The NDIS one year in

Experiences of carers in the Hunter trial site

Carers NSW AUSTRALIA

A Carers NSW issues paper

September 2014

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Carers NSW wishes to acknowledge and thank the many carers and service providers whose comments and stories have informed this paper.

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Foreword

The National Disability Insurance Scheme (NDIS) presents an unprecedented opportunity for people with disability to receive the support they need to achieve their goals. The greater choice and control offered by the NDIS will change the lives of many people with disability and the family members and friends who provide them with informal support, their carers.

Carers NSW has been following the development of the NDIS with great interest. The presence of a trial site in New South Wales (NSW) has also enabled Carers NSW to hear directly from carers and service providers about their experiences and concerns. In addition to a number of positive stories, Carers NSW has identified some key challenges which require consideration and responsive solutions.

As this paper demonstrates, many carers in NSW are having difficulty understanding and engaging with the NDIS and supporting participants to prepare and implement their plans. The recognition of carers in the NDIS policy framework is promising but remains limited, and the future of carer support as NSW transitions to the NDIS is highly uncertain.

Carers are not the focus of the NDIS, however they will be expected to provide ongoing informal support for many participants. Gaining the trust of carers and adequately supporting them to care sustainably into the future will therefore be essential for the NDIS to succeed.

Carers NSW urges the National Disability Insurance Agency (NDIA), the NSW and Commonwealth governments, the community and other key stakeholders to make supporting carers a key priority in any NDIS related policy and practice. It is imperative that carers' support needs are properly addressed into the future, either as part of the NDIS or in conjunction with it.

Elena Katrakis

Chief Executive Officer

Carers NSW

Executive Summary

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The National Disability Insurance Scheme (NDIS) presents an unprecedented opportunity for Australians with permanent and significant disability to receive the lifelong support they need to pursue their goals and participate in their communities. The greater choice and control offered by the NDIS promises not only to benefit people with disability but also the family members and friends that provide informal support to people with disability, their carers.

The first year of the four initial NDIS trials has produced significant achievements, but has also highlighted a range of key challenges. The National Disability Agency (NDIA) has been responsive to the challenges identified and has clearly stated its intention to continuously improve the Scheme based on stakeholder feedback during the trial period.

Carers NSW has been closely following the rollout of the NDIS in the NSW trial site in order to identify any issues emerging for carers. While people with disability, not carers, are the focus of the NDIS, sustainable informal care arrangements will be critical for the Scheme to succeed.

This paper draws on Carers NSW research, consultation and policy analysis from throughout the first year of the NSW trial. It summarises key issues arising for carers and intends to contribute to the ongoing refinement of NDIS design and implementation.

Benefits for carers in NSW

Carers NSW supports the introduction of the NDIS in NSW and acknowledges that it is already changing the lives of many people with disability and their carers for the better. Benefits experienced by carers in NSW include:

- Significant improvements in the amount, quality, value and flexibility of support received by the NDIS participant since entering the Scheme;

- Flow on benefits for carers, including the ability to return to work, reduced stress and less financial pressure;
- Some funded supports directly supporting the caring role, including domestic assistance, respite and family therapy; and
- Positive working relationships with NDIS planners.

Challenges for carers in NSW

While many carers in NSW have had positive experiences of the NDIS, a number of key issues have come to our attention.

Understanding the NDIS

Many carers in NSW – within and outside the trial site – are struggling to understand, and therefore to embrace, the NDIS. This is largely due to:

- limited and inconsistent information;
- unclear language;
- uncertainty about the Scheme rollout at national level; and
- inadequate communication with carers about what to expect.

Carer recognition and assessment

The NDIS policy framework recognises that:

- The role of carers in the life of the person they care for should be acknowledged and respected;
- Planners should determine whether the informal support provided by carers is sustainable and reasonable; and
- Where appropriate, a plan should build the capacity of carers to provide support.

While Carers NSW welcomes these key values, we have identified the following issues:

- Treatment of carers by NDIS planners has varied and some carers feel their perspective has not been adequately taken into account; and
- A separate conversation between the planner and the carer is only a possibility, not a formal entitlement for carers.

Carer supports and services

Carers of NDIS participants are likely to benefit from the funded supports provided to the participant, and the NDIS policy framework also allows for some supports to be funded especially to sustain informal care arrangements. However:

- A large number of people with disability will not be eligible for the NDIS, and therefore they and their carers will not receive funded supports;
- It is clear that the NDIS is not about carers, and that carers of NDIS participants are not entitled to referral or funded support in their own right through an NDIS package;
- Carers of people with disability may no longer have access to Commonwealth funded carer supports *outside* the NDIS, since funding is being redistributed into the NDIS and Commonwealth Home Support Program; and
- In NSW, people with disability who are not eligible for the NDIS, and all carers of people with disability, may no longer have access to State funded disability and carer supports in future, as the NSW Government will withdraw from providing disability services once the NDIS is fully rolled out.

Carers NSW is highly concerned about the major gap in carer support that will result from current model and urgently calls upon the Commonwealth and NSW Governments to address this.

Preparing and implementing the plan

A number of capacity building initiatives are underway in NSW to prepare people with disability and their carers for the NDIS. However:

- Not all carers are able to access these opportunities, and many carers still feel underprepared when they attend planning sessions;
- Many carers feel that the NDIS has created more work for them, leaving them overwhelmed;
- Many carers are finding NDIS plans difficult to read, understand and implement.

Summary of recommendations

Recommendation 1: Carers NSW recommends that the NDIA and NSW Government improve the availability, consistency, timeliness and accessibility of information provided to people with disability and their carers in NSW regarding the NDIS.

Recommendation 2: Carers NSW recommends that the NDIA simplify and define the language used in their communications.

Recommendation 3: Carers NSW recommends that the Commonwealth, State and Territory governments finalise the rollout timetable as soon as possible and clearly communicate any changes to carers within and outside the trial sites.

Recommendation 4: Carers NSW recommends that the Commonwealth, State and Territory governments develop a nationally consistent communications strategy that includes a focus on carers.

Recommendation 5: Carers NSW recommends that the guideline *Supports for sustaining informal support* require that all carers involved in the planning process be offered a separate assessment of their own goals and support needs that is formalised and nationally consistent.

