



Carers Victoria's submission to the inquiry into the
National Disability Insurance Scheme Bill 2012

January 28, 2013

Carers Victoria is the statewide voice for family carers, representing and providing support to carers in the community. We provide the following services: systemic advocacy and representation; education and training; information and support services; professional counseling; and policy and research.

Family carers provide care and support to family members and friends who have a disability, mental illness, chronic condition, terminal illness or who are frail aged.

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Introduction

Carers Victoria welcomes the opportunity for input to the Senate Standing Committee on Community Affairs' inquiry into the National Disability Insurance Scheme Bill 2012 exposure draft. We note that the Bill is difficult to appraise without access to the 'Rules' which are likely to provide essential details. It is understood that the Rules will be released mid March. They will be carefully appraised by Carers Victoria and the National Network of Carer Associations.

Carers Victoria shares the concerns of Carers Australia and the state and territory carer associations concerning the limitations of the Bill. Our major concerns about the exposure draft relate to:

- The need for the legislation to set a framework which differentiates processes and policies to accommodate the needs and circumstances of adults 'with capacity' and the needs and circumstances of adults with significant lifelong decision making disabilities and their families.
- The need to recognise the roles, responsibilities and importance of families in the lives of many people with a disability, and their contribution to the quality of life of the person with a disability. We note that 84% of people with a disability under 65 live with family.¹
- The need for family involvement in supporting the decision making of people with lifelong decision making disabilities, and the need for substitute decision making in some circumstances.

The Bill should reflect this.

Carers Victoria also notes the semantic difficulties in the term 'carer' in reference to unpaid (family) care. This may include 'families / significant others'. We have chosen to use the latter terminology in this document.

Chapter 1—Introduction: Comments and suggested improvements

Carers Victoria is disappointed at the lack of recognition of:

- The interdependence of many people with a disability and their family / significant other and the interconnected nature of their needs.²
- The needs and goals of caring families / significant others which may both relate to and be separate from the needs and goals of the person with a disability.
- The need for information and advice to families / significant others at key lifecycle transitions and key events.

¹ AIHW (2008) Disability In Australia: Trends in prevalence, education, employment and community living. Bulletin 61.

² Fyffe, Pierce, Ilsley and Paul (2010) The next steps: adults with a disability and caring families. www.carersvictoria.org.au

- The need of some families / significant others for direct assistance and support to sustain family care, to avoid family breakdown and to avoid the high costs to disability systems of relinquishment or crisis care.³

We understand from the Agency⁴ that the development of participant plans will:

- Explore with families and people with a disability the sustainability of informal care. This will include separate conversations with family / significant others where needed.
- As necessary, include family support in the participant plan package on an as needed basis. Itemised dollar amounts for the purchase of support for families / significant others will be included. Funding for family support will be ring fenced: family support expenditure will be monitored.
- Direct support services may include respite, domestic assistance, behaviour management support, counselling support, and alternative care support to enable families / significant others to participate in employment.

Carers Victoria considers that the Legislation and/or Rules should:

- Recognise the autonomy of individual adults with a disability on request, but:
- Recognise that interdependence and interconnected needs are common among people with a disability and their families; particularly between couples and between parents and offspring. This includes care situations where decision making disabilities are an issue.
- Accommodate joint (or family) plans rather than masking family needs in a participant plan:
 - where this is a couple/family preference
 - for families / significant others who need direct support to sustain caring roles.

Differences in the needs and goals of the person with a disability and their family / significant other can be made explicit through the development of joint plans, as can the means of combining formal and informal care in the interests of the person with a disability.

- There is potential for the legislation to set an initial policy framework which acknowledges and differentiates the role of family / significant others who care for adults with decision making disabilities, from those who care for adults 'with capacity'. Such a framework would help to promote the development of improved policy and practices concerning the engagement of people with decision making disabilities, their family / significant other and services providers in supportive partnerships to achieve shared goals.

³ Carers Victoria (2012) NDIS Feedback; 'Eligibility' and 'reasonable and necessary' support. A response to the Select Council. www.carersvictoria.org.au

⁴ Informal communication with David Bowen and Susan Thompson FaHCSIA, 21/1/2013.

