



## **Submission to the Disability Care and Support Inquiry**

Carers NSW response to the draft report

April 2011

## **About Carers NSW**

Carers NSW is the peak organisation for carers in NSW. It is a member of the National Network of Carers Associations and has an exclusive focus on supporting and advocating for all carers in the state.

The core work of Carers NSW is to:

- be the voice for carers in NSW
- undertake research, policy development and advocacy
- provide carer services and programs
- provide education and training for carers and services providers
- build capacity in the sector.

Carers NSW's vision is that caring is accepted as a shared community responsibility and that all carers in NSW are recognised, valued and supported by their communities and by governments.

## **Who Carers NSW represents**

Carers NSW defines a carer as any individual who provides unpaid care and support to a family member or friend who has a disability, mental illness, drug and alcohol dependencies, chronic condition, terminal illness or who is frail.

Carers come from all walks of life, cultural backgrounds and age groups. For many caring is a 24 hour job that is often emotionally, physically and financially stressful. Across NSW there is an estimated 750,000 carers, comprising individuals as young as 8 years of age through to the very elderly.

## **About this submission**

This submission will address various issues arising from the draft report of the Disability Care and Support Inquiry that have particular relevance to carers. The submission will address some overarching themes relating to the role and conceptualisation of carers, and will also engage with more specific components of the draft report and recommendations.

Although this submission does detail some concerns relating to various aspects of the Commissions proposals, Carers NSW remains strongly supportive of the introduction of an NDIS, and optimistic about the significant improvements that it will bring about to the lives of many.

Carers NSW acknowledges and supports the submission being made on behalf of the National Network of Carers Associations, and the submissions made to this Inquiry by other members of the National Network of Carers Associations.

## 1. Invisibility of carers in the draft report and recommendations

The National Health and Hospital Reform Commission has described carers as the “invisible health workforce” in acknowledgement of their critical and often unrecognised role as the major providers of care. Although the Productivity Commission rightly acknowledges that carers provide the majority of care and support to people with a disability and that the current disability system places an “unreasonable reliance” on carers, their invisibility is perpetuated throughout the draft report by the Commission’s failure to adequately and consistently recognise and address their role and needs.

The draft report is largely silent on carers and their place in the proposed schemes. Very little consideration is given to their needs, the supports they will receive in the proposed schemes, their inclusion and role in assessment and planning, and other issues which should have been explicitly and more extensively addressed. The draft recommendations of the report are a case in point. Of the 71 recommendations made in the report, only six explicitly reference carers, and just two relate to their particular needs as carers.

One of the cameos provided in the ‘Key Features of the Proposed Scheme’ document released by the Commission demonstrates how carers could be more visible and receive greater consideration in the report without significant material changes to the proposed schemes or recommendations. The cameo on a newborn with severe disability is the only one which acknowledges and explores (to some extent) carers support needs and how they would be met in the proposed schemes.

It is important that more exploration and acknowledgement of carers in the proposed schemes is included in the final report. Carers NSW is concerned that the low profile of carers in the draft report may contribute to, or create, a culture of carer invisibility in the reformed disability service system. The profile of carers and the consideration that they are given in the final report should reflect the significance of their role and needs, and the extent to which they will be recognised, included and supported in the proposed schemes.

**Recommendation 1:** Carers NSW strongly recommends that the Productivity Commission address the invisibility of carers in the draft report by giving them greater recognition and consideration in the final report and recommendations.

## 2. Carers are unique stakeholders, not part of the workforce

The inclusion of carers in the chapter of the draft report relating to workforce issues is extremely disappointing. This is an issue that Carers NSW, Carers Australia and other Carers Associations have already raised with the Commission in relation to the parallel inquiry into aged care. It was disappointing to see that the draft reports of both Inquiries have inappropriately included carers within the paid workforce section.

Carers are a unique stakeholder in the disability system, and have been the main provider of care in the community in the absence of a disability care system. Although carers have been described as the ‘invisible workforce’,<sup>1</sup> there are significant and overwhelming differences between carers and the paid workforce which renders their inclusion with the workforce inappropriate and problematic.

Unlike the paid workforce, carers do not receive remuneration and are not entitled to other supports such as supervision, training and professional development. Carers

do not have a safe working environment and they do not receive compensation and sick leave in the case of injury or ill health. Carers are not entitled to annual leave and there is no limit on the hours they spend caring, or the length of time they are on duty. Whilst the workforce is able to save for the future through the accumulation of superannuation, carers often experience a reverse savings effect as a result of the financial and opportunity costs that come with their caring role.

The needs of carers and their place in a reformed system can be better understood by conceptualising them as consumers of disability services, rather than as a subset of the paid workforce. It is often the carer who has to fight to access services and who coordinates the services and supports that are provided. Often the carer acts as an advocate for the person with a disability and for themselves, and is responsible for much of the interaction with government departments and service providers. Carers also have their own needs for services and support, independent of the needs of the person they care for. Carers, the person with a disability, together with caring and family relationships need to be supported and sustained. This is more likely to be achieved if carers are dealt with in their own right and conceptualised as consumers and not as part of the workforce.

According to advice given in the public hearings of the Caring for Older Australians Inquiry, the final report of that inquiry will deal with carers in a separate chapter, a decision which should be followed in this Inquiry.

