



**Carers Australia Submission to the
Senate Standing Committee on Community Affairs
Inquiry:
National Disability Insurance Scheme Bill 2012**

February 2013



Carers Australia is the national peak body representing the diversity of Australians who provide unpaid care and support to family members and friends with a:

- disability
- chronic condition
- mental illness or disorder
- drug or alcohol problem
- terminal illness
- or who are frail aged.

Carers Australia believes all carers, regardless of their cultural and linguistic differences, age, disability, religion, socioeconomic status, gender identification and geographical location should have the same rights, choices and opportunities as other Australians.

They should be able to enjoy optimum health, social and economic wellbeing and participate in family, social and community life, employment and education.

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National Disability Insurance Scheme Bill 2012 Exposure Draft

Foreword

The essence of the National Disability Insurance Scheme is focussed on improving the lives of people with disability. That is how it should be. People with disability, their carers and families want the NDIS to deliver the necessary services and supports to transform lives for the better.

They applaud the NDIS vision to reshape the approach to people with disability in Australia. They want people with disability to be given genuine choice about how they live their lives, appropriate early intervention and supports and every encouragement to participate fully in the broader community. In short, they want the NDIS to be the best it possibly can be.

Carers are extremely interested in how the NDIS will work, what it may provide and how it can enrich the lives of those they care for. They are clear about what will and what will not work in a practical sense. They can articulate both the advantages and pitfalls of particular approaches, because they have experienced many years of trying to interact with a system that is broken. They know what is needed for the NDIS to work in an optimal way. Carers have important insights into the pragmatic issues that can mean the difference between a successful approach and an ineffective or detrimental one.

Carers Australia has consulted widely with carers, people with disability and service providers as part of the engagements on the NDIS conducted jointly with the National Disability and Carer Alliance. Views were obtained on a number of issues and practical concerns relating to the proposed NDIS eligibility, administration, and operation. Quotes throughout this submission are drawn from these engagements. We have highlighted the key points which we believe need to be taken into account in the Bill, the Rules, the proposed reference packages and the administration of the NDIS.

We offer these recommendations in the hope that they will be adopted and so will contribute to fulfilling the promise of the NDIS to people with disability, their families and carers.

Introduction

The Bill does some things very well. There is an emphasis throughout on the importance of giving people with disability choice in what services and supports they want and how they want them delivered. The person with a disability is placed 'front-and centre'. Efforts have been made to allow for as much flexibility as possible in the choice of supports and how these are sourced whilst at the same time ensuring accountability for public funds. The importance of ensuring that families are properly supported to provide the best possible environment for the person with a disability is also recognised.

Carers Australia's concerns about the Bill stem from the practical implications of some of the approaches being proposed which we believe could seriously undermine the effectiveness of the NDIS for individuals with a disability. We are concerned that some carers and families, particularly those who are less well organised or able to clearly articulate their situation to a planner, may find themselves caught in precarious situations where their own health and wellbeing, their participation and financial stability are compromised. We believe that if these issues are appropriately addressed the scheme will work significantly better for people with disability, their families and carers.

It is clear from the Bill that carers will not be participants in the NDIS in their own right. We seek assurance that the support needs of carers, and the difficulties many currently have in accessing appropriate and adequate services and assistance, will be addressed by Government as a matter of urgency, if necessary outside the parameters of the NDIS.

Interaction between and contents of the exposure draft Bill, the Rules, the reference packages and administrative guidelines

It is not clear how these different elements will interact. Presumably the Bill is intended to contain the fundamental issues of importance with the supporting documents providing additional guidance and examples. The Bill is silent on many issues of concern to Carers Australia. Some of this may be due to the Government's stated intention to put a lot of the detail relating to the actual implementation of key aspects of the scheme into the 'Rules'. Other factors will be explained in the administrative guidelines and proposed reference packages.

We have summarised and articulated these concerns below. We have included direct quotes from carers obtained as part of the National Disability and Carers Alliance Engagement Project,¹ to illustrate how the various options for resolution of these matters impact on real people in their day to day lives.

Appendix A contains a detailed commentary on the Bill.

¹ National Disability and Carer Alliance Engagement Project, <http://disabilitycareralliance.org.au/ndis-engagement-project/> .

Major Recommendations

1 - The disability requirements should be clarified

2 - It should be a standard requirement that the capacity and willingness of families and carers to provide care and sustain it should inform the relevant participant plans

3 - Some carers will need to contribute to the assessment/planning process

4 - Individual, independent advocacy will be needed by some people with disability or their carers

Discussion of Major Recommendations

1 - The disability requirements should be clarified

The majority of prospective applicants² under the NDIS will need to meet the disability requirements. These are set out in clause 24(1) of the Bill. Prospective participants must meet each of the criteria.

We have particular concerns relating to the interpretation and administration of clauses 24(1)(c), 24(1)(d) and 24(1)(e) and believe that a strict application of these would mean that many people with disability may not be eligible for assistance under the NDIS.

Clause 24(1)(c) requires that a person's impairment or impairments

result in substantially reduced functional capacity to undertake....one or more of the following....

This formulation, which requires a prospective applicant to demonstrate reduced functional capacity in one or more of the specified areas, may be difficult for some individuals with disability to establish. For example, an adult who has been blind or deaf since birth or early childhood may be perfectly capable of fulfilling all of the activities listed, with or without various aids and equipment. This does not negate the fact that at times they may need assistance in replacing aids or upgrading skills under the auspices of the NDIS.

Another requirement that must be met is that the person's impairment or impairments

affects their capacity for social and economic participation³

It is not clear how this will be ascertained except through obtaining evidence of the individual's capacity as demonstrated through their involvement in social and economic activities. Presumably there must be some level in mind whereby a person with a disability who does participate socially or economically will not meet this criterion, as their impairment clearly doesn't affect their social and economic participation. However, this doesn't mean that they don't need assistance in many aspects of day-to-day living.