Carers Victoria recommends modifications to **Chapter 1, Part 2, 3 Objects of Act** so that they are inclusive of the Carer Recognition Act (2010). These include:

- The modification of (b) to: ‘support the independence and social and economic participation of people with a disability and their family / significant other.’
- The modification of (c) to: ‘provide reasonable and necessary supports including early intervention supports for participants in the NDIS scheme and their family / significant other.’
- The modification of (e) to: ‘promote the provision of high quality and innovative supports to people with a disability and their family / significant other as needed.’
- The addition of (i) to: ‘give effect to the Commonwealth Carer Recognition Act 2010 and the Principles of the Statement for Australia’s Carers.’

Carers Victoria further recommends that **Chapter 1, Part 2, 4 General principles guiding actions under this Act** include the addition of 11 (c): ‘ensure the sustainability of care provided by family / significant others in certain circumstances.’

In addition we recommend that **Chapter 1, Part 2, 4 General principles guiding actions under this Act (12)** should be modified to: ‘the role of family / significant other in the lives of people with a disability will be respected, and their roles and responsibility recognised. Where appropriate, the development of partnerships between families, the Agency and services providers will be promoted.’

Carers Victoria also recommends a modification of **Chapter 1, Part 3, 8 Simplified outline (c)** to: ‘individual plans or joint plans under which reasonable and necessary supports will be funded for certain people (participants), and necessary supports will be provided for certain families / significant others.’

Chapter 3—Participants and their plans: Comments and suggested improvements

Part 1—Becoming a participant

18 Person may make a request to become a participant

Carers Victoria assumes families / significant others can make an access request on behalf of their family member.

24 Disability Requirements

Carers Victoria is pleased about the inclusion of reduced functional capacity in social interaction, learning and self management in the access criteria. We look forward to seeing the outcomes of current work on priority of access.

We are equally pleased at the inclusion of people with a psychiatric disability.

Carers Victoria recommends modifications to **Chapter 3, Part 1, 24 Disability requirements (1), (c)** to become: ‘the impairment or impairments are of a chronic or episodic nature which results in the need for ongoing and long term support.’

This we consider is a better definition than permanent impairment. It is more inclusive of people with a psychiatric condition.

We suggest that the age related option for people 65 plus to elect to stay in NDIS be specifically included in the legislation.

Part 2—Participants’ plans

Division 1, 31 Principles relating to plans

These Principles allow family engagement in the development and delivery of the participants plan, but:

- They are not inclusive of a person centred and **family focused** principle which is essential in some situations.
- While the exposure draft names the inclusion of ‘early intervention and family capacity building’:
 - There is no definition of early intervention for different cohorts and their families and no definition of capacity building.
 - The Principles assume the right of control/choice by the person with a disability to the maximum extent possible in the context of supported decision making. This is strongly supported. However this ignores the lived experience of some families of adults with significant decision making disabilities where informal substitute decision making is required. Differentiation of the legislation and rules to accommodate the diversity of people with a disability and their families is needed.
 - Some families find such high level and difficult to attain principles painful or frustrating.

Carers Victoria recommends that **Chapter 3, Part 2, Division 1, 31 (g)** be modified to: ‘be underpinned by the right of the participant to exercise control over his or her own life to the maximum extent possible, while recognising that the support, assistance and judgement of family / significant others may be essential the development of plans for some people with a disability.’

Divisions 2 and 3: Preparing and managing participant plans

33 Matters that must be included in a participants plan (1)

This section should acknowledge the role of family / significant others in supporting people who are unlikely to be self determining to establish a statement of goals and aspirations.

In many instances families will inform and facilitate needed assessments and plans in partnership with NDIA. They will be Communication or Plan nominees.

There are issues concerning:

- The capacity of some people with a disability to nominate a Plan or Communication nominee or to indicate agreement.
- The capacity of the Agency CEO to reject family appointment (including in some instances the parents of children) as nominees in circumstances of 'exploitation, risk or over-protectiveness.'
- There is a need for detailed exploration of the interface between the Agency and state or territory child protection and family support services and adult protective services (Guardianship and Administration, Public Advocates).
- There is also a need to ensure that due process is guaranteed both to people with a disability and to their family / significant other. While decisions regarding nominees are reviewable decisions, no independent right of appeal for families / significant others is proposed.

Carers Victoria supports the flexible options proposed for the management of participant plans.