**Recommendation 2:** Carers NSW strongly recommends that carers are not included with the workforce, and that a separate chapter is dedicated to carers in the final report.

### **3. Statement for Australia's Carers**

The Commonwealth *Carer Recognition Act 2010*, which commenced in November 2010, should inform the Commission's efforts to ensure that carers are adequately and appropriately included in the final report and recommendations of the Inquiry.

The Act includes a *Statement for Australia's Carers*, which contains ten key principles that establish how carers should be considered and treated. These principles must be reflected in, and supported by the Commission's final recommendations. It is of particular importance that those recommendations which relate directly to carers are in line with the Statement, as should recommendations which indirectly relate to or impact upon carers. Recommendations that impact upon people with a disability inevitably have flow-on effects to their families, and particularly to their carers.

The ten principles are that:

1. All carers should have the same rights, choices and opportunities as other Australians, regardless of age, race, sex, disability, sexuality, religious or political beliefs, Aboriginal or Torres Strait Islander heritage, cultural or linguistic differences, socioeconomic status or locality.
2. Children and young people who are carers should have the same rights as all children and young people and should be supported to reach their full potential.
3. The valuable social and economic contribution that carers make to society should be recognised and supported.

4. Carers should be supported to enjoy optimum health and social wellbeing and to participate in family, social and community life.
5. Carers should be acknowledged as individuals with their own needs within and beyond the caring role.
6. The relationship between carers and the persons for whom they care should be recognised and respected.
7. Carers should be considered as partners with other care providers in the provision of care, acknowledging the unique knowledge and experience of carers.
8. Carers should be treated with dignity and respect.
9. Carers should be supported to achieve greater economic wellbeing and sustainability and, where appropriate, should have opportunities to participate in employment and education.
10. Support for carers should be timely, responsive, appropriate and accessible.

The Commission should use the *Statement for Australia's Carers* as a tool to reassess the discussion and proposals relating to carers in the draft report. The principles of the Statement should assist the Commission to increase the visibility of carers, and the degree of consideration given to their role and needs. An application of these principles may also help develop a better understanding of carers as consumers, and not as part of the workforce.

**Recommendation 3:** Carers NSW recommends that the *Statement for Australia's Carers* be adopted as a tool to reassess the Commission's conceptualisation and treatment of carers in the final report.

## 4. Assessment

Carers should be supported to enjoy optimum health and social wellbeing and to participate in family, social and community life.

Principle 4 from the *Statement for Australia's Carers*

Carers NSW supports the principals of the assessment process proposed by the Commission, including that assessment; assess the nature, frequency and intensity of the needs of the person with a disability; is individual, independent, objective and benchmarked; draw on multiple sources of information, including information provided by the carer; and is also available for carers in their own right. However, the Commission should give further consideration to some elements of the assessment process being proposed here, particularly in relation to carers.

### 4.1 Carer assessment

It is promising that the draft report acknowledges the need of carers for assessment in their own right, and considers the need in many cases for assessment to occur in the absence of the person requiring care, in order to enable a frank and open discussion of the carer's wellbeing, capacity and needs.

More consideration of how carer assessment would occur, what tool would be used and what the assessment would cover should be included in the final report of the Inquiry. Carer assessment should be considered a crucial component of the overall assessment process, and its importance should be reflected in the degree of consideration and analysis that it is given in the final report and recommendations.

**Recommendation 4:** Carers NSW recommends that detailed analysis of carer assessment is undertaken and recommendations made.

## 4.2 A 'substantial' share of the care package – substantial for whom?

The draft recommendation relating to carer assessment states that “Where an informal carer provides a substantial share of the care package, they should receive their own assessment...” Clarification of what is meant by ‘substantial’ is required. The need for carer assessment should not be solely determined by the proportion of the care package they provide, or by the significance of the care to the person with a disability, but should also take into account the significance of the caring responsibilities to the carer.

The level of need of a carer is determined not only by the intensity of the care they provide. There are manifold factors which can influence a carer’s capacity and their own need for support including the carer’s life stage, their own health and wellbeing, the existence of other life or care responsibilities, the supports available to them, and their position on the carer journey or carer life course<sup>\*</sup>.<sup>2</sup> The diversity of carer experiences means that the same caring responsibilities can have very different impacts on different individuals.

Determining what constitutes a ‘substantial’ share of the care package must therefore take into account the significance of the care responsibilities to the carer as well as to the care recipient, if carer assessment is to occur when needed. There must be avenues to request carer assessment for cases where assessment is needed but does not result from the assessment of the care recipient.

**Recommendation 5:** Carers NSW recommends that carer assessment takes into account what is ‘substantial’ for the carer.

**Recommendation 6:** Carers NSW recommends that carers have the right to request assessment for themselves.

## 4.3 Willing and reasonable

All carers should have the same rights, choices and opportunities as other Australians...

Principle 1 from the *Statement for Australia’s Carers*

Draft recommendation 5.2 states that the assessment process should “consider what reasonably and willingly could be provided by unpaid family carers and the community (‘natural supports’). Carers NSW strongly supports the recognition of carers right to choice that is suggested in the ‘reasonably and willingly’ clause of this recommendation. It is hoped that the intention of the Commission here is to protect the right of carers to choice in their caring role, relating to how much care they provide, what kind of care they provide, and importantly, whether they choose to continue caring at all. As the first principle of the *Statement for Australia’s Carers* states, all carers should have the same rights, choices and opportunities as other Australians, and this includes the choice to provide informal care, or not.

