

**Submission
No 275**

**INQUIRY INTO IMPLEMENTATION OF THE NATIONAL
DISABILITY INSURANCE SCHEME AND THE PROVISION
OF DISABILITY SERVICES IN NEW SOUTH WALES**

Organisation: Carers NSW
Date Received: 14 August 2018

14 August 2018

The Director
Portfolio Committee No. 2 – Health and Community Services
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Inquiry into the implementation of the National Disability Insurance Scheme and the provision of disability services in New South Wales

Carers NSW wishes to thank Portfolio Committee No. 2 for the opportunity to provide a submission to the inquiry into the implementation of the National Disability Insurance Scheme (NDIS) and the provision of disability services in New South Wales (NSW).

Carers NSW is the peak non-government organisation for carers in NSW. A carer is any individual who provides care and support to a family member or friend who has a disability, mental illness, drug and/or alcohol dependency, chronic condition, terminal illness or who is frail. Our vision is an Australia that values and supports all carers, and our goals are to:

- Be a leading carer organisation in which carers have confidence
- Actively promote carer recognition and support
- Actively support carers to navigate a changing service landscape that will be characterised by ongoing policy reform
- Promote connected community experiences and opportunities for carers that are inclusive of diverse carer groups
- Lead and advocate for carer-specific and carer-inclusive policy making, research and service delivery
- Continue to be a quality-driven, responsive and carer-focused organisation.

Carers NSW has been closely monitoring the rollout of the NDIS in NSW since the commencement of the Hunter trial in July 2013. Our focus has been the recognition of carers in policy and practice and the experiences of carers engaging with NDIS processes. While many families are experiencing positive outcomes from the NDIS, we also have heard from many carers who have experienced confusion, exclusion and inadequate support.

This submission focuses on items (a), (b), (c), (e), (i) and (k) from the Terms of Reference, drawing on case studies, quotations and survey data collected by Carers NSW to highlight key issues for carers. Thank you once again for accepting our submission.

Yours sincerely,

Elena Katrakis
Chief Executive Officer
Carers NSW



Carers NSW submission:

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the National Disability Insurance
Scheme and the provision of
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AN AUSTRALIA THAT VALUES AND SUPPORTS ALL CARERS

INTRODUCTION

The National Disability Insurance Scheme (NDIS) holds great potential to improve the lives of people with disability, their families and carers living in New South Wales (NSW). However, since its launch in NSW in July 2013, the implementation of the NDIS has resulted in a number of key concerns for Carers NSW. We have raised these concerns continually through papers, submissions and contact with Ministers and Shadow Ministers, at both State and Commonwealth levels and have seen some improvement over time. However there remain a number of key issues remain ongoing for many carers.

Drawing on statewide surveys of carers in 2016 and 2018, consultation with carers and service providers via focus groups and working groups, carer case studies and our experience working with carers of people with disability through government funded programs, this submission highlights the key areas of the Terms of Reference for this inquiry that are ongoing priorities in Carers NSW advocacy: (a), (b), (c), (e), (i) and (k). These are explored in relation to four broad topic areas: carer support, eligibility, continuity of support and choice and control.

CARER SUPPORT

While not identified in the Terms of Reference, the issue of primary importance to Carers NSW in the context of NDIS implementation is the impact on carer support. The NDIS policy framework recognises the importance of carers and to some extent takes into account the support that they provide. Carers can also assist the person they care for to access the NDIS, play an active role in planning and implementing support, and benefit from the funded supports in the person's plan. However, the support that carers are entitled to receive in their own right from the NDIS (including the Information, Linkages and Capacity building, or ILC, component) is very limited, and completely dependent on the initiative of the person they care for and the NDIA delegate preparing and reviewing that person's plan.

This is concerning given that most funding supporting carers of people with disability – both at a State and Commonwealth level – has been absorbed into the NDIS. Nearly all Ageing, Disability and Home Care (ADHC) and Department of Social Services (DSS) programs directly servicing carers are in scope for transition to the NDIS, leaving carers of people ineligible for the NDIS without ongoing support, and carers of NDIS participants at the mercy of a system that does not mandate their direct assessment and support.

