

Carers ACT submission to

ACT Legislative Assembly Standing Committee
on Health, Ageing and Social Services Inquiry
on the implementation, performance and
governance of the National Disability Insurance
Scheme in the ACT

March 2018

About Carers ACT

Carers ACT is the ACT peak body representing the diversity of Canberrans who provide unpaid personal care, support and assistance to family members and friends living with a:

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

Carers are partners, spouses, parents, children, family, friends and neighbours who provide informal unpaid help with the activities of daily living. Whilst caring is rewarding, it can also bring financial hardship, social isolation, stress and other health and wellbeing issues.

There around 48,500 unpaid informal carers in the ACT, and they are an integral part of our aged, health and disability systems.

Carers ACT has a constitutional mandate to represent the voices of carers to government and the wider community. We consult regularly with a diverse range of carers and caring families to enable improved understanding of their needs, and better inclusion for them and the people they care for.

Carers ACT also provides advocacy support to Canberra's many Foster and Kinship carers that care for children and young people in out of home care.

Carers ACT CEO Lisa Kelly Co-Chairs the ACT Carers Strategic Taskforce 2018 with the ACT Community Services Directorate Executive Director Strategic Policy. The Taskforce's purpose is to develop the *ACT Carers Strategy 2018-2028* first three-year action plan. The community vision for the Strategy is:

- Canberra is a community that cares for carers and the people they care for
- Supporting carers is investing in Canberra's future.

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EXECUTIVE SUMMARY

Carers ACT is the peak organisation for unpaid family or friend carers in the ACT. Carers ACT has direct contact with more than 7,000 carers per year.

The primary focus of our submission to the ACT Legislative Assembly Standing Committee on Health, Ageing and Social Services Inquiry on the implementation, performance and governance of the National Disability Insurance Scheme (NDIS) in the ACT is to:

- increase awareness of the need to acknowledge the significant role carers provide to participants in the NDIS;
- encourage the recognition of and respect to carers, and;
- ensure the role of carers as partners in care is better supported by the NDIS.

According to Australian Bureau of Statistics, there are 28,000 unpaid family or friend carers in the ACT who care for people with disability under the age of 65 years. Of these, 6,500 are primary carers (the person who provides the most care to a person with disability needing support) and 1,430 carers provide care to people with severe and profound disability under the age of 65 years.¹

The ACT NDIS site trial commenced in July 2014 as a full scheme site with full roll-out of all age cohorts and disability conditions. All ACT residents who met the NDIS eligibility criteria would transition to the Scheme over a two-year period. Nearly 6,500 Canberrans² are now Scheme participants. The challenges to implement a full scheme site are discussed in Section 4, Our NDIS provider journey, and Section 5, Unique factors impacting the ACT NDIS implementation.

People living with disability are the primary clients of the NDIS. However, in its invitation to provide a submission to the Inquiry the Standing Committee acknowledged the NDIS journey is shared by individuals and their family members. It was anticipated that services funded in the NDIS participant plan would provide direct or indirect benefits to carers, and these would be supported by information, linkage and referral provided by the National Disability Insurance Agency (NDIA) to ensure carers and families are able to access supports in the community to assist them in their caring role.

The Productivity Commission's 2017 *National Disability Insurance Scheme (NDIS) Costs, Study Report*³ (Productivity Commission Report 2017) identifies the relevance of these elements to help people with disability to live ordinary lives, and drive the success of the Scheme:

- Scheme culture (a move from current disability systems to one that provides person-centred lifetime reasonable and necessary support)
- other support systems (carers, families, friends and neighbours)
- community supports (social, sporting and interest groups)
- mainstream supports (public transport, health and education).

The Commission says if these support systems are not available, people with disability could seek NDIS funding to fill the gap and pose a risk to Scheme costs. Financial sustainability of the NDIS also needs to be considered in the context of the efficiency and effectiveness of the NDIA, the readiness

¹ Australian Bureau of Statistics (2017) *Survey of Disability, Ageing and Carers Summary of Findings*, released 12 January, Canberra.

² Australian Government Department of Human Services (2017) *Report to COAG Disability Reform Council Q2 Yr5*, Canberra. Accessible <https://www.ndis.gov.au/about-us/information-publications-and-reports/quarterly-reports.html>

³ Productivity Commission (2017) *National Disability Insurance Scheme (NDIS) Costs, Study Report*, Canberra. Accessible <https://www.pc.gov.au/inquiries/completed/ndis-costs#report>

of participants and providers, and the integration of the Scheme with mainstream and other disability services.