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<sup>\*</sup> The Carer Life Course Framework, developed by Deanna Pagnini for Carers NSW, identifies six distinct phases that many carers go through on their caring journeys: ‘something is wrong’, confirmation of diagnosis, adjustment/readjustment, management, purposeful coping, and the end of the active caring role. The Carer Life Course is not prescriptive, and progression may not be linear. Many carers cycle between stages, and not all reach the management or purposeful coping stages. More information is available at [www.carerlifecourse.com.au](http://www.carerlifecourse.com.au).

Although the inclusion of the “willing and reasonable” clause is encouraging, the discussion of this issue in the draft report does raise some concerns about how ‘willingly and reasonably’ is to be interpreted. The Commissions states

For example, it would not be reasonable to expect elderly carers to provide the bulk of support, but it would be appropriate (in most instances) to expect parents of a young child to provide overnight support and for a reasonable period during the week, as this what all parents do for their children.

This example suggests that the Commission envisages that it is reasonable to expect all (or the vast majority) of children with a disability to remain at home with their parents until they are adults. Comparing the support provided to children with disabilities, particularly those with high care needs, to the ‘overnight support’ a parent provides to a child without care needs is extremely concerning, and demonstrates an ignorance or disregard for the intensity of the care that many carers of a child with a disability provide. This care, in the case of profound disability, is ongoing, life long, and extends well beyond the child with a disability reaching adulthood.

The contention that it is ‘reasonable’ to expect all children with a disability to remain at home under the care of their parents until adulthood ignores the circumstances of those families where a child (or children) has high care needs. For some children with a disability, and their carers and family, care and accommodation outside of the home may be required. An example is the support provided by Kingsdene Special School and Residence in Sydney prior to its closure.

As raised by one carer in a discussion of this issue, this is also a question of equity. There are many children and young people in Australia who reside in boarding schools for the greater part of the year. The families of children with a disability should have similar options available to them, particularly in the circumstances where the care they are providing is not reasonable, not comparable to any ‘normal’ parenting role, and is certainly not what “all parents do for their children”.

#### **4.4 Reassessment**

Support for carers should be timely, responsive, appropriate and accessible

Principle 10 from the *Statement for Australia’s Carers*

Carers NSW supports the Commission’s proposals relating to reassessment. It is important that reassessment be triggered at key points such as upon entry into school, high-school, adult education and the workforce; and at other life transition points such as marriage, divorce and moving out of home. As the Commission states, it is important that reassessment occurs when an individual’s circumstances have changed, or are about to change.

Reassessment should also occur when changes occur relating to the carer’s circumstances or desire to care, regardless of whether they have yet, or if they will affect the care received by the care recipient. For example, if the carer is at one of the transition points given as examples above, such as marriage, divorce, entry to education or the workforce, or moving out of home/moving home, reassessment should occur. This is no less important than reassessment when the circumstances of the person with a disability changes. The NDIS must be responsive to changes in the carer’s capacity to care and to changes in the carer’s choices regarding caring, such as how much or what kinds of support they are willing to continue to provide.

It is important that both carers and the people who receive care are able to approach the scheme for reassessment, due to changes such as those mentioned above, or due to a change in the health of either the care recipient or the carer. Both the carer and the care recipient, as individuals, should have the right to request and receive reassessment.

**Recommendation 7:** Carers NSW recommends that reassessment also occurs at transition points in the carers' life, and that carers have the right to request reassessment.

## 5. Carers as individuals in their own right

Carers should be acknowledged as individuals with their own needs within and beyond the caring role.

Principle 5 from the *Statement for Australia's Carers*

Carers are individuals who have their own needs, priorities and responsibilities independent of their caring roles. The Commission fails at times to appreciate carers as individuals in their own right, instead focusing upon carers as a resource in the care of the person with a disability and as an 'alternative' to increasing the formal workforce.

The Commission must give greater consideration to the services and supports available to carers in their own right in the proposed schemes. The draft report is quite circumspect in its discussion of carers needs. In the main discussion of carers, 'Alternatives to increasing the formal workforce', the only supports discussed are respite, counselling and training. There is scope for other types of services and support to be considered, such as carer support groups, superannuation for carers, and measures to support carer safety and wellbeing such as health check-ups and assessments of the safety of the care environment.

### 5.1 A person and family centred approach

More consideration should also be given to the role of carers in the NDIS, and how their needs and choices will be balanced with those of the person they care for. The services and supports that are provided in the NDIS, and the way in which they are provided need to be appropriate for the carer, the care recipient and other family members.

Carers NSW supports the Commission's commitment to a 'consumer choice' model that shifts decision making and control to people with a disability and their carers. However, it is important that the Commission give some consideration to how the needs and choices of different individuals will be responded to in the assessment and planning process. It is important to understand and recognise that the carer and care recipient are individuals whose interests and choices will not always coincide, and in some instances may conflict considerably. The Commission must ensure its proposed scheme is truly person and family centred, and able to meet the needs and respect the choices of both carer and care recipient.