² Productivity Commission Inquiry Report, *Disability Care and Support*, (2011) Vol 1 p160.

³ *National Disability Insurance Scheme Bill 2012* (Cth) Cl 24(1)(d).

Many people with disability, often with significant effort on their part over a period of years, do manage to participate socially and economically and should not be excluded from the NDIS. Whilst some of these people may not require intensive assistance on an ongoing basis, there would certainly be occasions when they do need the assistance of the NDIS. This could be in terms of requiring help if their condition deteriorates, they acquire another condition which necessitates different interventions or their essential aids or equipment need replacement or refurbishment. We believe that this criterion is too tight and perhaps should be reworded along the lines of

24(1)(d) the impairment or impairments would, without supports, adjustments or training affect the person's capacity for social or economic participation; and

Another of the disability requirements is that the 'person's support needs in relation to his or her impairment or impairments are likely to continue for the person's lifetime'.⁴ It is not clear what purpose this provision serves. Clause 24(1) already requires that the impairment or impairments are likely to be permanent, i.e. either permanent or long-term. In the administration of Disability Support Pension eligibility, the term 'permanent impairment' is defined as 'an impairment resulting from a permanent condition which is more likely than not, in light of available evidence, to persist for more than 2 years'.⁵ The Productivity Commission suggested a 5 year time frame may be more appropriate.⁶ Insisting that the person's support needs due to the impairment must be likely to continue for the person's lifetime seems overly prescriptive. Some chronic and debilitating conditions may resolve over time, particularly with the development of medical advances and new treatment regimes. Usually, neither the treating medical professional nor the patient will know far ahead of time whether their condition is likely to eventually improve, and therefore reduce or eliminate their need for support.

2 – It should be a standard requirement that the capacity and willingness of families and carers to provide care and sustain it should inform the relevant participant plans

There are a number of points in the Bill where it is clear that the presence of a carer and the importance of the family in assisting a person with a disability will be taken into account. These include determining eligibility for the minority of people with a disability who apply under the early intervention requirements,⁷ developing a participant's plan,⁸ and what is considered reasonable for families, carers, informal networks and the community to provide.⁹

The Bill envisages family and carer assistance being included in the participant plans of some people who might qualify because they meet the early intervention requirements, or because the participant is a child. This is explicitly done to

⁴ *National Disability Insurance Scheme Bill 2012* (Cth) Cl 24(1)(e).

⁵ Guide to Social Security Law, 1.1.P.220 http://guidesacts.fahcsia.gov.au/guides_acts/ssg/ssguide-1/ssguide-1.1/ssguide-1.1.p/ssguide-1.1.p.220.html.

⁶ Productivity Commission Inquiry Report, *Disability Care and Support*, Vol 1 p184.

⁷ *National Disability Insurance Scheme Bill 2012* (Cth) Cl 25(c)(ii).

⁸ *National Disability Insurance Scheme Bill 2012* (Cth) Cl 33(1)(b).

⁹ *National Disability Insurance Scheme Bill 2012* (Cth) Cl 34(e).

'strengthen the sustainability of the informal supports available to the person, including through building the capacity of the person's carer'¹⁰

And

'where possible, strengthen and build capacity of families and carers to support participants who are children'¹¹

It is really not clear why these provisions are restricted to participants who qualify under the early intervention requirements.

3 – Some carers will need to contribute to the assessment/planning process

The capacity and willingness of carers who will provide the majority of care to the person with a disability should automatically be included as part of the planning/assessment of the participant's plan. This is necessary so that issues relating to the sustainability of care can be taken into account in the decision-making process – in other words the participant's plan should be based on the actual circumstances of the person with a disability, their carer and their family.

We are concerned that unless this action is taken plans may not reflect the reality of the person with disability's circumstances, and may need to be reviewed in a short space of time.

Carer information needed by the assessor/planner

Where an assessor/planner is gathering material to inform a participant's plan for a person with a carer who provides a significant amount of care, there must also be consideration of the carer's personal circumstances. Under the legislation, the participant's plan must include the 'environmental and personal context of the participant's living'.¹² The CEO must also be satisfied that funding or provision of supports for an individual takes account of 'what it is reasonable to expect families, carers, informal networks and the community to provide'.¹³

We believe that the assessor/planner must obtain a good understanding of the current extent of care being provided, whether the amount of care provided is reasonable and sustainable (given the carer's personal circumstances), and whether the carer is willing and able to continue to provide the existing level of care.

It needs to be recognised there are individual differences between how well people cope with a given situation. There are often very individual responses to emotional, physical and economic stressors and these should be taken into account by the assessor. It cannot be assumed that two people, in what externally appears to be quite similar situations, will react in a similar way, have the same needs or that the care they provide is equally sustainable. The individual's holistic needs and responses to their family situation and circumstances will need to be ascertained.

¹⁰ *National Disability Insurance Scheme Bill 2012* (Cth) CI 25(c)(ii).

¹¹ *National Disability Insurance Scheme Bill 2012* (Cth) CI 31(d).

¹² *National Disability Insurance Scheme Bill 2012* (Cth) CI 33(1)(b).

¹³ *National Disability Insurance Scheme Bill 2012* (Cth) CI 34(e).

If information concerning the extent and sustainability of the current care arrangements is obtained from the carer, the participant's plan should reflect reality. The assessor/planner should take into account how much and the intensity of care that is being provided. They should also consider the implications of the carer's age and state of health. An older carer may have concerns about how much longer they can continue to provide the same level of care due to their own health problems or increasing frailty. The carer's age, level of fitness or health conditions may result in some aspects of their current caring role becoming more difficult and potentially risky. This is particularly the case in relation to lifting/carrying, a deterioration in the person with disability's condition, or physical, emotional and psychological burn-out after years of intensive caring.

