about the abuse, neglect or exploitation of people with disability.
 - e. supporting the operation of Public Advocates and community visitor schemes in the states and territories.
 - f. investigating, reporting on and making recommendations to the Minister about any aspect of the operation of the Act referred to the National Public Advocate by the Minister.
 - g. reporting annually to the Parliament; and
 - h. providing free access to the National Public Advocate.

Lay Advocacy for Applicants and Appellants - Addition of the Right to Advocacy

Council is pleased to see the Bill establishes a range of mechanisms to safeguard the protection of people with disability under the NDIS.

Council proposes that one of the most important safeguards for people with disability is the right to access independent advocacy. Council proposes that independent lay advocacy is vital in order to give effect to the UNCRPD in particular Articles 13 and 16. Council therefore believes the NDIS legislation should recognise the right of participants in the NDIS to have access to independent lay advocacy support.

RECOMMENDATION

35. Council recommends that under Section 4, *General principles guiding action under this Act*, an additional principle be inserted that states:

“People with disability have the right to an independent lay advocate to assist them in securing their human rights including access to services”. A source of lay advocates could be DSO’s.

CHAPTER 5 - COMPENSATION PAYMENTS

PART 1 - REQUIREMENT TO TAKE ACTION TO OBTAIN COMPENSATION

SECTION 104 - CEO MAY REQUIRE PERSON TO TAKE ACTION TO OBTAIN COMPENSATION

SECTION 105 - CONSEQUENCES OF FAILURE TO COMPLY WITH A REQUIREMENT TO TAKE ACTION TO OBTAIN COMPENSATION

Council recognises the imperatives for sustaining the financial viability of the NDIS and the need to resist taking on costs that are rightfully borne by existing compensation systems. Council also recognises the critical complementary role of the National Injury Insurance Scheme in ensuring maximum no-fault injury cover in Australia.

However, Council has significant concerns with Section 104 that gives the CEO power to compel a participant to take legal action to seek compensation from another source.

Council notes that the Bill makes no distinction between common law schemes and no fault schemes. The route to accessing entitlements from compensation is markedly different depending on whether they are no fault or common law claims. Council believes it is imperative to make this distinction and lay out separate requirements for each type of action.

Council believes that the process for compelling a participant to seek access to a no-fault scheme should be relatively straightforward, and it is reasonable that the CEO has the power to ensure that this occurs.

However, Council believes that the power to compel a participant to embark on common law action to access compensation as described in Sections 104 and 105 is highly problematic. The following difficulties are evident:

- The aims of the NDIS to support people on the basis of functional need, to be independent and engaged in the community, are not consistent with the medico-legal imperatives where incentives to maximise and escalate the degree of impairment/disability exist to ensure the financial value of a claim is maximised. Compelling participants to pursue external compensation claims could undermine the objectives of the NDIS.
- The NDIS should not be in a position to assess the individual legal position of participants. Doing so will require the NDIS to initiate medico-legal assessments and seek legal advice, on behalf of participants regardless of consent. This would place an unreasonable assessment burden on participants for no tangible benefit to their support program or life opportunities. This runs counter to the fundamental principles of the NDIS to encourage self-determination and control and choice, and to focus on community participation.
- This type of approach risks medico-legal commodification of the participant (i.e. treating the participant as a commodity) with all detrimental outcomes that will accrue with such actions.

- The cost and risks associated with pursuing such action are not mentioned in this part of the Bill, but would require the NDIS to indemnify the participant for all costs. This must not mean that funds set aside for support services, will be diverted to cover the costs of legal action pursued.
- The threat to suspend the NDIS plan for a participant who does not comply with a request from the CEO is unfair and will impose costs and risks involved in taking legal action that will fall on the participant. Withdrawing essential NDIS support from a participant runs counter to the no-fault principles underpinning the NDIS.

RECOMMENDATIONS

36. Council recommends that any legal action that is taken by an NDIS participant needs to be voluntary and informed by advice totally independent of the NDIS, rather than giving the CEO power to compel a participant to pursue common law action and creating a scenario of risk for participants.
37. In this regard, Council further recommends that it would be appropriate to enact a provision for NDIS participants to subrogate their common law rights to the CEO (as is the case with the TAC scheme and Comcare), allowing the CEO to take common law action on the participants behalf. This would relate to all heads of damage where compensation received for pain and suffering or economic loss would be paid back to the participant.

PART 3 – RECOVERY FROM COMPENSATION PAYERS AND INSURERS

SECTIONS 109-115

Right of recovery is an important power for the scheme and is indicated in sections 109-115. The NDIS certainly needs the power to recover costs and to have other funders (including insurers and compensation schemes) contribute to its costs where necessary to ensure fairness and to assist the financial sustainability of the scheme.

The Council believes that the NDIS should pursue recovery and other actions administratively and not involve the participant directly. Where recovery actions are being pursued, the NDIS should meet participants support needs in a “business as usual” with the focus on achieving full participation rather than the perverse incentive of maintaining disability to maximise claim outcomes manner while the recovery process is undertaken.