**Recommendation 8:** Carers NSW recommends that the NDIS be a truly person and family centred scheme, able to respect the choices of the carer as well as those of the care recipient.



## 5.2 Carer access to support under the NDIS

Carers NSW is concerned that the NDIS has been formulated with eligibility for the scheme entirely based on the needs of the person with a disability, and with the person with a disability very much conceived as the client of the scheme. At best, the carer appears to be treated as a client by default in situations where the person with a disability is unable to make their own choices.

This raises the concern that the intensity of the care provided, and the nature and severity of the impacts on the carer, will be irrelevant in determining eligibility for support. Carers with intensive caring responsibilities for a person with a disability who is not eligible for the NDIS will be excluded, despite the fact that they may be providing similar levels of care, and experiencing similar impacts to other carers who care for a person with a disability who is eligible. For example, a carer who cares for two people with a disability, neither of whom meets the eligibility criteria, will not be eligible for support under the NDIS despite the fact that the combined intensity of these two caring roles may be equivalent to the care provided to someone who is eligible. Twenty-two per cent of respondents to the *Carers NSW 2010 Carer Survey* were caring for more than one person,<sup>3</sup> indicating that this example may become a very real issue in the proposed scheme.

## 5.3 Carers as clients of the NDIS

The Commission must give greater consideration to the role of the carer in the NDIS. The final report and recommendations should provide a clear role for the carer in the scheme, which enables a person and family centred approach, and ensure that entry to the NDIS takes into account the carer as well as the person (or people) with a disability.

Carers NSW recommends that the Commission moves toward an understanding of carers as clients or consumers in their own right. Based on the decision of the Caring for Older Australians Inquiry to remove carers from the discussion on the workforce, Carers NSW expects a similar change in the final report of this Inquiry. A reconceptualisation of carers as not a sub-sector of the workforce nor an adjunct to the person with a disability but as consumers or clients in their own right would ensure that carers are adequately supported in the NDIS, and would enable a truly person and family centred approach in the NDIS.

**Recommendation 9:** Carers NSW recommends that the Commission consider conceptualising carers as clients of the NDIS in their own right.

## 6. Inclusion of people with a mental illness and their carers

Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.

UN Convention on the Rights of Persons with Disabilities<sup>4</sup>

Carers NSW strongly supports the inclusion of people with a psychosocial disability and their carers in the NDIS. As the peak organisation for carers in NSW, and a former provider of the NSW Family and Carer Mental Health Program, Carers NSW is acutely aware of the significant unmet needs of people with a mental illness and

their carers, and believes that it would be unconscionable for the disadvantage experienced by these individuals to be perpetuated by their exclusion from the NDIS on the basis of the origin or cause of their disability.

The Terms of Reference of the Inquiry specify that the NDIS is intended to cover people with a severe and profound disability not acquired as part of the natural ageing process, and do not instruct the Commission to make any other exclusions based on the origin or cause of disability.

The Commission acknowledges that mental illness is recognised as a disability by the World Health Organisation and by the United Nations Convention on the Rights of People with Disabilities (which has been ratified by Australia), and acknowledges the burden of psychosocial disability in Australia. Carers NSW recommends that the NDIS include people with psychosocial disability and their carers.

The exclusion of people with a psychosocial disability would be contrary to the underpinning principles and objectives of the scheme. The rationales for reform outlined in the Introduction to the draft report support the inclusion of people with a psychosocial disability in the scheme. One such rationale is the 'lottery' of access to services where people with similar levels of impairment get different levels of support, depending on their location or the *origin of their disability*.

The objectives of the scheme proposed by the Commission also support the inclusion of people with a psychosocial disability. These include:

- to provide long-term support for *all forms of disability* for those most in need, *irrespective of the cause* and who is at fault
- to provide more comparable long-term care and support to people with similar levels of disability, *regardless of the source of disability* or the location of the person.

The Commission's concerns relating to the 'dilemma' of to what extent the NDIS should compensate for a poorly performing mental health system are unfounded so long as the boundaries (and linkages) between the two sectors are firmly and clearly set. Carers NSW does not have the expertise to make detailed recommendations relating to this issue, but supports the proposal by organisations such as National Disability Services that treatment remain a responsibility of the mental health sector, and that the NDIS provide the ongoing support required for people to remain living in the community. This would not be significantly different to the supports that would be used by people with other disabilities in the scheme. For example, people with a psychosocial disability and their carers may require respite, specialist accommodation support, specialist employment services or community access supports. These are all supports detailed in Box 4.1 'Specialist disability supports provided by the NDIS'.

**Recommendation 10:** Carers NSW recommends that people with a psychosocial disability and their carers be eligible for the NDIS.

## 7. Carers and their right to social and economic participation

Carers should be supported to achieve greater economic wellbeing and sustainability and, where appropriate, should have opportunities to participate in employment and education.

Principle 9 from the *Statement for Australia's Carers*

Carers NSW commends the Commission for its recognition of the importance of supporting the workforce participation of carers and supports its decision to make recommendations relating to the need to amend the Fair Work Act 2009. Better support and greater flexibility in the workplace is one vital component to improving the workforce participation and overall wellbeing of carers.