A young carer may need additional assistance in caring for a person with a disability in order to complete their own education. Other carers may provide varying levels of care for a number of different individuals.

Some carers will have other commitments, such as employment or a young family, which they have to juggle with their caring commitments to the person with a disability whose plan is being prepared. The carer's longer term goals and aspirations should also be taken into account to establish whether they are willing to continue providing the current level of care or whether they believe this to be unsustainable.

Additional insights the carer can provide

Some carers, particularly those who care for individuals with mental health issues whose condition fluctuates, are concerned that the assessor may not get an accurate picture of the individual's situation and capacity based on one meeting. They know that the person with a mental health issue may vary dramatically in terms of perceptions and presentation from time to time, but that many will put on their best face for an official assessment

One thing we've often noticed too, is that the person we're looking after can appear quite well for an hour long assessment. Because like everyone they want to put their best face forward. They go 'oh yes I'm managing'. They look great..... Well actually, on a day to day basis, ...they're not coping so well. Because often the public face they manage to get together is actually the best they could do for that entire month, for that hour. And then they're assessed on that.¹⁴

Armidale, mental health carer

These carers worry that without further background information from them or other family members the plan/assessment will not reflect the participant's real ongoing needs.

Arrangements for obtaining information from the carer

Many carers support the concept of having a separate discussion with the planner, usually so that they could speak freely about exactly what they do without embarrassing or upsetting the person with a disability. It has to be remembered that, although the assessment/planning process may take an hour or so, there is an ongoing relationship

¹⁴ Quote from the Carer Engagement on the NDIS conducted jointly with the National Disability and Carer Alliance.

between the individuals concerned which should not be potentially jeopardised or threatened by disclosures to a government official.

My daughter understands everything, she would get quite upset if I really got explicitly in detail with an assessor on how I actually do support her. She does a lot of surface sort of stuff and thinks she's 100% brilliant, but she doesn't see me coming in from the background and tidying everything up.¹⁵

Melbourne, decision-making difficulties

My daughter can't wipe herself properly, so I have to. We don't want to have to explain that to an assessor in front of her.¹⁶

Melbourne, ageing carers

Clearly, this approach would also assist people with a disability in some circumstances. A separate discussion/conversation with the person with a disability would also allow them to provide information which they may otherwise feel uncomfortable about disclosing in front of their carer. A person with a disability may want to confidentially explain that there are aspects of the care that they currently receive that they have serious concerns about, for example worries that an elderly or frail carer may drop them.

Preparation for an interview/discussion

Many carers stress the need to be prepared for the interview with the assessor/planner and feel that without some sort of prompt/guide that many carers would not mention how much assistance they actually provided because this had become part of their routine, day to day existence. Many feel that they would need to prepare beforehand in order to cover off everything they did.

I think that carers probably don't know...as much as you know you care 24/7 you don't really realise how much you do..... When I came to list the things that he had to know for a fortnight away, when we actually wrote it down, I was amazed that we do so much for him.¹⁷

Melbourne, ageing carer

During the National Disability and Carer Alliance engagements, carers were asked whether some sort of questionnaire/pro forma that they could consider or fill out beforehand would be useful to help prompt them to express both their personal circumstances and what they did for the person with a disability. The majority of carers were very keen on this approach, but differed somewhat on what such a tool should look like.

Prior to a face to face assessment, the family should be given a list of things that they could respond to. To tell what they're doing for their son or daughter. And then take that with them to the meeting and say well look this is what we want. Because sometimes when you're put on the spot, you don't remember everything you want to say. And I think a pro-forma that would have, yes/no to this, this and this would be quite helpful.¹⁸

Melbourne, decision-making difficulties

¹⁵ Ibid.

¹⁶ Ibid.

¹⁷ Ibid.

¹⁸ Ibid

And also I think a checklist is good about our caring role, what we are doing every day. Or some other days. And then the check list I think should be simple, just tick, tick. Not descriptions, for CALD people descriptions is not very good.¹⁹

Korean carer

Carers Australia's preference would be for people with disability and their carers to have a separately documented discussion/conversation with the assessor/planner where either of the parties expresses a wish to do so. However, if this approach is not considered financially or administratively feasible, at a minimum a checklist or prompt sheet for carers to use in a joint interview or to provide in writing should be mandated. We believe that if this is done, the resulting participant's plan will be significantly more useful, dependable and robust

4 – Individual, independent advocacy will be needed by some people with disability or their carers

The NDIS promises significant changes to the way decisions are made and supports provided to people with disability. It encourages people with disability to make their own choices both in terms of what they need, how their funding is managed and who provides their various supports. Some people with disability and their carers may initially find this array of choices, the new processes of obtaining assistance through development of a participant's plan, and making decisions in relation to management of their plan somewhat confusing and overwhelming. They may require the assistance of independent advocates who they trust to support them through these interactions.

There are currently a number of organisations throughout the country that provide some advocacy/advocacy training of varying types for people with disability. However, the NDIS launch sites will also raise new issues thrown up by the scheme, such as individuals wanting to query the contents of individual participant plans. Although the Local Area Co-ordinators may be able to provide some assistance to people in navigating the system, we agree with the Disability Advocacy Network of Australia that

To maintain advocacy independence, avoid conflicts of interest and ensure that it is focussed on all the issues impacting on the rights, interests and well-being of people with disabilities, advocacy funding should be administered at arm's length from the NDIA and the NIIS....²⁰

Carers Australia believes that individual, independent advocacy relating to interactions with the NDIS will be needed by some people with disability, their families and carers. Such advocacy should be independent as at present, but also provide for people with disability and their carers to receive assistance in understanding and navigating the through the internal review process and legal assistance if the matter goes to the Administrative Appeals Tribunal.

¹⁹ Ibid

²⁰ Disability Advocacy Network Australia, Position Statement – *Independent Advocacy and the NDIS*, June 2012 <http://dana.org.au/submissions-publications/policy-statements/>

Many carers are concerned that the NDIS process will be so complex and difficult to understand/ negotiate that they and the person with a disability need advocates to act with them and support them through the assessment/planning process.