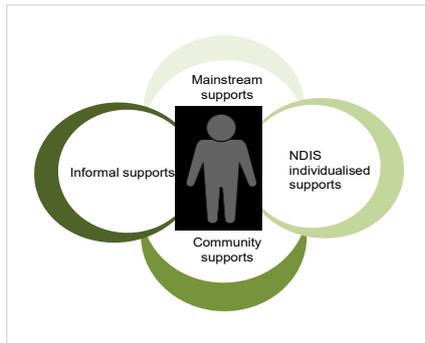


Figure 1: A person-centred approach relies on supports beyond the NDIS (Source: Productivity Commission, 2017)

Research by the National Institute of Labour Studies found while family and friend carers continued to provide the most care to NDIS participants,⁴ this care was detrimental to the health and wellbeing of the carers because of increased stress and time spent to manage NDIS participant plans, and the lack of awareness of their caring role by NDIA Planners. Research conducted by Carers ACT had similar findings. The research by both organisations identified the main benefits of the NDIS for carers is their satisfaction that the NDIS benefits the person they care for, and their decreased anxiety about future support for their family member or friend. Whilst acknowledging those benefits, Carers ACT research shows that the introduction of the NDIS did not improve the wellbeing of all carers. They often report feeling devalued, unacknowledged, disregarded and disrespected in the dealings with the NDIA and Local Area Coordination Service.

Because carers share the NDIS journey of the people they care for, Carers ACT believed it was important a strong carers' voice informed the Inquiry. We invited carers to provide input into the Inquiry through our *Carers ACT NDIS Inquiry and Carer Survey*, and they were encouraged to provide their own comments to the Inquiry. Our submission refers to Carers ACT research about carers and their NDIS experiences, and their experiences as a carer in the ACT. Our research also includes the *ACT Carers Strategy – Make Your Voice Count Survey*, which was part of the ACT Government's deliberative process to develop the Strategy. The findings are also drawn from our work in providing advocacy services to carers and through the stories we hear daily.

Our submission also considers gaps in NDIS service delivery, our journey as an NDIS provider and other issues.

Key recommendations relating to carers are discussed in Section 2, The NDIS journey for carers.

Psychosocial disability and the NDIS implementation in the ACT has not been addressed separately, but it is worth noting that psychosocial disability was the second highest primary condition of care recipients in the *Carers ACT NDIS Inquiry and Carer Survey 2018 (Carer Survey 2018)*.

Other activities that may inform the Standing Committee in its deliberations are the release of the Australian Government's report of the NDIS Pathways Review, *Improving the NDIS Participant and*

⁴ National Institute of Labour Studies (2016) *Evaluation of the NDIS, Intermediate Report*, Adelaide. Accessible https://www.dss.gov.au/sites/default/files/documents/11_2016/final_intermediate_report_wcag_compliant_24_nov_2016.pdf

*Provider Experience, 26 February 2018*⁵ and the ACT Government's ten-year commitment to develop and implement the *ACT Carers Strategy 2018-2028*.⁶

The NDIS Pathways Report, particularly the section – Designing new experiences for participants – addresses many things carers told us through the *Carer Survey 2018*, and other Carers ACT research and interactions. New NDIS Pathways are being trialled in Victoria and the ACT is trialling the Provider Finder digital resource.

Summary of Recommendations

Recommendation 1. Carers ACT recommends the ACT Government should ensure that NDIS Planners have a general understanding about different types of disability. For types of disability that require specialist knowledge (such as psychosocial disability), there should be specialised planning teams and/or more use of industry knowledge and expertise.

Recommendation 2. Carers ACT recommends the ACT Government raises with the NDIS the lack of application of the legislation in relation to carers rights to participate in planning and reviews and their right to determine the level of informal support they are willing or able to provide. All NDIS Planners and decision makers should receive immediate comprehensive training in carers and in the application of the NDIS legislation.

Recommendation 3. Carers ACT recommends that the ACT Government recommends the NDIA incorporates appropriate mechanisms in NDIS participant plan assessment tools to ensure that the rights of carers to be acknowledged and respected, and their right to be included as partners in the support of people with disability are an element of the NDIS participant assessment, plan development and review processes. These rights include:

- The right of carers to provide a Carer Statement during the initial NDIS participant plan assessment and subsequent NDIS participant plan reviews
 - The extent of their caring responsibilities and their capacity to provide a 'reasonable' level of care is considered in the development of the NDIS participant plan and plan review processes.
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Recommendation 4. Carers ACT recommends that the ACT Regulatory Body includes mechanisms for assessing the level of carer engagement in care planning and service delivery as part of the assessment of agencies and organisations in complying with the Disability Standards. This assessment should include evidence of carers being treated with respect and acknowledgment of the role as a partner in care.