As a result, many carers are reporting that their support needs are not being considered or addressed, and that they are losing the support to which they once had access. Data from the Carers NSW 2018 Carer Survey conducted in May-June 2018 indicates that while the majority of the 713 respondents caring for an NDIS participant had been included in the planning process, only around one third had been asked about their own needs as a carer. Of the 945 carers of individuals under the age of 65 years (including NDIS participants and non-participants), nearly one third reported that the support they have access to as a carer had decreased over the past two years, i.e. since the full rollout of the NDIS commenced in NSW.

Further, the recently released final report of the NDIS evaluation conducted by the National Institute for Labor Studies at Flinders Universityⁱ found that access to supports directly assisting carers in their caring role was limited under the NDIS and inconsistently included in plans. In fact, the proportion of carers *not* accessing carer supports was found to have increased over the course of the evaluation, while the proportion who had adequate daily or weekly breaks from providing support decreased.

Some of the carer support types previously delivered under the ADHC and DSS funded programs in scope for the NDIS have been replicated within the Scheme via participant-focused support that indirectly benefits the carer. Others may get picked up by the Integrated Carer Support Service (ICSS),

rolling out digital services from October 2018 and limited face to face services from September 2019. New carer programs funded by the NSW Department of Family and Community Services (FACS) under the Carer Investment Program have also allowed for the continuation of carer-specific support at a State level, complementing residual carer supports funded by NSW Health and FACS. However there remain several key types of carer support which are at risk of disappearing completely as a result of NDIS transition, in particular:

- Planned breaks from the caring role – including after school / vacation care and carer retreats – that focus on carers' needs, preferences and wellbeing
- Funding to directly support the operation of carer support groups – including subsidised recreational activities – which are often run by volunteers and may incur venue, catering and activity costs
- Intensive individual support and referral for, or including, the carer, previously delivered under carer-focused support coordination programs and family-centred case management models
- Financial assistance for household purchases that are not directly disability related

Planned breaks focusing on the carer's needs

In the current and emerging service landscape in NSW, there appears to be very little availability of planned breaks from the caring role which are focused on the needs and preferences of the carer, designed to enhance their health and wellbeing. This includes not only conventional respite service arrangements and carer-focused retreats, but also after school and vacation care, which many carers have reported to Carers NSW are not being included in NDIS plans for school aged children, even if those children's support needs are too high for them to be safely accommodated in mainstream programs.

When Mohamed's plan was reviewed, the funding was drastically reduced, leaving only around \$700 for the year to cover respite, and no funding at all for vacation care. This loss of funding greatly distressed his mother Fatimah, who will not be able to work until the matter is resolved.

Many carers have also reported that they have requested that the plan include breaks to support their own health and wellbeing and/or participation in paid employment, only to have this request denied on the basis of the NDIS being 'not about them'. Many others have received funding within an NDIS plan for the purpose of a break, but found that this funding is inadequate to cover the necessary costs, or is reduced or removed completely upon plan review. Some others have had funding approved for this purpose but have not been able to find an appropriate service in their area, especially when the person they care for has complex needs. As carers of NDIS participants are ineligible to access planned and emergency respite through DSS funded Commonwealth Respite and Carelink Centres (CRCCs), no safety net remains for those carers.

However, while carers of people with disability ineligible for the NDIS can technically still access CRCC support, service offerings are becoming more and more limited due to sector changes. The ICSS promises to link carers to brokered respite servicesⁱⁱ, however the funding envelope for the ICSS and the inclusion of respite in its delivery framework remains unclear and somewhat limited. Carers NSW is therefore concerned, along with many other stakeholders within the carer support sector, that the coverage of respite within the ICSS will be completely inadequate to meet demand, let alone replace the respite services lost within the NDIS transition. Carers NSW has heard from carers that the lack of

Linda's daughter Kellie is an NDIS participant. Kellie is fairly happy with her supports, however Linda feels she has lost out. She used to be able to access funded carer retreats, which provided her with a real break from worrying about things at home.

a carer-focused opportunities for a break from the caring role is putting the paid employment arrangements and health and wellbeing of many in jeopardy.