I think a good way to go would be for each family member (the carer) to have a friend or an advocate of some description, to be a witness really, and to maybe offer suggestions. Because again, a lot of people just don't deal with bureaucratic stuff very well, and can be fragile mentally over the whole situation. I think having an advocate, being allowed to have an advocate participate would be a good idea.²¹

Melbourne, decision-making difficulties

Complaints and reviews

Other carers are mainly concerned with how confident, or otherwise, they would feel in dealing with complaints or seeking reviews of decisions on their own.

What should be done is a guideline explaining the process and decision making. So you can have a look at it, see what's involved and make an educated decision about whether you want to go down that line, or whether you want a person to act as an advocate for you. Knowledge is power.²²

NSW mental health carer

This is particularly salient to a group who for many years have had very little redress for complaints regarding the level of funding or services they receive, and often feel that making a complaint or raising issues about a particular service provider or their employee can frequently result in withdrawal of services or forms of covert retribution.

There does not appear to be any mechanism to assist individual participants or prospective participants to seek review or appeal of the decision in their case, despite the complexity and apparent subjectivity and opacity of the proposed decision-making process. There seems to be no mechanism to reassure participants that the decision is consistent, fair, robust and that all relevant matters have been documented, given appropriate weight and taken into consideration.

Carers Australia supports the Australian Human Rights Commission recommendation that paid advocacy support on a sessional basis could be made available to participants or prospective applicants who are appealing or considering appealing against a decision to the AAT.²³ As they have pointed out this would not only assist participants in dealing with an unfamiliar and relatively formal avenue of appeal, but could also give them access to an independent advocate who could explain the process and explain their relative prospects of success.

²¹ Quote from the Carer Engagement on the NDIS conducted jointly with the National Disability and Carer Alliance.

²² Ibid.

²³ Australian Human Rights Commission, *Submission on the National Disability Insurance Scheme Bill 2012*, 24 January 2013, Submission No 492
http://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Committees?url=clac_ctte/ndis/submissions.htm

Detailed Commentary on Bill

Clause 3 Objects of Act

It is notable that family and friends in a caring role are not mentioned. This seems to be contrary to the *Carer Recognition Act 2010* (Cth).²⁴

Cl 3(2)(b) What is actually meant by the term ‘informed by actuarial analysis’? Is this intended to be applied to the provision and funding of supports to individual participants or to the costs of the NDIS as a whole?

Clause 6(2) Agency may provide support and assistance

Although the NDIS Launch Transition Agency will provide support and assistance for prospective participants and participants in the Scheme for doing things under the Bill, this does not extend to providing legal assistance or presumably individual legal advocacy in relation to review of decisions (cl 6(2)).

Given the enormous ramifications for an individual, their carers and families of the contents of the NDIS statement of participant supports and the funding attached to it, the diversity of individual circumstances, and the apparently subjective and opaque nature of the decision-making process, there needs to be additional funding for legal advocacy organisations to provide this assistance to individuals.

Clause 9 Definitions

Definition of access request

There is no meaning given in cl 18, just a statement that a person may make a request.

Definition of carer

The draft Bill includes a definition of carer (cl 9) which has been modified from the definition provided in the *Carer Recognition Act 2010* (Cth). The draft definition refers to a carer of a person with a disability (not defined), but does not explicitly include carers of a person with a medical condition or a mental illness in the same way as the *Carer Recognition Act*. We would suggest that it is more appropriate for the same definition of carer in the *Carer Recognition Act 2010* (Cth) to be used.

There is no definition of ‘cost of supports’

²⁴ S 8(1).

This term is used in relation to whether amounts of compensation payments are taken into account under the NDIS.

Definition of developmental delay

Is the definition also intended to cover children with an intellectual or psychiatric impairment? These are not usually wholly encompassed by the term 'mental impairment'.

Also, the draft Bill has a definition of developmental delay which takes into account a number of areas of reduction in functional capacity (cl 9), but there does not seem to be anything that would also take into account diagnosed behavioural difficulties. It will presumably be extremely difficult for a young child to demonstrate a substantial reduction in functional capacity before they have reached certain milestones. It will be obvious for some of these children that without early intervention and appropriate early therapies their impairment will increase in severity.

Definition of entity

This definition is used throughout the draft Bill in referring to the types of organisations and associations that can apply for registration as a provider of supports. Presumably in the relevant sections the term 'person' is also meant to cover body corporates as defined in *the Acts Interpretation Act 1901*(Cth).²⁵ Given that the term 'person' is used throughout the rest of the Bill to refer to an individual it would be useful to have this clarified.

There is no definition of what is meant by 'informal support'

This is despite this term being used extensively throughout the Bill.

Definition of National Disability Insurance Scheme and National Disability Insurance Scheme launch

These have both been modified since the first exposure draft we saw to remove references to 'the provision of general supports for certain people who are not participants'. Presumably this is to exclude carers.

Definition of parental responsibility

This is given the meaning in Clause 75 and refers to the actual parents or a person who has taken legal action through the courts to obtain parenting or guardianship orders. This simply does not reflect the diversity of individuals who take on parental responsibilities within their families or cultures. Many adults who take on the role of 'parent' for their grandchildren, nieces or nephews are particularly reluctant to take legal action against their adult children or siblings as they judge, usually quite rightly, that this will simply further damage their relationships with the actual parent.

The current formulation, with its emphasis on legal guardianship, will not reflect the reality for many grandparents, indigenous people, or those from different cultural

²⁵ Section 2C(1).

backgrounds which have a much broader concept of ‘family’ and ‘family responsibilities’.

There is no definition of ‘person with a disability’ or ‘people with a disability’

This is despite these terms being used within the Bill.