Recommendation 6: Carers NSW recommends that NDIS planners be provided with training in carer recognition and support.

Recommendation 7: Carers NSW recommends that the guideline *Supports for sustaining informal support* allow for carers to be referred to appropriate services and supports and provided with NDIS funded supports addressing their needs, as identified in the carer assessment.

Recommendation 8: Carers NSW recommends that there be greater information sharing between organisations in the NSW trial site, including the NDIA, to ensure that capacity building opportunities are available to all people with disability and their carers.

Recommendation 9: Carers NSW recommends that more detailed information, guidance and one-to-one support be made available to more carers as they prepare for the planning meeting.

Recommendation 10: Carers NSW recommends that regard be had for the potential for the NDIS to increase carers' workloads, and that information and support be provided to assist carers in implementing the plan.

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Introduction

The National Disability Insurance Scheme (NDIS) presents an unprecedented opportunity for Australians with permanent and significant disability to receive the lifelong support they need to pursue their goals and participate in their communities. The greater choice and control offered by the NDIS promises not only to benefit people with disability but also their families and carers.

Reports on the first year of the NDIS trials have identified significant achievements as well as key challenges moving forward[i]. In line with its "learn, build, learn, build" approach[ii], the National Disability Agency (NDIA) has been responsive to criticism and continues to welcome feedback from stakeholders in order to build a strong Scheme by full rollout.

As the peak organisation for carers in New South Wales (NSW), Carers NSW has taken great interest in the experiences of carers in the NSW trial site. This paper intends to summarise our learnings from the first year of trial and contribute these to the body of evidence being used to continuously improve the NDIS. It draws on research, consultation with carers, service providers and other stakeholders and analysis of the NDIS policy framework.

About carers

A carer is anyone who provides informal care and support to a family member or friend who has a disability, mental illness, drug or alcohol dependency, chronic condition, terminal illness or who is frail. There are approximately 2.7 million carers in Australia, of whom more than 857,000 live in NSW[iii].

While not all people with disability have a carer, informal care is the main source of support for people with disability[iv]. The majority (81 per cent) of people with disability who require assistance are supported by a carer, as defined above. People with disability who need help with self-care, mobility or communication are particularly likely (91 per cent) to receive support from a carer.[v]

Carers are not the focus of the NDIS, however, they are critical to its viability. Carers are expected to continue to provide a 'reasonable' level of support to NDIS participants[vi], as "the NDIS is designed to complement, rather than substitute, informal supports"[vii]. As part of this continued role, many carers will also be either invited by participants to contribute to the planning process, or be required as nominees, and many will help the participant to manage and implement their plan.

About Carers NSW

Carers NSW is an association that supports and represents carers in NSW. We are the peak organisation for carers in NSW and the only state-wide organisation that has all carers as its primary focus. We are part of a national Network of Carers Associations and work collaboratively to lead change and action for carers. Monitoring and sharing the impacts of the NDIS rollout on carer supports and services has become a priority within the Network.

The New South Wales trial

NSW was one of four states to commence trialling the NDIS in 2013-14. The NSW trial is located in the Hunter region and involves a staged rollout, from Newcastle in 2013-14, to Lake Macquarie in 2014-15 and finally Maitland in 2015-16.

The NSW trial is open to all people with disability aged 0-64 years who meet the eligibility criteria and is expected to bring in 10,000 participants by its completion in mid-2016. At the time of writing, the Hunter trial has more than 2,000 registered participants.[viii]

From July 2016 the NDIS will progressively roll out across the remainder of NSW to cover approximately 140,000 people by mid-2018[ix]. At that point, the NSW Government will cease to fund or provide any disability or community care services, as per their agreement with the Commonwealth in December 2012.[x]

Carers NSW strongly supports the introduction of the NDIS in NSW and commends the hard work of the NDIA and NSW Government in implementing the trial so far and the great efforts made to transition people with disability, their families and carers. The support provided by the NDIS is already changing the lives of many carers for the better, reducing the emotional, physical and financial pressure of caring for many and providing increased opportunities to participate in the community and workforce.

It has also come to our attention, however, that the future of carer support in the new system is not clear cut, especially in NSW, and that some aspects of the design and implementation of the NDIS may unintentionally disadvantage carers. Carers NSW has been closely following the development of the NDIS and its implementation in the Hunter trial site in order to determine how the NDIS affects carers, whether there are any issues that need to be addressed before full rollout, and how carers across NSW can be best prepared to transition to the NDIS.

This paper

This paper brings together the information gathered by Carers NSW in the first year of the NSW trial. It focuses on the experiences, both positive and negative, of carers in the Hunter trial site and reflects on key issues arising for carers in NSW with regard to the design and implementation of the NDIS. It is not intended to be a comprehensive analysis of issues arising from the NDIS and has a deliberately narrow focus on the treatment and experiences of carers. Other issues of which we are aware, for example issues with transport provision, housing supply and support worker pay rates, we have left to the formal reviewers of the NDIS and other stakeholders with more expertise in these areas.

The purpose of the paper is to provide constructive feedback to the NDIA, NSW and Commonwealth governments, the community and other key stakeholders about the NDIS from the perspective of carers in NSW. It is our hope that in sharing our learnings we can contribute to the fine tuning of the NDIS and build toward a full scheme that achieves the best possible outcomes for people with disability and their carers.

The information in this paper draws on our analysis of the NDIS policy framework and our ongoing consultation with carers, service providers and other stakeholders in the Hunter trial site and across NSW. It also draws on unpublished qualitative data from the Carers NSW Carer Survey 2014 (Carer Survey)[1] and real-life case studies based on stories shared with Carers NSW staff. All Carer Survey quotations and case studies included in the paper are de-identified.

1 Carers NSW undertakes a biennial survey of carers in NSW. The 2014 survey was conducted in May-June 2014 and included a section for carers of NDIS participants. There were 39 respondents to this section.

Benefits for carers in NSW

Contact with individuals and organisations in the Hunter trial site has indicated to Carers NSW that many carers are experiencing positive outcomes from the NDIS. Consistent with the recently published progress report by the Joint Standing Committee on the NDIS[xi], Carers NSW has received positive feedback in relation to the level of support participants have been able to access, experiences of the planning process, and the effects of NDIS supports on the lives of people with disability and their carers.