Funding to directly support the operation of face to face carer support groups

While carer peer support is a priority of the ICSS and FACS Carer Investment Program, Carers NSW is not aware of any plans to continue to financially support the operations of face to face carer support groups as the NSW Government did previously under the ADHC funded *together* program, which ceased on 30 June 2018. Small, annual sustainability grants delivered through this program enabled many carer support groups to cover minimal operational costs such as venue hire, catering and recreational activities, which may have otherwise been unaffordable, especially for the many volunteer-led carer support groups whose members are facing financial hardship and other barriers prohibiting their community engagement.

Irene runs a carer support group for recently arrived migrants from all over Sydney who do not speak English. Over time, these funding opportunities for the group have reduced, reducing their ability to meet together. When the together program ends, it will be impossible for them to afford the venue and catering costs associated with them meeting regularly. For many of the members, the group is a key source of service information, emotional support and affordable recreation.

The only grants available to carer support groups for such items moving forward are the annual Carers Week Grants, which provide a valuable opportunity for carer support groups and organisations working with carers to celebrate the contribution of carers. While these grants support carer recognition, peer support and recreation, carer support group facilitators and members have frequently reported to Carers NSW that they rely on more regular meetings and outings to share ideas, learn about services, take a break from their caring role, access emotional support and invest in their own health and wellbeing. Many face to face groups will simply be unable to continue to meet regularly without ongoing financial support. While the new digitally based peer support programs being funded by DSS and FACS commencing in 2018 are welcome initiatives, they do not address this need.

Intensive individual support and referral for, or including, the carer

Coordination of Supports (CoS) can be funded in NDIS plans, however this is only allocated to participants who are deemed by the NDIA as likely to have particular difficulty implementing their plan, and in need of intensive capacity building. While the decision making criteria for allocating CoS are not publicly available, it is Carers NSW understanding that CoS is considered 'reasonable and necessary' on the basis of particular criteria indicating 'complexity' that do not explicitly include the circumstances and the needs of the carer. As a result, Carers NSW is aware of many cases in which carers and their supporters – even LACs in some cases – have explicitly requested that CoS be funded on the basis of the carer's lack of capacity to implement the plan and have been denied this support, or have received inadequate funding for it.

In most of these cases, there was a clear expectation that the carer – who is often ageing, experiencing their own health or mental health issues, from a culturally and linguistically diverse (CALD) background and/or lacking skills and confidence with dealing with service providers and using the internet – would take responsibility for coordinating the supports of their son or daughter with disability. Some of these carers were previous clients of the ADHC funded Ageing Parent Carer Support Coordination program, which provided carer-focused case management and other support, but were still deemed as not requiring CoS.

Most were completely overwhelmed by the prospect of having to coordinate the participant's supports, received inadequate guidance to do so and as a result either did not successfully implement the plan, did so at the cost of their own health and wellbeing, or relied heavily upon the support of service providers who felt they had a duty of care but were no longer funded to offer this service.

Financial assistance for household purchases that are not directly disability related

The NDIS will only fund supports that are directly related to the participant's disability.ⁱⁱⁱ It will strictly not fund anything that is not disability related and/or more appropriately covered by another service system or the community. Under ADHC, small amounts of discretionary funding were available through the Family Assistance Fund to help families purchase items and services that were not available from other funding sources, but that were essential to household and family wellbeing and would otherwise be unaffordable.