There is no definition of ‘reasonable and necessary supports’

This is despite these terms being fundamental to the decisions relating to the participant’s plan.

Clause 11 Definitions relating to compensation

These are extremely broadly drawn and refer to amounts made under an award of compensation that is ‘wholly or partly in respect of costs of support that *may* be provided to a participant’ (cl 11(1)). Given that no-one will know what will be provided under the NDIS into the future this formulation seems to capture any amounts made under an award that can be characterised as perhaps being in respect of future support.

It is also of concern that the legislation proposes to pick up as compensation payments ‘wholly or partly in respect of the costs of supports that may be provided to a participant’ even if the award does not specifically identify an amount as such.

Clause 18 Person may make a request to become a participant

Since the first exposure draft, the reference to another individual being able to make an access request on behalf of a potential participant has been removed. It needs to be made clear that this is still an option, particularly in relation to children.

Clause 19 Matters relating to access requests

Cl 19(1)(c) requires the access request to include all the information and be accompanied by all the documents required by the CEO that are ‘in the possession or control of the person’. What does ‘in control’ mean?

Cl 19(2) assumes that the person making the access request has to meet the access criteria themselves. There needs to be provision for another person to make a request on behalf of a person with disability who is not able to do so themselves.

Clause 20 CEO must consider and decide access requests

Although a 21 day period to decide an access request seems reasonable, it appears that cl 204(1) allows rules to be made to effectively double this period. This would be of serious concern to individuals waiting for a decision which would only start the NDIS process.

Clause 23 Residence requirements

In developing the rules in cl 23(3), the situation of newborns needs to be taken into account. It would be unreasonable for some of these children to be excluded from the scheme, simply because they weren't resident in an area for the required period.

Clause 24 Disability requirements

As set out in the major recommendations, we have particular concerns about the content, interpretation and proposed administration of clauses 24(1) (c), 24(d) and 24(e). If strictly construed, it appears that many people with disability who have significant support needs may not meet the access criteria for the NDIS.

Under clause 24(1)(c) a person's impairment or impairments must

result in substantially reduced functional capacity to undertake....one or more of the following....

This requirement may be difficult for some people with disability to establish, particularly where over time they have learnt alternative means of managing the results of their impairment so that their functional capacity in a particular activity can no longer be considered as 'substantially reduced'. For example, an individual who has been blind or deaf since birth or early childhood may be perfectly capable of fulfilling all of the activities listed, with or without various aids and equipment. A young person with a disability, who is currently fitted with a suitable prosthetic leg, may have no current 'substantially reduced functional capacity' in relation to mobility, but they certainly will have if they grow 15 cms. in the following year (as teenagers are wont to do), and need a larger prosthesis and training to use it.

At times people with disability may need additional assistance in replacing aids, upgrading skills or participating in economic and social life and this should be able to be provided under the auspices of the NDIS. Requiring people with disability to demonstrate a currently substantially reduced functional capacity in one or more activities, as a prerequisite for access to the scheme undermines the longstanding philosophy that government and the community should focus on ability rather than disability.

Another requirement that must be met is that the person's impairment or impairments

affects their capacity for social and economic participation²⁶

²⁶ *National Disability Insurance Scheme Bill 2012 (Cth) Cl 24(1)(d).*

It is not clear how this will be ascertained except through obtaining evidence of the individual's capacity as demonstrated through their involvement in social and economic activities. Presumably there must be some level in mind whereby a person with a disability who does participate socially or economically will not meet this criterion, as their impairment clearly doesn't affect their social and economic participation. However, this doesn't mean that they don't need assistance in many aspects of day-to-day living.

Many people with disability, often with significant effort on their part over a period of years, do manage to participate socially and economically and should not be excluded from the NDIS. Whilst some of these people may not require intensive assistance on an ongoing basis, there would certainly be occasions when they do need the assistance of the NDIS. This could be in terms of requiring help if their condition deteriorates, they acquire another condition which necessitates different interventions or their essential aids or equipment needs to be replaced or refurbished. We believe that this criterion is too tight and perhaps should be reworded along the lines of

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Another of the disability requirements is that the 'person's support needs in relation to his or her impairment or impairments are likely to continue for the person's lifetime'.²⁷ It is not clear what purpose this provision serves. Clause 24(1) already requires that the impairment or impairments are likely to be permanent, i.e. either permanent or long-term. In the administration of Disability Support Pension eligibility, the term 'permanent impairment' is defined as 'an impairment resulting from a permanent condition which is more likely than not, in light of available evidence, to persist for more than 2 years'.²⁸ The Productivity Commission suggested a 5 year time frame may be more appropriate.²⁹ Insisting that the person's support needs due to the impairment must be likely to continue for the person's lifetime seems overly prescriptive. Some chronic and debilitating conditions may resolve over time, particularly with the development of medical advances and new treatment regimes. Usually, neither the treating medical professional nor the patient will know far ahead of time whether their condition is likely to eventually improve, and therefore reduce or eliminate their need for support.

Clause 25 Early intervention requirements

The requirement that a child have a developmental delay needs to be clarified. It is important that parents of young children are not forced to obtain a diagnosis of a particular condition before they are considered to have a developmental delay. Many parents have to wait for years to obtain a definitive diagnosis, although it is clear from very early on that they would benefit substantially from various forms of early intervention.

²⁷ *National Disability Insurance Scheme Bill 2012* (Cth) CI 24(1)(e).

²⁸ Guide to Social Security Law, 1.1.P.220

http://guidesacts.fahcsia.gov.au/guides_acts/ssg/ssguide-1/ssguide-1.1/ssguide-1.1.p/ssguide-1.1.p.220.html .

²⁹ Productivity Commission Inquiry Report, *Disability Care and Support*, (2011) Vol 1 p184.