David* cares for his adult son Gary*, who recently went through the NDIS planning process with the support of his Dad and his service provider. They had a very helpful planner and were very happy with the process. David now gets four times as much respite as he did previously and Gary has sufficient therapy, personal care and domestic help for the first time.

* Names have been changed for all case studies

Support for the person they care for is typically a carer's first priority. A number of Carer Survey respondents wrote about significant improvements in the amount, quality, value and flexibility of support received by the person they care for since becoming an NDIS participant.

"The NDIS is allowing my son to receive invaluable support, especially speech therapy, which we could not afford to provide at the current level without the assistance of the NDIA. The difference it is making to his abilities will have a life-long impact on how he interacts with the world. It has given us a renewed hope for his abilities to cope with adult life, and will hopefully reduce the level of financial assistance he will require as an adult."

"Recently we opted for direct payment and direct employment of support workers and this is FANTASTIC. A little bit of work to set up but assisted by a bookkeeper who also does payroll of support workers. We promoted one support worker to co-ordinate the support arrange rosters and verify time sheets. We have more choice and control, support is totally tailored to my son, support workers undertake the training we want and we get more bang for our buck."

Improved support for the participant was also shown to have flow on benefits for carers themselves, including the ability to return work and reduced stress and financial pressure.

"They are coming to our son instead of us going here, there and everywhere which is exhausting for all."

"Able to access to the therapies required without putting a financial strain on family income."

"Allows me to perform part time work."

In addition to these indirect benefits, some respondents also benefited from funded supports directly supporting the caring role, including domestic assistance, respite and family therapy.

"A limited amount of family therapy has been funded (which will be good for our daughter)."

"Didn't have any funding before - has been very helpful with providing assistance to carer, respite etc."

Two respondents also reported positive experiences of working with planners.

"Has a plan of treatment set up by NDIS planner and go through in details and if need to, the planner I can approach and liaise."

"It is nice to have a Planner (case manager) who is familiar with myself and my son, to have the same person to deal with consistently, and to feel like we are people and not just a case file."

Challenges for carers in NSW

This section focuses on broad issues facing carers in NSW with regard to the design and implementation of the NDIS. These are summarised by four themes: understanding the NDIS, carer recognition and assessment, carer supports and services and preparing and implementing the plan. The section also contains a number of recommendations proposed by Carers NSW as options for improving carers' experiences of the NDIS.

Understanding the NDIS

Many carers are already experiencing, or are anticipating, positive outcomes from the NDIS. However, many others are struggling to understand, and therefore to embrace, the new

system. Clearer information and more extensive communication will be required to support carers to engage with the NDIS as the trial continues.

Quality and consistency of information

Consultation with carers and service providers by Carers NSW indicates that the information made available to carers in the Hunter trial site is often limited and inconsistent. Information has often been received in an untimely manner, is inequitably distributed across the trial site or is inaccessible to groups with special needs, such as carers with disability, culturally and linguistically diverse (CALD) carers, Aboriginal and Torres Strait Islander carers and older carers unable to use the internet. Clear, accessible and timely information has also been identified in the KPMG, Joint Standing Committee and NDIA reports on the first year of the NDIS as a key area for improvement.[xii]

The NDIA has used a number of communication channels to provide information to people with disability and their carers. The NDIS website contains a wealth of useful information, documentation and resources, and together with the trial site offices and 1800 number, acts as a centralised gateway to information and support. Community Forums are also held regularly across the Hunter trial site in order to keep people with disability, their families and carers informed about the NDIS. While these modes of communication have been useful for many carers, others have reported limitations, including inconsistent advice from the 1800 number, overly general information at the Community Forums, and a prior lack of access to templates of the participant statement and planning form on the NDIS website.

Trudy cares for her son James. At the forums Trudy attended before the NDIS trial commenced, she was assured she would continue to get respite. However, early in the trial, the message changed. She was told that respite was not available under the NDIS and that the NSW Government would no longer be providing respite services. Trudy rang the 1800 number to ask about how respite would be provided in future, and the person she spoke to did not know what to say. Trudy was angry and concerned about the inconsistent messages.

Recommendation 1: Carers NSW recommends that the NDIA and NSW Government improve the availability, consistency, timeliness and accessibility of information provided to people with disability and their carers in NSW regarding the NDIS.

Use of language

Information difficulties in the Hunter trial site have been compounded by the use of acronyms and jargon that are difficult for many participants and carers to understand. For example, there has been confusion between the terms 'NDIS' and 'NDIA', many carers are aware that the term 'respite' is out of favour but are unaware of what alternative language

to use, and terms are often taken from technical legislation and guidelines and are not adequately translated or defined in context.

Recommendation 2: Carers NSW recommends that the NDIA simplify and define the language used in their communications.

Misunderstanding and anxiety

The lack of information available to carers, together with the constantly evolving nature of the NDIS and the lack of clarity at national level about its funding arrangements and rollout timetable, has resulted in widespread anxiety and scepticism among carers both within and outside the trial site. Carers regularly ask Carers NSW staff whether the NDIS will proceed as planned, or express their incredulity that this will be the case. The Joint Standing Committee and KPMG reports also acknowledge the pressure that delays in government decision making is putting on participants and carers, and the importance of finalising and communicating what the transitional arrangements are as soon as possible.[xiii]

"The wonder of when or if the funding will cease."

Recommendation 3: Carers NSW recommends that the Commonwealth, State and Territory governments finalise the rollout timetable as soon as possible and clearly communicate any changes to carers within and outside the trial sites.

It is not only carers in the Hunter trial site who require more information. Carers NSW has observed that many carers outside the trial site are hungry for information about how the NDIS will impact them, but are receiving mixed messages from service providers and limited communication from both State and Federal governments. As a result there is considerable misunderstanding about the NDIS, leading some carers to have false expectations about what it will deliver for them, and other carers to fear and even dread the NDIS.

Many carers are yet to be convinced that the NDIS will be a positive change for them and the person they care for. While some trepidation is rational given the concerns held by Carers NSW, much of the uncertainty among carers appears to hinge on a lack of knowledge or misunderstanding of the principles behind the NDIS and how it works in practice.