Grants from the Family Assistance Fund could go towards the purchase of assistive equipment, resources to promote family interaction, recreation activities for children and their siblings, services to increase parenting skills and family resilience, counselling for family members, home and car modifications and household appliances such as washing machines and dryers to assist with laundry for children with incontinence. Priority was given to families on low to moderate incomes where the care of the child or young person was significantly impacting sibling wellbeing.^{iv}

While there is some scope in the planned ICSS framework for carer-directed financial support – both one-off and in the form of packages – to purchase services related to employment, education, respite and transport^v the scope of these

Marta is a CALD carer in her 60s and cares for her adult son Andre, who has an intellectual disability. Marta received support through the Ageing Parent Carer Support Coordination Program from 2011 to 2017. This program supported Marta to set up Andre's disability supports, navigate Centrelink and the social housing system, set up arrangements for respite, counselling and transport, and transition to the NDIS. When Andre received his NDIS plan, Marta became ineligible for support through the Ageing Parent Carer Support Coordination Program. Funding for Coordination of Supports was not included in Andre's plan.

Jennie's household is financially stressed due to the additional costs of caring for her son Adam, for whom she left paid work to become primary carer. Adam is incontinent, which means the family's whitegoods wear out quickly. Under the Family Assistance Fund, Jennie was previously able to purchase a new washing machine when theirs broke. They would not otherwise have been able to afford this and could not access funding for it elsewhere. Adam now has an NDIS plan, and Jennie is concerned that should a similar situation arise again they may not be able to access this kind of financial assistance.

grants and the funding pool available remain unclear.

The disappearance of these support types threatens to severely disadvantage carers. In line with the NSW *Carers (Recognition) Act 2010*, the NSW Government is responsible for ensuring that carers continue to be recognised and supported in NSW. Carers NSW brings this to the attention of the NSW Government in order to highlight the Government's ongoing responsibility under the Act and accompanying NSW Carers Charter to ensure that carers in NSW are adequately included, recognised and supported.

ELIGIBILITY

A second and related key concern for Carers NSW regarding the implementation of the NDIS is the large number of people with disability, their families and carers who are being found ineligible for an NDIS package, or who are otherwise prevented from testing their eligibility in order to qualify for a package.

The total number of NSW participants expected to access the NDIS in NSW at full scheme is 141,957, including 78,808 (56%) from the NSW specialist disability service system, funded by Ageing, Disability and Home Care (ADHC).^{vi} However, early in the NDIS rollout in NSW, the existing number of ADHC clients was estimated as 90,000^{vii}, leaving a potential gap of approximately 11,192 former ADHC clients. Carers NSW assumes that this group are likely to be a combination of ADHC clients who: do not meet the NDIS access criteria, have dropped out of the service system and/or no longer need support, were unable to be contacted, or declined to phase into the NDIS.^{viii}

Australian Bureau of Statistics (ABS) data indicates that, in addition to ADHC clients being unable to transition, a large number of other people with disability and their carers will be unable to benefit from an NDIS package. The 2015 Survey of Disability, Ageing and Carers (SDAC) counted more than 776,000 people with disability aged 0-64 living in NSW, including more than 227,000 with a profound or severe core activity limitation (i.e. particular difficulty with communication, mobility and/or self-care).^{ix} This is significantly more than the total 140,000 participants anticipated to enter the NDIS in NSW.

Carers NSW has heard numerous reports of eligibility criteria being unclear and/or being applied inconsistently. Further, many individual decisions appear to be being challenged or appealed and overturned without a broader policy change. The application of eligibility criteria in relation to certain conditions, such as cystic fibrosis, mild to moderate disability, episodic mental illness and degenerative and terminal illnesses also continues to be contested and unclear.

Carers and stakeholders have reported to Carers NSW that NDIS assessors and planners often do not appear to be adequately equipped to fairly and consistently determine eligibility and need. In many cases people with disability, their families and carers have not been able to acquire and submit adequate documentation and 'proof of disability', especially as health professionals are often not aware of what is required. Carers are not always listened to or provided the opportunity to convey their expert knowledge, which can be a particular problem with the participant has a cognitive impairment that may affect their insight into their condition and/or the effectiveness with which they can communicate their needs and circumstances.