The report of the *Who Cares...?* Inquiry recommended that section 65(1) of the Fair Work Act 2009 "...be amended to extend the right to request flexible working arrangements to all employees who have recognised care responsibilities, including those caring for adults with disabilities, mental illness, chronic illness or who are frail aged."<sup>5</sup> Carers NSW, the Network of Carers Associations and the Australian Human Rights Commission have all advocated for the extension of this Act to include all carers regardless of the age of the care recipient or the nature of the care relationship. Carers who care for their siblings, parents, partners or other family members or friends should not have lesser rights than parents with care responsibilities for their children.

The Commission's draft recommendation 13.4 states that the Australian Government should amend the Fair Work Act 2009 "to permit parents to request flexible leave from their employer if their child is over 18 years old but subject to an NDIS assessment indicating that parents are providing a sufficiently high level of care". Carers NSW believes that this recommendation should be strengthened, and that all carers should have the right to request flexible working arrangements, regardless of why the care recipient needs care, or the nature of the relationship.

**Recommendation 11:** Carers NSW recommends that draft recommendation 13.4 be amended to support the need for all carers to have the right to request flexible working arrangements, regardless of the age of the care recipient, the nature of their relationship, or their eligibility for the NDIS.

## 8. Advocacy and representation

Carers should be considered as partners with other care providers in the provision of care, acknowledging the unique knowledge and experience of carers.

Principle 7 from the *Statement for Australia's Carers*

### 8.1 Carers and the complaint system

Carers in the NDIS must have the right to make complaints and challenge decisions on the behalf of the person with a disability, and on their own behalf. The discussion of the complaint systems proposed by the Commission refers to 'clients', people with disabilities, support providers, 'people' and a 'person with a complaint' without clarifying who is able to make complaints and challenge decisions and in what capacity.

The final report and recommendations must make clear that carers are able to make complaints and challenge decisions on behalf of the person they care for, where appropriate. It must also explicitly state that carers will be able to make complaints or challenge decisions in their own right, relating to their own experiences or issues within the NDIS. In many cases carers will be having high levels of contact with the NDIA, Disability Support Organisations and service providers assisting the person they care for, as well as receiving services and assessment in their own right.

**Recommendation 12:** Carers NSW recommends that carers have the same rights as people with a disability to make complaints and challenge decisions on their own behalf as carers, or, when appropriate, on the behalf of the person they care for.

## 8.2 Carer advocacy

The Commission must ensure that there are adequate advocacy services built into the NDIS to support the people with a disability and carers who require such services. There is little discussion of the need for individual advocacy in the draft report, although it is listed as one of the specialist disability supports that will be provided by the NDIS. Under 'Case management, local co-ordination and development' in Box 4.1 it is stated that "An individual could also elect to have a disability support organisation assist with case management and advocacy".

There is a significant need for advocacy services for carers and families. The report of the *Who Cares...?* Inquiry identified this need, and recommended that the National Disability Advocacy be extended to provide formal advocacy for carers in their own right when this is required, and to provide family advocacy services which better recognise the role of carers providing individual advocacy on behalf of, and with, care receivers.<sup>6</sup> This recommendation was not taken up by the Australian Government.

The Commission must give due consideration to where formal advocacy services for people with a disability should lie. The Commission must ensure that carers and families also have access to formal advocacy services. There may be scope for such services to be incorporated into or funded by the NDIA. Alternatively the Commission may make recommendations to the effect that the National Disability Advocacy be extended as recommended by the *Who Cares...?* Report, or that an advocacy service for carers is established, perhaps as a component of the National Carer Strategy and Framework.

**Recommendation 13:** Carers NSW recommends that the Commission address the need for formal advocacy services for carers and families in its final recommendations.

## 8.3 Carer representation on the advisory council and commercial board

Carers NSW strongly supports the Commission's proposals relating to the inclusion of carer representatives on an independent advisory council to the NDIS. It is important that carers and people with a disability are represented on the advisory council, and that there is a clear differentiation between their roles. Carers and people with a disability will have different experiences and perspectives on the implementation and operation of the NDIS, and it is generally inappropriate for a carer to represent the consumer perspective, or for a consumer to represent the carer perspective. Both carers and people with a disability must have their voice heard through this advisory council.

Carers NSW also supports the proposal for an independent commercial board, but contends that there should be some experience of disability and caring within the board. The Commission's proposal for the board to be comprised of people with the appropriate commercial and strategic skills, rather than a representational board is sound. However, the board selection criteria should be expanded to recognise expertise or direct experience in the areas of disability or caring, in addition to expertise in insurance, finance and management. The omission of disability or caring expertise from the selection criteria would mean that it would be possible for the board to be formed without a single member who has this expertise. A board without any disability or caring expertise may not have empathy for the objectives of the NDIS and the people it has been created for, nor will it inspire the confidence of people with disabilities, their carers and other stakeholders.

**Recommendation 14:** Carers NSW recommends that the selection criteria for the commercial board be extended to recognise expertise in disability and caring alongside the commercial and strategic skills currently recognised.

## 9. Supported Accommodation

Carers NSW first submission to this Inquiry highlighted the importance of making supported accommodation available to people with a disability. Carers NSW agrees with the Disability Investment Group that “of all disability services, the most significant unmet demand and the greatest anxiety for families relates to housing and accommodation”.<sup>7</sup> Carers NSW is acutely aware of the large number of individuals who need supported accommodation, and of the intensity of their need. Many carers are at breaking point. Sadly, there are others who have already broken, or who have died without the comfort of knowing that appropriate housing and support was being provided to their loved one. It is of the utmost importance that the NDIS brings about significant reform in this area.