Mary lives in a regional area and cares for her friend Joan who has younger onset dementia. She believes that the NDIS is being used as an excuse to cut services and that there is not enough planning to ensure adequate services will be available in regional areas in the future. Mary is also concerned about how support will be provided in the years leading up to the full rollout, especially as her own health and Joan's condition are rapidly deteriorating, which will increase her need for respite and help at home.

Annabel cares for her adult son Aaron and is very distressed about the potential implications of the NDIS. She says that many other carers she knows feel the same. Annabel believes Aaron will never be able to live independently and she has been continuously disappointed with the lack of support available in the community, and therefore thinks the new system cannot possibly work for them.

Patricia cares for her son, Jeremy, who has high support needs and currently receives individualised funding. She has many questions about the NDIS: When will it roll out in her area? Will her son's level of funding stay the same? Will they have to go through all the planning and paperwork again? She has been unable to get solid answers, making her and her partner unable to plan for the future and increasingly anxious.

Recommendation 4: Carers NSW recommends that the Commonwealth, State and Territory governments develop a nationally consistent communications strategy that includes a focus on carers.

Carer recognition and assessment

Another key issue for carers in engaging with the NDIS is how the caring relationship is conceptualised in the NDIS policy framework. The NDIS legislation, rules and operational guidelines broadly recognise the role of carers, and NDIS representatives consistently point to the benefits that carers will, and do, experience from the funded supports received by the person they care for. However, Carers NSW is concerned that these provisions do not go far enough.

Carers and the NDIS legislation

The *National Disability Insurance Scheme Act 2013* (the *NDIS Act*) entitles carers to certainty that the person they care for will receive the care and support they need over their lifetime[xiv] and to acknowledgement of, and respect for, their role in the life of the person they care for[xv]. Furthermore, the funding or provision of any support by the NDIA must take into account what is reasonable to expect families, carers, informal networks and the community to provide[xvi], and the participant's support plan should, where relevant, consider and respect the role

of family members and carers in the life of the participant. It should also, where possible, strengthen and build the capacity of family members and carers to support participants[xvii].

While Carers NSW applauds the inclusion of carers in the NDIS legislation, none of these provisions require a carer's own needs to be either formally assessed or met through the provision of funded supports. The *Operational Guidelines on Planning and Assessment* published and revised in early 2014 have addressed these concerns in part, however there is still considerable room for improvement.

Carers and the operational guidelines

The operational guideline *Supports in the Plan* details how a planner may decide what is reasonable to expect carers to provide, including the following considerations:

- The extent of any risks to the short or long term wellbeing of the carer in providing the required support; and
- The suitability of the carer to provide the required support, with reference to factors such as:
  - Age and capacity
  - Availability of supports to sustain them in their caring role
  - Intensity and type of support required
  - Whether providing the support is age and gender appropriate (e.g. a child should not be expected to provide care to an adult; it would not be reasonable to expect the son of a 50 year old female to assist her with showering and toileting)[xviii].

The lower level operational guideline *Supports for Sustaining Informal Support* recognises the importance of supporting carers to ensure the sustainability of the caring role, and further specifies that planners should take into account:

- The carer's circumstances and capacity;
- The carer's future plans, relevant to the caring role;
- The impact of providing support on the carer (e.g. adverse impacts of challenging behaviours);
- The sustainability of the caring arrangement; and
- What supports may be required to sustain (or replace, in some cases) the carer's ongoing provision of support[xix].

This guideline acknowledges that establishing the impact of providing support on the carer and their capacity to continue providing support may involve a separate conversation with the carer, but only "in some circumstances[xx].

Inconsistency in the treatment of carers

While Carers NSW welcomes the increased awareness and recognition of carers' support needs reflected in these guidelines, we are concerned that they do not guarantee any kind of formal or consistent assessment of carers' support needs. According to our consultation with carers and service providers in the Hunter trial site, carers' experiences with the planning process have varied greatly depending on the planner they encounter. Some carers feel their needs have been thoroughly considered and met, however others have felt excluded from the conversation and as though their needs and opinions did not matter.

Sylvia supports carers in the Hunter trial site. Some carers she has spoken to have had positive experiences with planners, but mostly their experiences have been negative, with some families being told quite rudely that "it's not about them". One carer Sylvia spoke to was thrilled with the amount of financial support offered to her son, but was upset that nobody asked her at any time how she was coping.

Annette cares for her adult daughter, Daisy, who is an NDIS participant and lives at home. Daisy has considerable personal care needs and challenging behaviours, which has strained their relationship. Annette is not coping and would prefer not to live with Daisy, but Daisy disagrees. Annette has tried to renegotiate this with the NDIA but without success. She is afraid her own need for respite will be outweighed by her daughter's unrealistic representation of the situation.

The Joint Standing Committee Report highlights the importance of the operational guidelines in promoting consistent decision making among NDIS planners, and recommends regular review and scrutiny of these guidelines, taking into account the views of a range of stakeholders, including carers.[xxi] Amending these guidelines to include clearer guidance on how carers' support needs are assessed will be critical in securing a consistent approach among planners. In addition, Carers NSW argues that a formalised needs assessment and separate conversation be offered to all carers, in keeping with Recommendation 7.6 of the Productivity Commission's 2011 report on *Disability Care and Support*:

> *"Where an informal carer provides a substantial share of the care package, they should receive* ***their own assessment if they wish*** *[emphasis added]. This should seek to identify their views on the sustainability of arrangements and the ways in which the NDIS should support their role.*[xxii]*"*

However, even if the guidelines are made clearer, further support will be required for planners to ensure these are understood and implemented correctly and consistently, as guidelines can be open to interpretation. Planners will also require training in carer awareness to understand how the needs of diverse carers should be assessed. Training

would need to confront difficult issues that may arise for planners such as conflict between the interests and preferences of a participant and carer. Carers NSW is concerned that carers may be disadvantaged and not equally heard if they disagree with the participant, as in the case study of Annette and Daisy.

Recommendation 5: Carers NSW recommends that the guideline *Supports for sustaining informal support* require that all carers involved in the planning process be offered a separate assessment of their own goals and support needs that is formalised and nationally consistent.

Recommendation 6: Carers NSW recommends that NDIS planners be provided with training in carer recognition and support.