Key groups that Carers NSW has identified as missing out on the NDIS due to the above issues include, but are not limited to:

- People over the age of 65 who have a congenital, pre-existing or acquired disability (e.g. quadriplegia) that is not well accommodated by the aged care system
- People with mild to moderate or episodic disability or mental illness which is just under the NDIS threshold or difficult to demonstrate
- People with a condition that the NDIS would deem is health related rather than a disability, including people with degenerative diseases such as dementia, Parkinson's and Huntington's
- People who do not meet the residency criteria for the NDIS

In many cases, these people previously received support through a State or Commonwealth government funded program which is in scope to transition to the NDIS (for example, the ADHC funded Community Care Supports Program (CCSP) or the DSS Personal Helpers and Mentors Program (PHaMs), yet are still not able to transition themselves. If these former recipients of government funded disability support, who often belong to vulnerable population groups and have complex needs associated with episodic or chronic health conditions, are not adequately supported, they risk ending up in inappropriate care situations, such as lengthy hospital stays or within unsustainable informal care arrangements, affecting carer health and wellbeing.

Elizabeth cares for her adult daughter Leonie who has a mental illness that affects her insight. Someone representing the NDIS rang to speak to Leonie and asked if she was well; she was that day so she said yes. The planner said 'Well, I don't think you'll be eligible.' She heard Elizabeth in the background and asked who was speaking. When told it was Leonie's mother, she said, 'Oh, we don't need to speak to her.'

" I have failing health and use a wheelchair and am housebound with an advanced degenerative neuroimmunological disease...my claim for ndis for self was refused citing illness is not a permanent lifelong disability."

- 2018 Carer Survey respondent

Rachel was previously receiving CCSP services, but since that program ceased she and her husband Errol have no longer been receiving in home support. Rachel has been caring for Errol for the past 20 years. He has a spinal cord injury and health related complications that have left him with chronic pain and severe depression. Rachel is not coping and has experienced mental health problems herself. They applied for the NDIS but Errol was knocked back, even after appeal.

In addition to those who are ineligible, Carers NSW has found via our research and consultation that considerable access barriers are preventing many other people with disability, their families and carers from testing their eligibility and therefore from accessing the NDIS. These access barriers include negative past experiences leading to mistrust of government services, language barriers, cognitive impairment and/or reluctance to identify as having a disability, as well as system barriers such as digital literacy and financial resources.

Furthermore, many other carers are supporting someone who is eligible, or are likely to be eligible, for the NDIS but are temporarily unable to access a package due to delays. Commonly identified causes of delays include system errors such as lost paperwork, incorrect advice or non-response, as well as misinformation and administrative waiting periods. In Carers NSW experience, delays appear to have been particularly problematic for families of children under the age of 7 years attempting to access NDIS support via the Early Childhood Early Intervention (ECEI) pathway.

James was 3 years old in 2017, when his family were waiting indefinitely to meet with their local ECEI partner. In the meantime, they lost access to the ADHC funded social skills groups, occupational therapy and weekly speech therapy he had been using. In June they were told by their ECEI partner that they would likely be waiting until Christmas. In the meantime, the loss of support caused a downward spiral in James' behaviour, severely impacting his family's routine and wellbeing.

CONTINUITY OF SUPPORT

The key issue for people who are found ineligible for the NDIS, or otherwise prevented from testing their ineligibility or accessing a package, is that there is little available to them in terms of ongoing support. 1 July 2018 signalled the closure of Ageing, Disability and Home Care (ADHC) and the official end of the NSW Government's provision of specialist disability and community care services. This means that in NSW, there are very few direct supports available to people with disability outside the NDIS.

Under the Information, Linkages and Capacity Building (ILC) component of the NDIS and the continuity of support program delivered in NSW by Ourcare through the ADHC funded Pathways Project during transition, all people with disability and their carers can theoretically access ongoing support. However the support offered in these programs is limited to information, referrals and skills development, which, while useful to some people with disability and their carers, will be completely inadequate to meet the ongoing direct support needs of others, such as those who have serious functional impairments as a result of a chronic health condition.