Recommendation 5. Carers ACT recommends that the ACT Government encourages the NDIA, LACs and disability provider organisations to provide carer awareness training to staff to ensure the role of carers is understood and reflected in the development of NDIS participant plan supports and Information, Linkage and Capacity Building services to assist carers maintain their caring role.

Recommendation 6. Carers ACT recommends the ACT Government advocates with the NDIS to implement the new NDIS pathways as a matter of urgency. As participants in the NDIS pilot there has

⁵ Australian Government Department of Human Services (2018) *Improving the NDIS Participant and Provider Experience, 26 February 2018* – the report of the NDIS Pathway Review. Accessible at <https://www.ndis.gov.au/medias/documents/pathway-review-report/Report-NDIS-Pathway-Review.pdf>

⁶ ACT Directorate of Community Services (2017) *ACT Carers Strategy 2018-2028: Canberra Carers, Ordinary people doing extraordinary things*, Canberra. Accessible <http://www.communityservices.act.gov.au/home/act-carers-strategy-2018-2028/act-carers-strategy>

been significant change and confusion that the new pathways will resolve. As an interim measure the NDIA and LAC improve communication and transparent decision making with participants and carers.

Recommendation 7. Carers ACT recommends that the NDIA reviews the processes that LACs use to assess the need for and level of support coordination to be included in NDIS participant plans to reduce the stress and time carers need to spend on coordination services.

Recommendation 8. Carers ACT recommends that the ACT Government encourages the NDIA to consider the evidence in the Productivity Commission Report on NDIS Costs (2017) for the need for appropriate respite with a view to initiating this in the ACT, including the Commission's recommendation on the provider of last resort:

- ensure planners take into account the amount of respite care that is reasonable and necessary under an individualised support package, based on the amount of informal care that is expected to be provided by informal carers
 - label short-term accommodation supports provided in participants' plans in a way that makes it clear that these supports can be used for respite
 - better inform participants and their informal carers that core supports provided in individualised support packages can be used to fund additional in-home care or support in shared facilities to provide respite
 - include specific measures to ensure a supply of respite services in its provider of last resort policies.
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Recommendation 9. Carers ACT recommends the ACT Government liaises with the ACT NDIA on the projected need for respite beds and as a priority increases respite beds in the ACT to meet the current unmet need.

Recommendation 10. Carers ACT recommends the ACT Government as a matter of urgency identifies and funds a service of last resort.

Recommendation 11. Carers ACT recommends the ACT Government monitors the delivery of services provided by the growing number of ACT NDIS approved providers to ensure the services comply with standards, service gaps are identified and a market place that meets demand, including demand for supports for high need, challenging and complex participants. The ACT Government should consider recommending registration of providers who are not actively providing services be revoked so the true nature of the current marketplace can be determined.

Recommendation 12. Carers ACT recommends the ACT Government agencies responsible for education and disability and the NDIA work together to develop a process to improve access to schools for children with needs, including funding allocation and other responsibilities.

1. Introduction

Carers ACT welcomes the opportunity to respond to the ACT Legislative Assembly Standing Committee on Health, Ageing and Social Services Inquiry on the implementation, performance and governance of the National Disability Insurance Scheme (NDIS) in the ACT.

Carers ACT has strongly supported the trial of the NDIS in the ACT since its inception. Our response reflects our experience in its design and implementation, our experience as a registered NDIS provider, and the voice of carers through our surveys and avenues for telling their experiences with its implementation.

We provided support to over 1,000 carers in accessing the NDIS and obtaining a first plan through our Pathways Program during the NDIS rollout in the ACT. We currently provide care coordination and a living skills and community access program through the NDIS and have previously provided after school care. We provide support on understanding participant plans, participating in plan reviews, finding service providers and understanding rights to carers on a daily basis through our Carer Information and Advice Service. We advocate with carers who have difficulties with the National Disability Insurance Agency (NDIA) through our Carer Advocacy Service. We listen to carers through our consultations, social activities, peer support programs, counselling sessions and educational programs. We seek the views of carers to inform our programs and policy advice and ensure that government hears the voices of carers.

Many of our carers provide assistance with daily living for people living with a disability, including psychosocial disability. Many care for more than one person with a disability, or another family member or friend who is ageing, has a terminal illness or a chronic condition.