Carer supports and services

In addition to highlighting the need for carer assessment, the Productivity Commission report specifies that carers should be provided with appropriate referral and funded support under the NDIS:

> *"In order to sustain informal care and support, the NDIS should:*
>
> - *assess carer needs as well as those of people with disabilities (recommendation 7.6) and, where needed, use the assessment results to:*
> - ***refer people to specialist carer support services*** *[emphasis added] including the 'Carer Support Centres' recommended in the Commission's parallel inquiry into aged care and to the National Carers Counselling Program*
> - ***include the capacity for accessing counselling and support services for carers*** *[emphasis added] as part of the individual support packages provided to people with a disability"*[xxiii].

However, the NDIS policy framework falls short of providing this level of support to carers. The operational guidelines allow for some carer specific support, but this is limited to supports that directly relate to the caring role and have the purpose of sustaining the informal support arrangements of the participant, such as family counselling or training for the carer on an aspect of the person's disability. It does not allow for supporting carers in their own right. There is no indication that carers are entitled to referral or funded support according to their own assessed needs.

Indirect benefits to carers

When Carers NSW and other stakeholders have raised this issue with representatives of the NDIS, the response has consistently been that the NDIS is appropriately centred on the person with disability and not the carer, and that carers will naturally benefit from the funded supports provided to that person. For example, where personal care, domestic assistance and/or support to participate in the community independent of the carer is provided, this should free up carers to have a break, and perhaps even increase their participation in employment or education, improving their overall wellbeing.

Carers NSW agrees that focusing on the participant's needs is important, and that funded supports for the participant will benefit many carers. However, more support for carers is required. If the existing system of carer referral and support were to continue, the limited support provided to carers under the existing NDIS policy framework may be sufficient. However, a series of planned changes to the carer support system associated with the NDIS make these limitations problematic, especially in NSW.

The impact of planned policy changes

The first challenge relates to the transition of Commonwealth carer support funding into the NDIS and Commonwealth Home Support Program (CHSP). Carer supports including information, referral, emotional support, counselling and respite are currently provided to carers of people with disability and other conditions, including frail age, through the National Respite for Carers Program (NRCP)[2], the Home and Community Care (HACC) program and a range of other programs, including Mental Health Respite: Carer Support and the Young Carer program. Most of this Commonwealth funded carer support is earmarked for redistribution as part of the concurrent disability and aged care reforms. NRCP and HACC will be absorbed into the CHSP which, it appears, will be accessible only to older people and their carers, while the disability specific programs are typically in scope for the NDIS.

Carers NSW is concerned that this will take away from carers of younger people with disability the key source of carer-specific support, reflecting an assumption that equivalent supports will be provided under the NDIS. However, it is evident from the earlier discussion on the limitations of carer supports under the NDIS that carers of NDIS participants are not entitled to the same level of support as they are currently.

The situation is even more problematic for the carers of people with disability who will not be eligible for the NDIS. Funded supports will be available to an estimated 460,000 Australians with disability at full rollout[xxiv], with eligibility being determined based on age, residence status and specific disability or early intervention criteria, in line with the model proposed by the Productivity Commission in 2011[xxv]. However, the numbers of Australians with a reported disability, even those with a profound or severe core activity limitation, in the target age group (0-64) who

2 In addition to a range of respite services, the NRCP funds non-government organisations to deliver Commonwealth Respite and Carelink Centres (CRCCs), the National Carer Counselling Program (NCCP) and the Carer Advisory Service. Carers NSW currently delivers the latter two programs in NSW.

needed assistance with at least one activity in 2012 are much higher than this, at approximately 1.4 million and 710,000 respectively[xxvi]. This leaves large numbers of people with disability support needs and their carers who will not benefit from funded supports under the NDIS.

The response from NDIS representatives to this issue has been that Tier 2 will have some role in addressing such gaps, but that this will largely be the responsibility of the States and Territories. In States and Territories where there is the will and capacity to provide supports to carers of people with disability, this may be a viable solution. However this is not the case in NSW, which will unequivocally relinquish all responsibility for providing such services.

The situation in NSW

The *Heads of Agreement* between the Commonwealth and NSW governments, signed in December 2012, included the following condition: "Following commencement of the full NDIS, the NSW Government will not provide any residual specialist disability services or basic community care services"[xxvii]. All current disability funding in NSW (including programs delivering respite and other HACC-type services and a number of smaller programs providing case coordination and other carer supports) will be channelled into the NDIS from 2018, and between now and then, all the staff and assets of the NSW Government agency of Family and Community Services, Ageing, Disability and Home Care (ADHC) will be transferred progressively to the non-government sector[xxviii].

Once again, this threatens the support available to carers: those caring for an NDIS participant will only be entitled to a limited amount of NDIS funded support and may not, at this stage, have access to any additional services outside the NDIS; and for those who have no link with the NDIS, no remaining government support may exist. Indeed, some of those currently receiving State Government respite or other services may actually lose what they have if not eligible for the NDIS. As of June 2014, NSW had the highest proportion of ineligible applicants for the NDIS of all four first-year trial sites, with 15% of people making access requests being deemed ineligible[xxix]. If more than one in ten people in NSW seeking support through the NDIS continue to be refused service due to not meeting the eligibility requirements, this leaves a large number of people, including carers, still requiring support.

In NSW the Ability Links program has been set up to provide support parallel to the NDIS, with a focus on people not receiving specialist disability supports[xxx]. However, as an ADHC funded program, it remains unclear whether it will continue after 2018. If it does, the support it provides will not compensate for the loss of State block funded programs and services. Ability Links offers only a time-limited 'linking' service to people with disability, their families and carers, helping them make connections with supports, mostly from mainstream services and the community. There is no funding within Ability Links to provide actual services or programs for people with disability ineligible for the NDIS, let alone carers, which will be a problem once all NSW disability funding has been subsumed by the NDIS.

Carers and service providers across the state and in the Hunter trial site are already concerned about the implications of this for existing, effective carer supports and services.