Despite the closure of ADHC, the NSW Government maintains key obligations regarding the support and inclusion of people with disability, their families and carers under the NSW *Disability Inclusion Act 2014* and the NSW *Carers (Recognition) Act 2010*. The NSW Government also committed to providing people with disability, their families and carers with continuity of support that "enables them to achieve similar outcomes to the outcomes they were aiming to achieve prior to the introduction of the NDIS" as part of its agreement with the Commonwealth in September 2015.

The Flinders University evaluation^x of the NDIS found that NDIS participants and their carers who remained outside of the NDIS were considerably less satisfied with the quality of disability support that they were receiving than those who were accessing the NDIS. The Flinders report also identified that the NDIS was having a negative impact on the availability and affordability of services and supports outside the NDIS. For people with disability accessing supports not funded by the NDIS most relied on family to pay for them. This is concerning given that carers are known to be particularly likely to live on a lower income and experience financial hardship.^{xi}

Lorraine cares for her husband Errol, who is in his early 60s and has a chronic illness that greatly affects his physical functioning. They previously received in-home support services, transport and respite services, however as he is not eligible for the NDIS, and these supports are being withdrawn at a state level, there is nothing left for Errol, increasing the pressure on Lorraine.

If the NSW Government does not take urgent action to address funding gaps resulting from NDIS transition in NSW, demands for health services are likely to increase, as people with disability without specialist support present to hospitals with unmet needs and their health consequences, and as carers' health and wellbeing suffers as a result of unsustainable caring arrangements.

CHOICE AND CONTROL

While continuity of support is the key issue for people unable to access an NDIS package, for those who are accessing the NDIS, the extent to which the NDIS offers them the promised 'choice and control' over their supports is at the forefront. NDIA quarterly reports consistently report high rates of satisfaction overall and in relation to choice and control,^{xii} consistent with findings from the Carers NSW 2016 Carer Survey that most carers responding agreed the NDIS had made their own life better as a carer. According to the Flinders University evaluation,^{xiii} most carers felt that the NDIS had improved their capacity to support the person they cared for, and the NDIS appeared to have had a positive impact on carer satisfaction with regard to their choice and control. However, the Flinders report also noted that many NDIS participants and their carers experienced continuing difficulties in accessing NDIS-funded supports, especially allied health, early intervention, respite and accommodation.

Challenges that carers have continually identified in relation to choice and control include:

- The types and/or levels of supports that are requested not being included in the NDIS plan, even when there is considerable evidence to support their inclusion
- Exclusion of either the participant or the carer from the planning conversation, leading to an incomplete picture of the participant's situation
- Ongoing provision of informal support and/or support coordination by a carer being assumed, without a genuine choice being provided

Supports not included in the plan

Many carers have reported to Carers NSW that the participant's level of support has decreased after entering the NDIS, despite being told that they would smoothly transition from state supports. Furthermore, there have been widespread reports in NSW of funding being significantly reduced following a plan review.

Carers have also reported gross inconsistencies between what they ask for and discuss with the LAC and what comes back to them in the approved plan. Sometimes basic information is completely incorrect, in other cases whole items have been left out, or inappropriately funded.

Inadequate funding for transport has been a particular issue for people with disability and their families and carers in NSW as they transition to the NDIS. Carers NSW has heard from many carers that the levels of transport funding being allocated represent only a fraction of the transport expenses they have in any given year. State funded taxi subsidies and eligibility for the Companion Card go some way to addressing these costs, but are themselves grossly inadequate compared to the drastic increase in costs that is reported, especially from people living in regional, rural and remote areas.

The main reason for this discrepancy is that transport was historically included in block funded programs, at little or no cost to the client and their family. The rollout of the NDIS has not only ceased block funding to disability support providers but also significantly impacted the operations of the community transport sector. As a result, many participants and families are being forced to either cut down on activities, meet the often excessive costs themselves or personally provide extensive transport, to the detriment of their own employment and/or wellbeing.