This is one of the few places in the draft legislation which specifically mentions support for carers. This is in relation to people with disability who might qualify because they meet the early intervention requirements. One of the requirements (in cl s25(c) (ii)) is that the provision of early intervention supports for the person with a disability is likely to assist the individual or 'strengthen the sustainability of the informal supports available to the person, including through building the capacity of the person's carer'. There is no indication in the Bill how the need for such supports will take into account the goals, willingness and aspirations of carers.

Clause 27(1)(f) does state that the Rules 'may prescribe circumstances in which or criteria to be applied in assessing whether'.....

(f) the provision of early intervention supports is likely to strengthen the sustainability of the informal supports available to the person, including through building the capacity of the person's carer...'

There is no certainty that the Rules will contain the specific details on how this is likely to be assessed, the process to be used or the options available to an assessor or planner and to what extent the decision will be left to the individual planner's judgement.

It is not clear why there is no similar provision for carers of people with disability who qualify under the disability requirements (cl 24). Generally, these will be the carers of people who have a disability where early intervention is unlikely to reduce the person's need for future support. This would seem to be the majority of carers.

Cl 25(c) (ii) – The meaning of 'informal supports' should be defined.

Clause 26 Requests that the CEO may make

Clause 26(1) allows the CEO of the Agency to ask for additional information from a prospective participant 'or another person' which is reasonably necessary for deciding whether or not the access criteria are met. Clause 26(2) puts a 14 day time limit on the CEO of the Agency to decide whether or not the prospective participant meets the access criteria or make a further information request. Presumably a further information request may be needed to follow up details of an additional condition disclosed in the first request. Although this sounds reasonable, we note that under clause 204(1), the rules can prescribe a doubling of any or all of the time periods allowed to the CEO.

Without any guidance to the CEO though, the use of these provisions have the capacity to indefinitely delay the requirement to decide on eligibility. There should be some restriction on how long the CEO can potentially delay the requirement to decide on eligibility.

Clause 26(3) provides the authority for the participant's access request to be taken to have been withdrawn if each report sought under clause 26(1) has not been received within 28 days (or such longer period as specified). This will occur unless the CEO can be satisfied that it was reasonable for the report to have not been provided within that period. There are some obvious difficulties with this provision, the first being that presumably many of the additional reports required will need to be obtained from specialists and these often have extensive waiting lists. Is the participant supposed to advise the Agency that their

appointment isn't for another 3 months and so probably a four month- time frame for the CEO's receipt of any report is more likely?

Another problem is that under clause 26(1)(a) the CEO can request 'another person' to provide information to help in deciding whether the access criteria are met. Will the prospective participant also be advised of this request and the time period specified? Theoretically, an access request by a potential participant could be taken as withdrawn under clause 26(3) because a response to a request to 'another person' has not been received within the appropriate time frame. The prospective participant has no, or very little, control over when 'another person' might respond to a request from the CEO of the Agency. In these circumstances it would seem grossly unfair for them to have their access request withdrawn due to the tardiness of another individual or organisation.

Another point is payment for requested examinations and assessments. Many people with disability and their families have few resources and some specialist reports are extremely expensive to obtain. Will there be appropriate Medicare rebates for obtaining these requested reports? There should never be a situation where a person is denied access to the benefits of the NDIS because they cannot afford to obtain a specialist report as a prerequisite.

Clause 27 National Disability Insurance Scheme rules relating to disability requirements and early intervention requirements

Without having seen the proposed rules it is very difficult to provide comment. , However, it is clear that the extensive nature of these proposed rules will impact significantly on: the ability of an individual to meet the access requirements for the NDIS; the types of assessments that can be conducted; and who will have the authority to conduct assessments and make decisions on whether a person meets certain criteria. These matters are so fundamental to the operation of the NDIS they should be contained within the primary Act rather than in legislative instruments.

Clause 30 Revocation of participant status

It would be clearer if clauses 30(1)(a) and 30(1)(b) referred to the person 'no longer meeting....' This provision needs to make clear that the revocation of a participant's status cannot be made retrospectively; otherwise potentially the participant could be liable for amounts of NDIS payments made prior to the determination to revoke their participation.³⁰

Clause 31 Principles relating to plans

At the beginning of the section there is a proviso that the preparation, review and replacement of a participant's plan should 'so far as is reasonably practicable', meet the principles set out. This seems to provide a pretty extensive loophole to avoid these

³⁰ *National Disability Insurance Scheme Bill 2012 (Cth)* CI 182.

principles. Perhaps a formulation that required a reasonable excuse to not meet a particular principle would help to put the onus on the Agency.

It is not clear why paragraph 31(d) 'where possible, strengthen and build capacity of families and carers' is restricted to child participants. This should be a principle that is applied to all participant plans where a family or carer is involved.

Clause 32 CEO must facilitate preparation of the participant's plan

Clause 32 is presumably intended to ensure that the preparation of a participant's plan is undertaken in a timely manner. It seems unlikely that the requirement that the CEO must 'commence facilitating' within 14 days will fulfil this objective. How does the CEO 'commence facilitating'? Does this actually have any real meaning? It would be more useful if an actual time frame was imposed for the next step, e.g. 'an appointment with a planner should be organised within one month'.

Clause 33 Matters that must be included in a participant's plan

Clause 33(1) specifies that the participant's statement of goals and aspirations must be prepared by the participant. How will this work with people who cannot make or articulate plans due to their age or impairment? There should be provision for parents, family members or an independent advocate to assist in the preparation of the plan, taking into account the best interests of the individual and their views.

33(1)(b) should refer to the participant's *current* environmental and personal context.

It is not clear what is meant by the phrase 'informal community supports'. If this is meant to refer to carers among others, there should be consideration given to how to establish the sustainability of the current level of care and supports as well as establish whether the care provided is consistent with the family or carer's goals and aspirations.

33(1)(b) (iii) should refer to the participant's current social and economic participation.