Linda's daughter Kellie is an NDIS participant. Kellie is fairly happy with her supports, however Linda feels she has lost out. She previously benefited from carer retreats, which provided her with a real break from worrying about things at home. However, this was block funded and is therefore no longer an option. She says, "I don't know how good or bad [the NDIS] is, but I know I had more before. There's a whole heap of carers that, because they're on the NDIS, are getting nothing now. It's as though they've wiped us. And it's a bit sad in a way."

Diana coordinates a local carer support group which is funded and facilitated by a block funded service provider operating in the local community. With the advent of individualised funding, the organisation will not be able to continue this service. She thinks it is unrealistic to expect the group members to run it themselves because of the high demands of their caring roles.

Karen is the sole carer for her two adult daughters and is struggling to manage her caring role due to her own deteriorating health. She has benefited from social support through the NSW Government funded Older Parent Carer Program, but has heard the program will be phased out when the NDIS is introduced. "It will be great for my daughter," she says, "but when she comes home at night, I will still be doing the caring…The kids can go out all day, but when they come home Mum is the one cleaning up poo in the middle of the night." Karen asks, "Who will care for the carer? Don't forget us. We were already forgotten, and then were grateful for the support we got under the Older Parent Carer program. We don't want to be forgotten again."

Obligations in carer legislation

Carers NSW sees the continuation of carer support, either within or outside of the NDIS, as not only a moral duty, but a responsibility under the *Commonwealth Carer Recognition Act 2010 (the Carer Recognition Act)*. While we recognise that the NDIA has a limited remit prescribed by the Commonwealth Government and is therefore not solely responsible for addressing the issue of carer support, it has a key role. Indeed, the Productivity Commission report noted that "one of the key goals of the NDIS is to relieve the excessive stress that is currently felt by some carers" and that "counselling services for carers service an important role"[xxxi]. Moreover, as a Statutory Agency under the *Public Service Act 1999*[xxxii] that funds care supports, the NDIA is required to ensure that its employees and agents are aware of and understand the *Statement for Australia's Carers* and take action to reflect its principles in developing, implementing, providing or evaluating care supports[xxxiii].

Although the *Carer Recognition Act* is mentioned and reflected in part in the *NDIS Act*[xxxiv], the NDIS legislation and guidelines only address the aspects of the Statement for Australia's Carers dealing with recognition and respect. In order to uphold its responsibilities under the Carer Recognition Act, the NDIA also needs to provide support to carers in keeping with the following principles of the Statement for Australia's Carers:

> *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.*
>
> *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.*[xxxv]

Carers NSW is very concerned that none of these are built into NDIS policy or being consistently put into practice in the Hunter trial site. We urge the NDIA, Commonwealth and State and Territory governments to urgently consider the need to properly incorporate a robust system of carer support into the new disability support system.

Carer respite

The fate of carer respite has caused particular confusion and anxiety among carers in NSW. While some carers have reported obtaining more and better respite under the NDIS, including David's case study included earlier, there have also been many cases to the contrary. Carers NSW is highly concerned that funding changes for carer support include no safeguards to guarantee that carers will continue to consistently have access to the respite support that they need.

It is our understanding, and that of carers like Trudy whose case study was mentioned earlier, that 'respite' is not part of the NDIS vocabulary, and that carer respite support per se will not be included in a participant's support plan, since the supports funded are to be focussed around the needs and goals of the person with disability. Supports for the person with disability that have a respite effect can be requested but will need to be justified primarily in terms of their benefit to the participant, for example, facilitating participation for the person with disability in community, civic or social activities that also happens to provide a break to the carer. Further, a participant's other supports, such as paid assistance with household tasks and assistance to enter the workforce, are expected to have a respite effect for carers by reducing the demands of their role and providing them with time out.

We recognise that for some carers, this is likely to be the case. However, given the extent to which respite funding is set to be incorporated into the NDIS, we believe this framework will be inadequate to meet carers' needs for respite support. Firstly, not all people with disability will be eligible for an NDIS funding package, with the carers of ineligible people therefore being unable to access funding for supports which may have a respite effect. Secondly, given that there is currently no formal requirement for carer assessment as part of the support planning process, and that supports are considered 'reasonable and necessary' based on the goals of the NDIS participant, there is no guarantee that the level of respite required by the carer will be communicated, considered or provided if the NDIS participant is not in agreement.

Carers NSW firmly believes that carers are entitled to a break in their own right, without having to justify this need in relation to its benefits for the person they care for. There is a multitude of evidence highlighting the importance of respite support in preserving the health and wellbeing of carers, and therefore in sustaining informal care arrangements[xxxvi].

Although a key goal of the NDIS is to increase options for paid support and so free up informal carers to participate in the workforce, sustaining informal care arrangements remains critical to the successful implementation of schemes like the NDIS, to the health and wellbeing of people with disability and to reducing the high costs of disability supports to governments. It was suggested to Carers NSW staff by an NDIA representative that a replacement for respite, for example, would be providing a support worker to attend family outings and provide the care to the family member with disability. This may well be a valuable service, but it is not carer respite and it does not provide the same effect as respite.

Carers NSW has already heard concerns from carers of NDIS participants about the approach to respite, which does not prioritise the carer's own need for a break.

Elizabeth is the primary carer for her young son Jake, an NDIS participant. Under the NDIS, Elizabeth is entitled to significantly less respite than she was receiving previously. She has asked for more assistance but her requests have been rejected. The planner has argued that it is not in the child's interest to spend too much time away from his mother, but she argues that if she is not able to properly look after her son this will negatively impact him.

Recommendation 7: Carers NSW recommends that the guideline *Supports for sustaining informal support* allow for carers to be referred to appropriate services and supports and provided with NDIS funded supports addressing their needs, as identified in the carer assessment.

Preparing and implementing the plan

A number of capacity building initiatives are already being undertaken to prepare people with disability, their families and carers for the NDIS. The Practical Design Fund resources available on the NDIS website and more recent resources developed by the NDIA on the planning process are available to carers in all trial sites. In NSW, Family and Community Services (FACS) has funded the NSW Consumer Development Fund, *My Choice Matters*, as well as the *Getting Prepared* workshops. A number of other organisations, including councils, service providers and peak bodies, are also delivering resources and workshops for people with disability and carers in the Hunter trial site.