Carers NSW appreciates the Commission's recognition of the diversity of the housing needs of people with a disability. There can be no one-size-fits-all solution to this issue, as the Commission is well aware. It is promising that in the discussion of this issue, the Commission has looked to more 'inventive' and innovative housing options, such as the cashing out of specialist disability housing to allow people with a disability the choice of purchasing accommodation services or housing, or entering the private rental market.

The Commission demonstrates an understanding of the importance of this issue, and of some of the complexities involved in meeting the considerable unmet need that currently exists. The Commission must ensure that this is a priority issue in its final report and recommendations, and that consideration is given to the full range of issues relating to the provision of supported accommodation, including the need to support and progress the devolution process, which in NSW is currently the cause of some concern.<sup>8</sup>

## 10. Diversity

All carers should have the same rights, choices and opportunities as other Australians, regardless of age, race, sex, disability, sexuality, religious or political beliefs, Aboriginal or Torres Strait Islander heritage, cultural or linguistic differences, socioeconomic status or locality.

Principle 1 from the *Statement for Australia's Carers*

Carers NSW was disappointed with the lack of acknowledgement in the draft report of the diversity of people with a disability and their carers. The report contains little consideration of the needs of people from culturally and linguistically diverse backgrounds in particular. There are no recommendations made relating to the provision of services to people from culturally and linguistically diverse backgrounds.

The final report should include greater consideration of the needs of people from culturally and linguistically diverse backgrounds for culturally appropriate and accessible services, particularly with regards to the capacity of the market to meet the needs of these individuals, and of the accessibility and appropriateness of information and other services provided by the NDIA. There should be a greater acknowledgement of diversity throughout the final report and recommendations.

**Recommendation 15:** Carers NSW recommends that the Commission give greater consideration to the needs of people from culturally and linguistically diverse backgrounds.

## **11. Linkages between disability and other systems**

The Commission demonstrates awareness of the importance of the NDIS and NIIS linking in with other sectors and with parallel reform processes. Carers NSW would again like to highlight the great importance of this issue. The NDIS and NIIS must have strong linkages with Carer Support Centres, the aged care system (and proposed 'gateway'), Medicare, Medicare Locals, Local Hospital Networks and the education system. The Commission must give due consideration to those individuals, particularly carers with multiple caring responsibilities, who will be accessing multiple systems.

**Recommendation 16:** Carers NSW recommends that the Commission give greater consideration to those individuals who will be accessing services from the NDIS or NIIS and other systems currently undergoing reform.

## **12. Individualised funding**

Carers NSW supports the move towards giving people with a disability and their carers more choice and control through individualised funding. Evidence from both local and international experiences demonstrates that self-determination and control have positive impacts on health and wellbeing for individuals and their carers.<sup>9</sup> People with a disability and carers are no different to other Australians in their desire to choice and control in their own lives.

### **12.1 Supports required for people receiving individualised funding**

It is pleasing to see that the Commission is taking a considered and cautious approach to the introduction of individualised funding. As Carers NSW raised in our first submission to the Inquiry, individualised funding must be introduced with appropriate supports in place to prevent possible negative impacts on people with a disability and their carers. There is some evidence that over time carers can experience an increased sense of social isolation and lack of support, and find it more difficult to navigate crisis points. For many carers, managing their own care budgets can be seen as increasingly burdensome over time.<sup>10</sup> Again it cannot be a one-size fits all approach.

Carers NSW detailed in its first submission to the Inquiry how its direct experience of individualised funding has demonstrated the importance of not leaving people on their own to navigate the system.<sup>†</sup> For many carers and people with a disability, assistance to plan and arrange support will be needed in the NDIS. It is promising that the Commission has recognised this in its draft report and recommendations.

Carers NSW strongly supports the Commission's decision to make self-directed funding an option, not an obligation, and the availability of support through DSOs to those who do choose this option. The self-directed funding option should be opt-out as well as opt-in.

It is also promising that some flexibility has been built into the 'choice of packages' options, so that those individuals who can exercise a greater degree of choice and control are able to do so without going to the extent of managing their own budget.

## 12.2 Introducing individualised and self-directed funding

The Commission has rightly identified the considerable barriers that exist to the take up of self-directed funding, and the need to address these. Carers NSW supports the Commission's draft recommendation 6.6 but recommends that the first point be amended to ensure that the NDIA informs people with a disability, their proxies *and carers and families* about the various options for self-directed funding.

**Recommendation 17:** Carers NSW recommends that the Commission amend draft recommendation 6.6 to explicitly recognise the need of carers and families for information about self-directed funding options.

Consideration should also be given to providing training or information sessions for people with disabilities and their carers, in addition to the training proposed for local case managers and front-line staff. The introduction of individualised funding entails a significant cultural shift, and many people will require assistance to understand what is involved and what it will mean for them. Some people will be made anxious by the changes, particularly those who have been receiving traditional disability services for many years. These individuals should be given every opportunity to understand and embrace what is a new conceptualisation of providing disability services and support.