33(3) It would seem to be advantageous (in terms of reporting on compliance) for the supports to be described generally rather than specifically identified. The Explanatory Memorandum gives the example of a particular model of wheelchair being specified – however, if it subsequently becomes clear that the particular model is no longer available or that a new model would meet the person with a disability's requirements better, there should be the flexibility to provide a 'replacement' model without needing to revise the statement of participant supports.

33(4) this is so vague as to be virtually meaningless. There should be some goal time frames included e.g. once the required information has been made available the CEO must decide within 28 days whether or not to approve the statement of participant supports.

33(5)(d) seems to allow for the Rules in relation to the funding of 'reasonable and necessary supports' to be used as a 'rationing' mechanism across the scheme.

33(6) where the funding for supports is managed by the NDIA the supports can only be provided by a 'registered provider of supports'. Does this mean by definition that anyone who wishes to receive supports from a local group, friend or family member must either:

1. Ask the local group, friend or family member to become a 'registered provider of supports' or
2. Not have their entirety of their funding managed by the Agency?

This may particularly impact on people with a disability and their families who live in rural, remote or regional areas which often will not have existing registered providers.

Clause 34 Reasonable and necessary supports

Reasonable and necessary supports are not defined. However, in order to specify that the supports that will be funded the CEO has to be satisfied on a number of fronts. Cl 35 makes clear that there will be rules around the assessment of reasonable supports and the extent to which they will be funded.

Cl 34(c) requires that the support represent 'value for money', presumably for the Government rather than the participant themselves. As this is a decision that has to be made before the support can be included in a statement of participant supports, it should look at the 'benefits likely to be achieved'.

Cl 34(e) takes into account 'what it is reasonable to expect families, carers, informal networks and the community to provide'. We have a number of serious concerns in relation to this point? Firstly, who decides what is reasonable and on what basis? Will the individual circumstances of the participant as well as their family and carers be taken into account? What process will be utilised to obtain this information? Will this take into account the family or carers' willingness and capacity to continue to provide care as well as the sustainability of such care? We are very concerned that if a general 'rule of thumb' is applied that the real needs of many of these people with disability will not be met by the NDIS.

For example, it is easy to imagine that the average person in the street would believe that as a general rule it is reasonable for a parent to provide all the care that their child needs. However, given the additional information that a particular child has severe physical disabilities, doesn't sleep for longer than three hours at a time and has serious behavioural difficulties the view would be very different.

Clause 35 National Disability Insurance Scheme rules for statement of participant supports

It is not clear who are 'prescribed participants' under cl 35(1)(c), this term does not appear to occur elsewhere.

This clause provides for rules in relation to assessment processes, and specifying what can and cannot be funded. It appears that there will also be rules concerning by whom certain supports can be provided,³¹ and the manner in which supports are to be provided.³² This

³¹ *National Disability Insurance Scheme Bill 2012 (Cth)* Cl 35(2).

³² *National Disability Insurance Scheme Bill 2012 (Cth)* Cl 35(3).

would seem to run counter to the objects of the Act,³³ and the principle of allowing maximum control and choice to the participant.³⁴

Cl 35(4) discusses having rules relating to how certain compensation payments are to be taken into account in assessing and determining the reasonable and necessary supports that will be funded under the NDIS. As already noted, the definition of 'compensation' in cl 11 is extremely broad and there is no definition of 'cost of supports'.

Cl 35(5) requires the NDIS to take into account amounts that a participant or prospective participant did not receive because they had entered into an agreement to give up his or her right to compensation. There is no explanation of how such an assessment will be made, presumably it would be for different amounts dependent on the state or territory in which agreement was reached as well as the likelihood or otherwise of success at hearing and the personal as well as the economic costs of continuing with the case?

Clause 37 When plan is in effect

Cl 37(2) says that a participant's plan cannot be varied after it comes into effect. However, it appears that the intention of cl 100(6) (b) is that on review a reviewer may confirm, vary or set aside a reviewable decision.

Clause 38 Copy of plan to be provided

Where a plan nominee or a correspondence nominee exists they should also be provided with a copy of the participant's plan, on the same basis as applies to CEO notices.³⁵

Clause 42 Meaning of *managing the funding for supports* under a participant's plan

Cl 42(1)(a) mentions 'paying any applicable indirect costs, such as taxes, associated with the supports'. This is extremely broad; does it mean that the person or entity managing the funding for supports has to cover employer costs such as sick leave, personal leave, long-service leave, superannuation, personal and property liability insurance etc.? This will make it very difficult for many individuals to take on. Will there be guidance on what are considered acceptable and unacceptable indirect costs in the rules? Or on what percentage of a participant's package may be consumed by indirect costs?

Clause 43 Choice for the participant in relation to plan management

Should cl 43(1) also refer to a plan nominee (as suggested in cl 42(2))?

³³ *National Disability Insurance Scheme Bill 2012* (Cth) Cl 3(1)(d).

³⁴ *National Disability Insurance Scheme Bill 2012* (Cth) Cl 4(4).

³⁵ *National Disability Insurance Scheme Bill 2012* (Cth) Cl 81(1).

We believe that it is imperative that the participant and the plan nominee (if they are not an organisation) has a very good understanding of the advantages, disadvantages and implications in terms of management responsibilities, reporting and record-keeping requirements of their plan management choices before making a decision.

Clause 46 Acquittal of NDIS amounts

Cl 46(1) is reasonable and seeks to protect the participant's funding. However, if part of the participant's plan is expressed in very specific terms,³⁶ for example the purchase of a particular model of wheelchair (cl 33(3)), there will be situations where the particular item is not available. In these circumstances, the participant cannot spend the money in accordance with their plan. Perhaps a better formulation would be to require that a participant or a person who receives an NDIS amount on behalf of a participant 'must only spend the money in accordance with the participant's plan'.

We believe that it is important for participants and plan nominees to receive information about and assistance in the acquittal process, in order to reduce the administrative burden as far as possible whilst reducing the chances of incurring a penalty.