Such initiatives will be critical in ensuring that carers have the opportunity to develop the skills and knowledge necessary to have positive experiences and outcomes in the planning process. As the KPMG paper notes:

> *"for people with disabilities and their families, changing services has high transaction costs. With tailored support through the right communication channels (e.g. face-to-face, technological assistance, education of support workers), there will be greater capacity to shape demand, maximise choice and control and inspire the confidence of participants. This will underpin the transition to an effective and sustainable Scheme."* [xxxvii]

Lack of adequate preparation and support

Despite the many capacity building opportunities already available, stakeholders in the trial site have informed Carers NSW that many carers, especially older parent carers, are feeling ill-equipped and underprepared going into planning sessions. As the Scheme develops, more opportunities will undoubtedly arise for carers, access issues will be alleviated and better information sharing will occur between organisations so that more carers are aware of what is available. However, there is a pressing need for capacity building opportunities to be mapped in the trial site so that carers and service providers can easily access this information. Better mapping and coordination will also increase the uptake of existing opportunities and mitigate against unnecessary service duplication.

Recommendation 8: Carers NSW recommends that there be greater information sharing between organisations in the NSW trial site, including the NDIA, to ensure that capacity building opportunities are available to all people with disability and their carers

Carers NSW has found that the more prepared carers are for engaging with the NDIS, the more satisfied they generally are with the planning process and the better the outcomes for them and the person they care for. This was also the finding of the Joint Standing Committee progress report, in which a number of carers and service providers discuss the benefit of solid preparation. It is noted several times in the report, however, that many people will present to the NDIS without having spent the necessary months or even years considering goals and support needs, and will therefore be disadvantaged[xxxviii]. More support is therefore required for carers without the time, knowledge or capacity to undertake detailed preparation.

Key areas of improvement identified by carers and service providers include:

- increasing the timeframe given to carers between the invitation to the planning meeting and the meeting itself, to ensure adequate time to gather information and prepare documentation;
- clearer guidance prior to the planning meeting on what information to prepare, including advice on how to access and present this information;
- increased input from service providers about the type and level of current supports received by the person with disability so that important items are not neglected;
- more opportunities for intensive one-to-one support to assist carers prepare.

Eleanor cares for her adult daughter Sadie. She felt very prepared for her daughter's planning process as she has worked for many years in the disability sector. However many carers she mixes with are confused and distressed about the process, with some failing to identify and mention important details about necessary supports.

Recommendation 9: Carers NSW recommends that more detailed information, guidance and one-to-one support be made available to more carers as they prepare for the planning meeting.

Carers NSW believes the NDIA, State and Commonwealth governments, service providers and other organisations, including Carers NSW, need to share the responsibility for supporting carers. For our part, Carers NSW is currently developing a suite of resources containing information and tools that will assist carers in preparing for the planning process. We also commend the NDIS Sector Development Fund for funding Carers Australia to build the capacity of carers through training and resources.

An increased workload for carers

With regard to implementing the plan, Carers NSW has heard that many carers feel that the NDIS has increased the amount of time and effort required for their caring role. While we understand that this is not the intention of the NDIS, which aims to simplify the already complex system and decrease the pressure on carers, and that the burden on carers is likely to decrease over time, this is not currently the case for many carers. Older carers who have been caring for a long time are finding the transition particularly difficult. Many carers who responded to the CNSW Carer Survey, and many other carers and service providers we have had contact with, have expressed concern that the NDIS has resulted in more work for carers.

Leanne feels that the NDIS has made life more difficult for her and her adult daughter Jenny and that they have been left worse off. She is very angry and says that she doesn't want to be still fighting like this at her age. She is in her 70s and has been caring for most of her adult life.

"Huge difficulty engaging service providers - a 100 page print out of all service providers (names, websites and addresses but NO phone numbers) was given to us at the plan approval meeting. As the carer I had to trawl through the document identifying from my own experience and knowledge which organisations specialised in mental health - as the service provider list is not categorised or filtered in any way…only 3 responded to my initial enquiry and only 2 were genuinely interested in taking him on as a client. The process took about 6 weeks to finally engage someone…In relation to the family therapy, we were told by the NDIA that although they had funded it, no-one yet was providing it! Again it is up to me (the carer) to chase this up. FRUSTRATING, and for me, more WORK!!!"

"Funding received under FAHCSIA provided one pool of money that was easier to manage than the segmented system NDIS has. I find it difficult to keep track of how many visits, at what duration/session cost for each visit, for each provider. With the way the Plan Statements are set up on-line it is frustrating to try and keep track of how much funds you have remaining for each individual service provider [sic]."

Confusion regarding the plan

A particular issue identified by carers and stakeholders has been the confusion many carers face in reading and interpreting the person's plan. This was also highlighted in the Joint Standing Committee progress report[xxxix]. It has been acknowledged that the plan document is hard to read, even for service providers, such as support item numbers and how they relate to the title of the support item. Navigating the embryonic service landscape has also proved to be a challenge for many carers.

"Creating support links with service providers is proving to be very stressful and difficult to understand. It must be a nightmare for very elderly people."

"It would be difficult to care for a newly diagnosed person with a disability & be starting in NDIS as there is little information on what services and opportunities are available."

"Co-ordinating services and dealing with the NDIA has been very difficult - Service providers are not sure of what documentation they should be providing and the NDIA personnel are not sure of procedure and what they can and cannot offer. Too many very busy people unsure of what is going on."

"Some service providers/organisations don't know how to claim or process payments."

Recommendation 10: Carers NSW recommends that regard be had for the potential for the NDIS to increase carers' workloads, and that information and support be provided to assist carers in implementing the plan.

While many of these issues will be straightened out as the trial continues, they have caused immense stress for many that needs to be acknowledged and must also be learned from. It is clear to Carers NSW that carers need to be more aware of the involvement they will be required to have in implementing the plan and that more one-to-one intensive support will be necessary for some carers, especially older parent carers. The consistent implementation of the principles in the operational guidelines *Supports for Sustaining Informal Support* will also be important in ensuring that carers are not burdened with too much responsibility when they are often already stretched in their capacity.

Conclusion

Carers in NSW have had varying experiences of the NDIS in the first year of trial. There has been considerable anticipation and celebration, but a number of key issues have emerged. Carers NSW hopes that sharing our learnings from the first year of trial will support the NDIA, NSW and Commonwealth governments, the community and other key stakeholders to fine tune the design and implementation of the NDIS so that it provides carers with the best possible outcomes.