Exclusion from the planning conversation

Carers NSW has received mixed messages from NDIA representatives, service providers and carers about whether or not participants, carers and supporters/advocates are encouraged to participate in planning meetings. In some cases, carers have been excluded. In other cases, participants have themselves been excluded, either because the planner has told the carer that they do not need to be there, or because appropriate communication aides have not been implemented. Other times, supporters and advocates, including service providers and practitioners, have been deterred from participating. Without involving the right stakeholders in the planning process, it will be impossible for

Aurelia and her husband James, who has a spinal cord injury and uses a wheelchair. Before the NDIS he accessed AT through EnableNSW, at which point an OT and seating specialist recommended that a leg raise be funded to address phantom pain he was experiencing. At James' NDIS planning meeting, he and Aurelia mentioned the leg raise and provided the EnableNSW report. This was included in the plan, subject to a further assessment and quote. The new quote was much higher and the NDIA disagreed that it was reasonable and necessary, contrary to the advice of to specialist OTs, seriously restricting his access to the community.

Ray's two sons often need to travel to regional centres for specialist care and recreational activities, which can take several hours. Ray is concerned that the transport coverage in their NDIS plans will not be sufficient, meaning that either his sons will miss out, the family will have to pay costly fees, or they will have to drive themselves, accruing petrol costs and meaning that they have to wait several hours and miss out on time for themselves.

the LAC or planner to get a clear picture of the participant's current support arrangements and overall support needs.

Ongoing caring role assumed

As noted earlier, initial findings from our recently completed 2018 Carer Survey indicate that most carers of NDIS participants felt they were included in the planning process. However, since the NDIS rolled out in NSW, many carers have reported to us that they have not felt their input was considered or respected. One example of this is the 'carer statement', something that the NDIA has referred to several times;^{xiv} it is meant to be an opportunity for the carer to formally share their own goals and circumstances. However, despite ongoing advocacy from the National Network of Carers Associations, this opportunity has never been formalised, consistently applied or actively promoted to carers.

According to the Flinders University evaluation^{xv}, the NDIS had a positive impact on carer satisfaction over their choice and control, but this impact was lower than for the NDIS participants themselves. Many carers, especially parents of young children, reported that their own needs and those of their family were not addressed in the NDIS planning process, and around one-third of carers noted they were *never* able to take adequate breaks from providing support.

Greg has a vision impairment and diabetes. His wife Jennifer works so cannot always be there to help out. Greg requested nursing support for the days Jennifer is at work, but both the NDIS and health system refused. As a result, Jennifer may have to leave work.

In addition to limited access to breaks, many carers have reported not being enabled by NDIS support to pursue their own wellbeing and community participation goals. A recent quarterly report to COAG by the NDIA^{xvi} found the following about carers of NDIS participants in NSW, the majority who were unable to work as much as they would like cite the situation of the participant as a barrier to working more, and more than half do not have friends and family that they see as often as they like. Further, the majority do not feel in control of selecting services.

CONCLUSION

This submission has detailed some of the key ongoing concerns Carers NSW has regarding the implementation of the NDIS and the provision of disability services in NSW. Carers NSW recommends that the NSW Government continue to work closely with the NDIA and DSS to ensure that people with disability, their families and carers receive genuine choice and control and genuine continuity of support as NSW withdraws from direct service provision to this group.

Carers NSW wishes to highlight the expertise the NSW Government has accrued in supporting people with disability, their families and carers and urge the NSW Government to make the most of the influence it has through the COAG Disability Reform Council to help shape policies and procedures within and outside the NDIS that are inclusive and supportive of all people with disability, their families and carers regardless of their eligibility for an NDIS package.

ⁱ Mavromaras, K., Moskos, M., Mahuteau, S, and Isherwood, L. (2018). *Evaluation of the NDIS: Final report*, National Institute of Labour Studies, Flinders University, Adelaide, February 2018. Available online at:

https://www.dss.gov.au/sites/default/files/documents/04_2018/ndis_evaluation_consolidated_report_april_2018.pdf, last accessed 14 August 2018.