In addition, the NDIS needs to have the internal machinery to effectively communicate and negotiate with other parties (insurers and other funded programs) as to the appropriate cost allocation, recovery and approvals for packages. This may also include agreements with other funders/programs to co fund certain parts of participant plans. This is an important administrative element of the NDIS.

RECOMMENDATION

38. Council recommends the revision of Sections 104 and 105 to clearly distinguish requirements in regard to accessing either common law or no-fault based compensation schemes, and to enable the subrogation of common law rights by NDIS participants to the CEO where access to common law compensation is required. This would better define actions in this area and replace the power for the CEO to compel participants to take common law action.

CHAPTER 6 - NDIS LAUNCH TRANSITION AGENCY

PART 1 - NDIS LAUNCH TRANSITION AGENCY

SECTION 118 – FUNCTIONS OF THE AGENCY

As noted earlier, Council considers that strong interface arrangements with mainstream sectors is a critical factor in enabling participants to maximise their goals as reflected in their plans, as well as ensuring the financial sustainability of the NDIS. These sectors include but are not limited to employment, building standards, education, transport, health, rehabilitation and mental health.

The NDIS Bill and Rules should establish principles and processes that guide the Agency in working with these mainstream sectors. These principles and processes should include that mainstream agencies need to meet their obligations to people with disability to prevent participants from falling through the cracks. The Agency should be required to collect data and report annually on all such temporary support arrangements.

RECOMMENDATIONS

39. The Council recommends the Agency be given robust powers to manage the interaction between the NDIS and mainstream services.
40. Further, the Council recommends that the legislation should include a provision to collect data and report on the impact of the response by mainstream services on its costs. This could be included under Section 118 (e).

PART 2- BOARD OF THE AGENCY

SECTION 127 – APPOINTMENT OF BOARD MEMBERS

As well as its other important roles such as ensuring the prudential management of funds, including financial sustainability of the NDIS, Council believes that the Board must reflect the NDIS's mission to advance the rights of people with disability.

RECOMMENDATIONS

41. The Council recommends adding “demonstrated knowledge of and commitment to disability rights” to the areas of knowledge, skills and experience listed in Section 117(2) of the Bill.

42. Council also recommends that the Board recruitment process should actively seek to identify people with disability who possess the skills, knowledge and lived experience required to be members of the NDIS Board and who are not currently participating in the disability sector to avoid any perceived conflict of interest.

Avoiding conflict of interest

Council strongly believes that the requirements for membership of the Board of the Agency need to be clearly prescribed in the area of avoiding conflict of interest.

Council believes that there is an endemic conflict of interest for any person who is already a Board member or executive with a service provider organisation likely to receive funding from the scheme (via participants), or who is a participant of the scheme, to be a NDIS Board member. This is because of the commercially and politically sensitive nature of documents that board members would see and the perceived advantage that would accrue to board members. These perceptions would include that a board member who is involved with a providing organisation would gain a commercial advantage in the market for their organisation.

While strongly agreeing that lived experience on the Board would be very valuable, Council believes that it would also be preferable to draw that from pools other than participants in the scheme. The perception of Board members who are also participants in the scheme would be that they could receive favourable treatment from the scheme by virtue of their status as a board member.

Given that the NDIS will be developing a range of markets for the provision of services, there will be close industry scrutiny of these appointments, so it is essential that the conflict of interest issue is dealt with comprehensively, and not simply left to the provisions of the Commonwealth Agencies and Companies Act 1997 (CAC Act).

Section 27F of the CAC Act that would normally apply to government agencies (*Material personal interest—director’s duty to disclose*) only covers the duty of directors to respond to particular issues under consideration, and does not deal with overall conflicts.

While Government organisations generally rely on the provisions of the CAC Act to deal with potential conflicts, the Council believes that given the scale of the NDIS, the fact that it is creating a more commercially driven market for providers in the transition to full implementation and that it will be the subject of significant political scrutiny over time, it is better to deal with the issue of governance conflict of interest directly in the NDIS legislation.

RECOMMENDATION

43. Council recommends that the NDIS legislation contain a specific provision dealing with this conflict situation. This requires an additional point in 127(2) which would read:
- (e) “who has no current involvement with a disability provider organisation(s) either in an administrative or board capacity”.

PART 3 - INDEPENDENT ADVISORY COUNCIL

Council is pleased to see the Bill establishes an Advisory Council. However, the Council proposes amendment to the composition of the proposed Advisory Council.

RECOMMENDATION

44. Council recommends that, in line with Article 4 of the UNCRPD as well as the overarching principle of the NDIS of choice and control for people with disability, the Advisory Council should consist of 15 members with the majority of 8 positions being for people with disability, 2 positions being for families/carers and the remaining 5 being for other stakeholders including service providers, academia or workforce representatives.

Council believes it is not sufficient to assume that the majority of people on the Advisory Council will have a disability. If this assumption is accurate then it should not be a problem to enshrine it in the legislation. If it is inaccurate then that is cause for it to be protected through the legislation.

References

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