Clause 47 Participant may change participant's statement of goals and aspirations at any time

We are concerned that the approach taken here suggests that regardless of the contents of the participant's statement of goals and aspirations, the Agency's statement of participant supports will usually remain unchanged. It needs to be remembered that the participant's statement of goals and aspirations is where they also set out their current living arrangements, informal supports and their social and economic participation. We believe that an understanding of this personal context is extremely important in informing the requirements of the statement of participant supports.

We believe that where a participant advises of a change in their statement of goals and aspirations that the new contents should be checked against the existing statement of supports and, if necessary, trigger a review. For example, if a participant advises that they are no longer living at home, that a primary carer has ceased providing care or they have obtained employment it is likely that the supports they require will have altered quite significantly.

³⁶ *National Disability Insurance Scheme Bill 2012 (Cth)* Cl 33(3).

Clause 51 Requirement to notify change of circumstances

The events or changes of circumstances which the participant is required to notify and the time frame for providing this notification must be specified in a notice given to them by the Agency.

Clause 69 Application to be a registered provider of supports

As already noted, we assume that the term 'person' here is also meant to cover body corporates as defined in *the Acts Interpretation Act 1901*(Cth)?³⁷

Clause 73 National Disability Insurance Scheme rules for registered providers of supports

CI 70(1)(d) specifies that a person or entity must be approved as a registered provider of supports, if they apply under s 69 and meet the criteria prescribed by the rules. We have concerns about whether these rules, specifically those concerning 'prescribed quality assurance standards and procedures' and 'qualifications' will restrict the choice of service provider as well as the choice of plan manager,³⁸ for individuals who may want a familiar service provider (either a local cleaning company or relative) to continue to provide some of their services. It appears that this will not be possible if the Agency manages that part of their plan. This will mean that the person will need to have alternative management arrangements for those parts of their plan where they have a particular person or service that they wish to continue providing them with services.

It does appear that the requirements for a registered provider of supports are very much geared towards organisations, associations and companies rather than members of the local community, family or friends.³⁹

Clause 75 Definition of parental responsibility

As mentioned in the discussion of the definition of 'parental responsibility' in cl 9, this is quite a legalistic formulation of who has parental responsibility which bears very little relationship to the lived experience of a significant number of children.

Although there is provision for another person to be considered as taking responsibility for the child where the CEO determines so in writing, again this is will be governed by the rules.⁴⁰ It is not clear how responsive this approach will be in communities where the sharing of parental responsibilities is commonplace and rather fluid.

³⁷ Section 2C(1).

³⁸ *National Disability Insurance Scheme Bill 2012* (Cth) CI 33(6).

³⁹ *National Disability Insurance Scheme Bill 2012* (Cth) CI 73(20(b)).

⁴⁰ *National Disability Insurance Scheme Bill 2012* (Cth) CI 74(6).

Clause 84 Statement by plan nominee regarding disposal of money

It would be useful if this section also included a reference to the CEO providing access to training for individuals who agree to take on the role of a plan nominee, so that they fully understand their responsibilities and how to fulfil them.

Clause 91 Suspension etc. of appointment of nominees in cases of severe physical, mental or financial harm

Whilst clearly these protections are required, we hope that there would also be follow-up procedures relating to concerns regarding harm to a participant. Where appropriate these matters should be reported to the relevant authorities and the previous nominee offered referral to counselling services.

Clause 99 Reviewable decisions

The list of reviewable decisions should include a decision under cl 77 to revoke a determination regarding who has parental responsibility for a child.

Clause 100 Review of reviewable decisions

It needs to be made clear that 'each person directly affected by a reviewable decision' includes family members and carers who may be affected by the supports provided (or not provided) in the individual's participation plan. This would then line up with the *Administrative Appeals Tribunal Act 1975* (Cth), which generally allows for a person to apply to the Tribunal if their interests are 'affected by the decision'.⁴¹

Clause 104 CEO may require person to take action to obtain compensation

Although presumably this is to prevent cost-shifting to the NDIS on the part of insurers and compensation providers, there are personal as well as financial costs involved in taking legal action to obtain compensation. There is no guarantee of success. It is also well known that the process of seeking compensation, and the unspoken requirement that to maximise the payout the person must not be seen to have been improving over time, entrenches individuals' and encourages them to focus on the negative aspects of their condition, rather than actively engaging in early intervention measures which may reduce their long-term impairment.

In considering whether it is reasonable for a participant or prospective participant to take action to obtain compensation, the CEO should also consider matters such as the person feeling unable to undergo further stress and anxiety with the uncertainty and cost of legal proceedings, and whether, even if successful, the costs of litigating will largely consume any award made.

⁴¹ *Administrative Appeals Tribunal Act 1975* (Cth) S 27(1).

Clause 120 Charging of fees

It is not clear what sort of fees are envisaged here. If the participants are not allowed to be charged a fee,⁴² who is?

Clause 175 Reporting by the Agency

There doesn't appear to be any requirement for reporting by the Agency in relation to its actual administration of the Act. To assist in transparency, information which would be of interest to people with disability, advocacy organisations and others would include:

- Details of the number of access requests received over a particular period, number denied or withdrawn in different jurisdictions
- Timeliness of decision-making for access requests, timeliness of development of a participation plan, how long it takes plans to come into effect, how soon the first payment was made
- Details of the number of current participants and their average packages in dollar terms
- The number and type of review and appeal requests, timeliness of resolving review and appeal requests, decision outcomes of review and appeal requests.

Clause 182 Debts due to the Agency

It should be made clear that participants who were aged under 18 and whose participation plans were being managed by another individual when the debt accrued will not be liable for NDIS debts arising a result of actions by the other person. Instead, the parent or other individual should be pursued for the amount of the debt.

⁴² *National Disability Insurance Scheme Bill 2012 (Cth) CI 120(3).*