The NDIA could deliver training directly to people with disabilities and their carers, or could consider a train-the-trainer approach and support DSOs or other organisations (such as peak bodies or advocacy organisations) to provide the training/information sessions. An online e-learning tool could also supplement the 'easy-to-understand guidance' proposed by the Commission, which must be of the highest quality if it is to assist people to understand and effectively use self-directed funding.

**Recommendation 18:** Carers NSW recommends that education and training in self-directed funding be made available to people with a disability and their families and carers.

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<sup>†</sup> Carers NSW has been involved in the Ageing, Disability and Home Care (ADHC) Department of Human Services NSW trial of *my plan, my choice*: Individualised (Packaged) Support. This pilot program provides support for the carer to be able to make and exercise an informed decision. In the *my plan, my choice* pilot being conducted by Carers NSW the carer receives assistance from a support planner (ADHC) and a support intermediary (NGO).

### **12.3 The continued need for block funding in some instances**

Carers NSW supports the Commission's acknowledgement that although individualised funding will be the norm, block funding should continue to play a role in the reformed disability system.

Although the move towards individualised funding comes with many potential benefits, Carers NSW is concerned at the very real prospect of market failure in some instances. Of particular concern is the capacity or likelihood of the market to provide for people from rural and remote areas, Aboriginal and Torres Strait Islander people, people from culturally and linguistically diverse communities, and people with high needs and challenging behaviours. Block funding may be required to address market failure in these cases.

The Commission refers to 'providers of last resort' to describe the situation in which a government department or agency is the only tenable service provider. Some guarantee is required that 'providers of last resort' will always step in where unmet need exists. The Commission must explore how common this scenario will be, what the long or medium term response will be when a 'provider of last resort' is required, and what the implications of this scenario are for person centred services and the right of individuals to choice and control.

As the Commission acknowledged in its draft report into the Caring for Older Australians Inquiry, particular service types may require block funding, particularly community oriented services such as community transport services, meal delivery services and perhaps some day programs or day activity centres. The Commission must address this issue in greater detail in its final report and recommendations to this Inquiry.

The Carer Support Centres proposed by the Commission will need significant levels of block funding in order to provide services and supports to carers within the NDIS and NIIS (some of whom may not receive funding allocations for their own support needs) and to carers who care for a person who is not eligible for the NDIS or NIIS but have significant needs for support. It is likely that there will be a large number of 'tier two' carers who will be referred to Carer Support Centres by the NDIS. Funding will be required to provide services and support to these carers, whose need for support may be compounded by their inability to access support through the NDIS.

**Recommendation 19:** Carers NSW recommends that the Commission give greater consideration to the need for block funding in some cases, including for the proposed Carer Support Centres.

### **13. Support for people with a disability and their carers who are ineligible for the NDIS**

Carers NSW strongly supports the introduction of the NDIS, and believes that the proposed schemes have the potential to transform the lives of those individuals who are eligible for services under the scheme. For many people with disabilities and their families and carers, the services and supports that will become available to them will greatly improve their health and wellbeing, their participation in the community, education and in the workforce, and their financial status. Carers NSW hopes that many of the carers who are currently plagued by concern for the future of the person they care for will finally have a satisfactory answer to the question "what will happen to them when I die?"



Although the proposals made by the Commission in the draft report have the potential to bring about transformational change for many individuals, Carers NSW has concerns relating to the situation of people who will be ineligible for the NDIS. The Commission must ensure that its final report and recommendations take into account the impacts of the introduction of the NDIS on the people who will not be eligible, and that they incorporate measures to counteract the development of a two-tier disability system (consisting of those within the NDIS and those outside of it), and prevent a considerable number of people being worse off after the introduction of the schemes.

In the consultations and discussions that have been occurring throughout the Inquiry, there has been little consideration given to the future provision of services and supports by Australian governments, particularly by state and territory governments, to people who will be ineligible for the NDIS or NDIS. The Commission's proposal for funding the NDIS involves a 'tax swap' where the state and territory governments either reduce inefficient state taxes by the amount of own-state revenue they currently use to provide disability services, or by transferring that revenue to the Australian Government.

Carers NSW concern is that this transfer will lead to a very significant reduction in state and territory funded disability services, and that people will lose the services and supports they currently depend upon. For those individuals who are eligible for the NDIS this will not be a problem, assuming a smooth transition to the scheme. The concern is that those people who are not eligible will receive no or much less support from the state and territory governments.

Carers NSW recommends that the Commission consider the likely impact of the funding arrangements that it proposes on people with a disability and their carers who will fall outside of the NDIS. Carers NSW does not suggest that the proposal for the funding arrangement should be changed, nor does this constitute a qualification of our support for the NDIS. Carers NSW does recommend that the Commission take measures to ensure that people with a disability and their carers who are ineligible for the NDIS will not be worse off. The Commission should consider other options than the 'no disadvantage test' it has already rejected.

It is important that expectations in the community regarding the NDIS are realistic, and that there is an understanding amongst Australian governments that the introduction of the NDIS does not mean an end to the need for funded services outside of the scheme. Although the NDIA is described by the Commission as a single agency to replace the nine governments that currently fund, organise and supply supports to people with a disability and their carers, there needs to be greater awareness that this agency will assist *some* and not all people with a disability and their carers. There will continue to be a significant role for the Australian and state and territory governments to support those people with a disability, and their carers, who remain outside of the scheme.