ⁱⁱ DSS. (2018). *Integrated Carer Support Service: Regional Delivery Partners: A draft regional delivery model discussion paper*, Appendix A – ICSS Service Blueprint. Commonwealth of Australia, 2018.

Available at: <https://engage.dss.gov.au/integrated-carer-support-service-regional-delivery-model/icss-regional-delivery-model-discussion-paper>, last accessed 14 August 2018.

ⁱⁱⁱ NDIA. (2018). 'What are reasonable and necessary supports?' Available online at:

<https://www.ndis.gov.au/participants/reasonable-and-necessary-supports>, accessed 14 August 2018.

^{iv} DADHC. (2007). *Family Assistance Fund Fact Sheet for Caseworker*.

^v DSS. (2018). 'New services for carers'. Available online at:

https://www.dss.gov.au/sites/default/files/documents/04_2018/fact_sheet_-_new_services_for_carers.pdf, last accessed 25 June 2018;

DSS (2018) *Integrated Carer Support Service: Regional Delivery Partners: A draft regional delivery model discussion paper*. Available online at:

<https://engage.dss.gov.au/integrated-carer-support-service-regional-delivery-model/icss-regional-delivery-model-discussion-paper/>, last accessed 25 June 2018

^{vi} National Disability Insurance Scheme (NDIS) – Bilateral Agreement between Commonwealth and NSW. (2015). *Schedule A: Participant Transition Arrangements in New South Wales*. Available online at: <http://webarchive.nla.gov.au/gov/20151020011806/http://www.coag.gov.au/node/525>, last accessed 26 June 2018.

^{vii} Media release – NDIS signs up 2,000 people in NSW, Senator The Hon Mitch Fifield and The Hon John Ajaka MLC, 6 June 2014. Available online at:

<http://mitchfifield.com/Media/MediaReleases/tabid/70/articleType/ArticleView/articleId/798/MEDIA-RELEASE--NDIS-signs-up-2000-people-in-NSW.aspx>, last accessed 26 June 2018.

^{viii} Tandem. (2017). *Tandem submission to National Disability Insurance Costs – Productivity Commission Position Paper 2017*, June 2017. Available at:

https://www.pc.gov.au/data/assets/pdf_file/0008/218870/subpp0212-ndis-costs.pdf, last accessed 23 July 2018.

^{ix} Australian Bureau of Statistics. (2015). *Disability, Ageing and Carers, Australia*, NSW tables. Table 14.3: All persons with disability, living in households, assistance needed, received and extent to which needs met, by disability status–2015, proportion of persons, data cube: Excel Spreadsheet, cat. No. 44300, <http://www.abs.gov.au/AUSSTATS/abs@.nsf/DetailsPage/4430.02015?OpenDocument>, last accessed 26 June 2018.

^x Mavromaras, K. et al. (2018).

^{xi} ABS. (2016) *Survey of Disability, Ageing and Carers, 2015*.

^{xii} NDIA. (2018). *COAG Disability Reform Council Quarterly Report, 30 June 2018*. Available online at:

<https://www.ndis.gov.au/medias/documents/report-q4-y5-pdf/2018-Q4-June-COAG-report-Part-A-Accessible-PDF.pdf>, last accessed 14 August 2018.

^{xiii} Ibid.

^{xiv} NDIA. (2014) *NDIS Chairman Bruce Bonyhady's speech to the Carers Australia Conference*, 16-18 November, 2014. Available online at:

https://www.ndis.gov.au/html/sites/default/files/documents/bonyhady_speech_carers_conference_nov_14.docx, last accessed 14 August 2018.

^{xv} Mavromaras, K. et al. (2018).

^{xvi} NDIA. (2018). *National Disability Insurance Scheme: COAG Disability Reform Council Quarterly Report*. Available online at: <https://www.ndis.gov.au/medias/documents/report-q3-y5-pdf/Report-to-the-COAG-Disability-Reform-Council-for-Q3-of-Y5.pdf>, last accessed 14 August 2018.