We understand from the Agency that ring fenced supports which are targeted to families / significant others to help sustain informal care will be included as needed in participants plan.⁵

Carers Victoria recommends that **Chapter 3, Division 2, 33 Matters that must be included in participants' plan** includes a replacement item (3), which states:
'A statement of the supports needed by some families / significant others to sustain informal care will be included with the statement of participant's supports. It will outline the reasonable and necessary supports needed by families / significant others to sustain and support their caring roles. This may be in the form of a joint plan. Plans will include general supports, specialist disability supports and reasonable and necessary family supports.'

Division 4—Reviewing and changing participants' plans

48 Review of participants' plan

Family / significant others of adults with decision making disabilities (who may be the plan nominee) must be able to request a review of the participant plan, for example:

- When there are tensions between views about the best interests and aspirations of the participant.

⁵ Informal communication with David Bowen and Susan Thompson FaHCSIA, 21/1/2013.

- When there is a need to negotiate different perceptions concerning the needs of the person with a disability and the needs of family / significant other.
- When individual or family circumstances change.

The scheduling of reviews around key lifecycle transitions and events is essential.

Chapter 4—Administration: Comments and suggested improvements

Part 5—Nominees

Division 2—Appointment and cancellation or suspension of appointment

Carers Victoria notes that an option for families to request an anticipatory review of appointment of Plan or Correspondence Nominees will be needed by ageing parents of people with lifelong decision making disabilities, as part of transition planning. Nomination of siblings or others can be made to facilitate changes in the roles and responsibilities of informal care prior to crises arising.

A mechanism for rapid changes of nominees in the event of carer death or illness for people with significant decision making disabilities will also be required.

These are likely to be matters for the Rules.

Part 6—Review of decisions

Carers Victoria recommends that **Chapter 4, Part 6, 99** is extended by a new item (e): ‘a decision under subsection 33 (2) to approve the statement of family support in a participant plan or joint plan.’

The in-house review process outlined in the Bill appears to be limited to specific decisions, and may be requested by participants and the CEO. Families or nominees must be included in the category of a person who is ‘directly affected’ and able to request reviews.

The need for an independent complaints mechanism

There is a strong case for the National Disability Insurance Scheme to be accompanied by an independent complaints system and mechanism for appeal about decisions, both for the person with a disability or their family / significant other.

An independent protective agency is required to safeguard the rights of vulnerable people with a disability and their families and to focus on the quality and efficacy of delivery of specialist disability services. A reliance on

regulations and standards or faith in a competitive market and consumer control is insufficient.

Independent monitoring and review of the quality of both Agency and provider services is essential; as is a vehicle for people with a disability and their families to make complaints and be supported in their resolution – an essential means of quality improvement.

The Office of the Disability Services Commissioner in Victoria⁶ performs vital functions which should be nationally available alongside an NDIS. A National Disability Services Commissioner would:

- Promote the development, operation and resolution of complaints (any person can complain).
- Receive and act on complaints concerning registered services providers; the Agency; contracted disability services providers and funded disability services providers.
- Promote cultural and organisational change through both consumer and provider education and training, the development of practice guidelines and annual reporting on complaints systems and their outcomes.
- Promote the need for any practices improvements needed in the sector, based on evidence from complaints.
 - Increasingly, and as a direct consequence of the work of the Victorian Office of the Disability Services Commissioner, complaints are being seen as an opportunity for policy and practices improvement by services providers.
- Independent monitoring and review of critical incidents is an essential form of monitoring the efficacy or quality of services.

An independent mechanism for both people with a disability and caring families or friends to complain regarding agency and services provider practices is essential.

- Sector policy and practices with regard to partnership and engagement with families of adults with decision making disabilities is currently poorly developed.
- The legislation should include a framework which recognises crucial family advocacy and support roles and which promotes partnership between formal and informal care where decision making disabilities are an issue.

While the Bill provides for a right of appeal to the Administrative Appeals Tribunal (Part 6, 103 Applications to the Administrative Appeals Tribunal) concerning reviewable decisions, the skill, training and expertise of AAT members in complex disability matters appears limited.

Carers Victoria recommends that the development of the National Disability Insurance Scheme be accompanied by the development of an independent Office of a National Disability Services Commissioner.

⁶ Website of the Disability Services Commissioner, Victoria www.odsc.vic.gov.au