**Recommendation 20:** Carers NSW recommends that the Commission consider the likely impact of its proposed funding arrangements on people who will be ineligible for the NDIS, and ensure that the NDIS can be implemented without leaving some individuals worse off.

## Summary of Recommendations

1. Carers NSW strongly recommends that the Commission address the invisibility of carers in the draft report by giving them greater recognition and consideration in the final report and recommendations.
2. Carers NSW strongly recommends that carers are not included with the workforce, and that a separate chapter is dedicated to carers in the final report.
3. Carers NSW recommends that the *Statement for Australia's Carers* be adopted as a tool to reassess the Commission's conceptualisation and treatment of carers in the final report.
4. Carers NSW recommends that detailed analysis of carer assessment is undertaken and recommendations made.
5. Carers NSW recommends that carer assessment takes into account what is 'substantial' for the carer.
6. Carers NSW recommends that carers have the right to request assessment for themselves as carers.
7. Carers NSW recommends that reassessment also occurs at transition points in the carers' life, and that carers have the right to request reassessment.
8. Carers NSW recommends that the NDIS be a truly person and family centred scheme, able to respect the choices of the carer as well as those of the care recipient.
9. Carers NSW recommends that the Commission consider conceptualising carers as clients of the NDIS in their own right.
10. Carers NSW recommends that people with a psychosocial disability and their carers be eligible for the NDIS.
11. Carers NSW recommends that draft recommendation 13.4 be amended to support the need for all carers to have the right to request flexible working arrangements, regardless of the age of the care recipient, the nature of their relationship, or their eligibility for the NDIS.
12. Carers NSW recommends that carers have the same rights as people with a disability to make complaints and challenge decisions on their own behalf as carers, or, when appropriate, on the behalf of the person they care for.
13. Carers NSW recommends that the Commission address the need for formal advocacy services for carers and families in its final recommendations.
14. Carers NSW recommends that the selection criteria for the commercial board be extended to recognise expertise in disability and caring alongside the commercial and strategic skills currently recognised.
15. Carers NSW recommends that the Commission give greater consideration to the needs of people from culturally and linguistically diverse backgrounds.

16. Carers NSW recommends that the Commission give greater consideration to those individuals who will be accessing services from the NDIS or NIIS and other systems currently undergoing reform.
17. Carers NSW recommends that the Commission amend draft recommendation 6.6 to explicitly recognise the need of carers and families for information about self-directed funding options.
18. Carers NSW recommends that education and training in self-directed funding be made available to people with a disability and their families and carers.
19. Carers NSW recommends that the Commission give greater consideration to the need for block funding in some cases, including for the proposed Carer Support Centres.
20. Carers NSW recommends that the Commission consider the likely impact of its proposed funding arrangements on people who will be ineligible for the NDIS, and ensure that the NDIS can be implemented without leaving some individuals worse off.

## **Conclusion**

Carers NSW appreciates the opportunity to provide another submission to the Inquiry into Disability Care and Support and looks forward to the final report and recommendations of the Inquiry.

If you require any further information about Carers NSW submission to this Inquiry, please contact Alison Parkinson on 02 9280 4744 or email [alisonp@carersnsw.asn.au](mailto:alisonp@carersnsw.asn.au).

Yours sincerely,



Elena Katrakis  
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Carers NSW

29 April 2011

## End notes

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<sup>1</sup> National Health and Hospitals Reform Commission, *A Healthier Future For All Australians: Final Report of the National Health and Hospitals Reform Commission*, Canberra, 2009.

<sup>2</sup> Deanna Pagnini, *Carer Life Course Framework: an Evidence-Based Approach to Effective Carer Education and Support*, for Carers NSW and NSW Health, Sydney, 2005.

<sup>3</sup> Carers NSW, *Carers NSW Carer Survey 2010*, Sydney, 2010.

<sup>4</sup> United Nations, *Convention on the Rights of Persons with Disabilities*, Article 1, 2006.

<sup>5</sup> House of Representatives Standing Committee on Family, Community, Housing and Youth, *Who Cares...? Report on the inquiry into better support for carers*, Canberra, 2009.

<sup>6</sup> House of Representatives Standing Committee on Family, Community, Housing and Youth, *Who Cares...? Report on the inquiry into better support for carers*, Canberra, 2009.

<sup>7</sup> Disability Investment Group, *The Way Forward – A New Disability Policy Framework for Australia*, Canberra, 2009.

<sup>8</sup> NSW Ombudsman, *People with disabilities and the closure of residential centres*, A special report to Parliament under section 31 of the *Ombudsman Act 1974*, Sydney, 2010.

<sup>9</sup> C Bigby and C Fyffe C, *Achieving their own lives: the implementation of individualised funding for people with intellectual disability*, Proceedings of the Third Annual Roundtable on Intellectual Disability Policy, La Trobe University, Melbourne, 2006.

<sup>10</sup> G Ottmann, C Laragy and M Haddon M, *Experiences of disability consumer directed care users in Australia: results from a longitudinal qualitative study*, *Health and Social Care in the Community*, 17 (5), pp 466-475, 2009.