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i Joint Standing Committee on the National Disability Insurance Scheme (2014), *Progress report on the implementation and administration of the National Disability Insurance Scheme*, July 2014, Commonwealth of Australia, Canberra; KPMG (2014), *Interim report: Review of the optimal approach to transition to the full NDIS*, prepared for the National Disability Insurance Agency, 16 July 2014, KPMG; National Disability Insurance Agency (2014), *Building the National Disability Insurance Scheme: Progress Report: Year One*, July 2014, National Disability Insurance Agency.

ii NDIA (2014), *Building the National Disability Insurance Scheme*, page 4.

iii Australian Bureau of Statistics (2014), *Disability, Ageing and Carers, Australia: Summary of Findings, 2012,* Catalogue no. 4430.0, Carer tables, Table 36.

iv Productivity Commission (2011), *Disability Care and Support*, Report no. 54, Productivity Commission, Canberra, page 704.

v ABS (2014), *Disability, Ageing and Carers, Australia: Summary of Findings, 2012,* Disability tables, Table 15.

vi NDIA (2014), *Operational Guideline – Planning and Assessment – Supports in the Plan – Supports for Sustaining Informal Support (v. 1.0),* 11 March 2014, National Disability Insurance Agency, Canberra.

vii Joint Standing Committee on the NDIS (2014), P*rogress report on the implementation and administration of the NDIS*, page xiv.

viii Family and Community Services (2014), *Client transition: National Disability Insurance Scheme Hunter trial status dashboard,* data as at 30 June 2014, Family and Community Services.

ix Family and Community Services (2013), *National Disability Insurance Scheme: Information for people with disability, their families and carers in NSW who receive services from ADHC,* December 2013, Family and Community Services.

x *Heads of Agreement between the Commonwealth and NSW Governments on the National Disability Insurance Scheme,* section 33, signed by The Hon. Julia Gillard MP and The Hon. Barry O'Farrell MP, 6 December 2012.

xi Joint Standing Committee on the NDIS (2014), *Progress report on the implementation and administration of the NDIS,* section 4.7.

xii Joint Standing Committee on the NDIS (2014), *Progress report on the implementation and administration of the NDIS, sections 6.13-6.17; KPMG (2014), Interim report: Review of the optimal approach to transition to the full NDIS,* page 11. NDIA (2014), *Building the National Disability Insurance Scheme,* page 4.

xiii Joint Standing Committee on the NDIS (2014), *Progress report on the implementation and administration of the NDIS, section 6.52; KPMG (2014) Interim report: Review of the optimal approach to transition to the full NDIS,* page 13.

xiv *National Disability Insurance Scheme Act 2013* (Cwth), Chapter 1, Part 2, Section 4(3).

xv Ibid, Chapter 1, Part 2, Section 4(12).

xvi Ibid, Chapter 3, Part 2, Section 34(e).

xvii Ibid, Chapter 3, Part 2, Division 1, Section 31(c),(d),(da).

xviii NDIA (2014), *Operational Guideline – Planning and Assessment – Supports in the Plan (v 2.0),* 16 January 2014, National Disability Insurance Agency, Canberra, section 26.

xix NDIA (2014), *Operational Guideline – Planning and Assessment – Supports in the Plan – Supports for Sustaining Informal Support (v. 1.0)*, sections 9-13, 23.

xx Ibid, Section 13.

xxi Joint Standing Committee on the NDIS (2014) *Progress report on the implementation and administration of the NDIS,* section 6.22.

xxii PC (2011), *Disability Care and Support,* Recommendation 7.6.

xxiii Ibid, Recommendation 15.4.

xxiv Joint Standing Committee on the NDIS (2014) *Progress report on the implementation and administration of the NDIS,* page xiv.

xxv PC (2011), *Disability Care and Support,* pages 750-762.

xxvi ABS (2014), *Disability, Ageing and Carers, Australia: Summary of Findings,* 2012, Disability tables, Table 14.

xxvii *Heads of Agreement between the Commonwealth and NSW Governments on the National Disability Insurance Scheme,* Section 33, signed in December 2012 by The Honourable Julia Gillard MP and The Honourable Barry O'Farrell MP.

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xxix NDIA (2014), *Quarterly Report to COAG Disability Reform Council,* 30 June 2014, NDIA, Table 1.3.2b.

xxx Ability Links NSW (2013), A*bility Links NSW Specification and Guidelines,* Ageing, Disability and Home Care.

xxxi PC (2011), *Disability Care and Support,* pages 704 and 725.

xxxii Australian Public Service Commission (2014), *Australian Public Service agencies,* http://www.apsc.gov.au/publications-and-media/current-publications/australian-public-service-agencies, last updated September 2014, Australian Government.

xxxiii *Carer Recognition Act 2010* (Cwth), Part 1(1), Part 3, Sections 7 and 8.

xxxiv *NDIS Act 2013* (Cwth), Chapter 1, Part 2, Section 3, (3)(ii).

xxxv *Carer Recognition Act 2010,* Schedule 1.

xxxvi e.g. Bruen, W. and Howe, A. (2009), *Respite Care for People Living with Dementia,* Discussion Paper 17, Alzheimer's Australia; Cockram, J., Hancock, P. and Jarvis, J. (2007), 'Supporting Older Carers of people with a Disability: an evaluation of a respite care program in Western Australia', *Asia Pacific Journal of Health Management,* 2(2): 58-62; Mollenhauer, J., King, S., Bodiam, T. and Bellamy, J. (2013), *Caring for a child with an intellectual disability and challenging behaviours,* ANGLICARE Diocese of Sydney; Wesley Mission (2014), *Giving disability carers a break,* The Wesley Report, no. 13, May 2014, Wesley Mission, Sydney.

xxxvii KPMG (2014), *Interim report: Review of the optimal approach to transition to the full NDIS,* page 14.

xxxviii Joint Standing Committee on the NDIS (2014), *Progress report on the implementation and administration of the NDIS* sections 4.10, 4.13, 4.25, 4.30 and 4.35.

xxxix Ibid, sections 4.13, 4.36, 4.37.