Our submission addresses:

1. The NDIS journey for carers
2. Gaps in NDIS services
3. Our NDIS provider journey
4. Unique factors impacting the ACT NDIS journey.

It also relates to the implementation of the NDIS in the context of Commonwealth and ACT Government legislation and guidelines that include the right of carers to be acknowledged and respected in their caring role, to be considered as part of the care team and to be supported in their caring role. Research about the impact of care giving on individuals and families clearly identifies the importance of increased awareness about what carers do, their contribution to the community, that they are respected and acknowledged by government, government agencies, service providers and the community. Increased recognition that carers are partners in care and have their own support needs and access to carer services and respite is known to increase their physical and mental health outcomes and helps them enter or remain in the workforce if they choose. These are the premises behind the ACT Government's 10-year commitment to the development and implementation of the *ACT Carers Strategy 2018-2028*.

(See Attachment B: Carer Legislative and Other Frameworks for more information on this issue. Information about the *ACT Carers Strategy 2018-2028* is available here: <http://www.communityservices.act.gov.au/home/act-carers-strategy-2018-2028/act-carers-strategy>)

2. The NDIS journey for carers

2.1 Introduction

Carers ACT invited carers to respond to the *ACT NDIS Inquiry and Carer Survey (Carer Survey 2018)* to inform our response to this Inquiry. Carers were asked about their NDIS engagement, their experience with the NDIS and some demographic data about themselves and the people with the disability they care for. This is a summary of the survey responses.

About carer respondents

Carer gender: 83% were female and 17% were male.

Age of carers: the majority (56%) were aged between 45-64 years, 1 respondent was aged under 24 years, 4% were aged 25-34, 19% were aged 35-44, 13% were aged 65-74 years, and 8% were aged over 75 years.

Length of caring: 2% had cared for less than 2 years, 8% had cared for 3-5 years, 23% for 6-10 years, 19% for 11-15 years, 11% for 16-20 years, 23% for 21-30 years and 14% had cared for over 30 years.

How many people with disability do they care for: 76% care for one person with disability, 15% care for two people, 5% care for three people and 4% care for four people.

Cultural diversity: 4% had Aboriginal or Torres Strait Islander origin and 7% were from a non-English speaking country from outside Australia.

About the people they care for with disability

Age of care recipients: 5% were aged under 6 years, 12% were aged 7-11 years, 11% were aged 12-14 years, 23% were aged 15-24 years, 14% were aged 25-34 years, 11% were aged 35-44 years, 8% were aged 45-54 years and 16% were aged 55 and over.

Primary disability ranking by condition: Autism (1), Psychosocial disability (2), Intellectual disability (3), Physical disability (4), Development delay (5), Acquired brain injury (6), Dementia (including early onset and Alzheimer's) were also included. Several care recipients had more than one disability. The top five primary disabilities are also the top five primary conditions supported by the NDIS nationally.

NDIS engagement by care recipients

Number of care recipients who had an NDIS participant plan: 69% had a plan, 24% didn't, and 7% were waiting for their plan assessment.

How long has the NDIS participant plan been in place: 9% had the plan in place for under 12 months, 35% for 1-2 years, 29% for 3-4 years, 6% were still waiting for plan assessment, and 21% didn't have a plan.

See Attachment A for more details about the survey and carer respondents' experiences of the NDIS assessment process, their engagement with the NDIA and LACs.

(Note: all percentages have been rounded to even figures)

We have also drawn on Carers ACT research – *Is the National Disability Insurance System supporting unpaid carers of people with disability?*, January 2017 (from data obtained in 2016)⁷ and the *Carers Voice Mental Health Survey*, February 2018⁸ to inform this submission.

⁷ Carers ACT (2017) *Is the National Disability Insurance System supporting unpaid carers of people with disability?*, Canberra. Accessible <https://www.carersact.org.au/wp-content/uploads/2017/09/Carers-ACT-NDIS-and-Carers-Survey-Report-February-2017-Final-Version1.pdf>

⁸ Carers ACT (2018) *Carers Voice Mental Health Survey February 2018*, Canberra, unpublished.

2.1.1 About carers and the NDIS

Informal carers provide an enormous amount of ‘reasonable and necessary’ care to NDIS participants, and the economic sustainability of the NDIS, among other things, is reliant on carers being supported to continue this care.

The Productivity Commission Inquiry into the NDIS Costs (2017, page 6)⁹ determined that:

The NDIS, as a person-centred approach to providing disability supports, relies on supports and services outside the scheme, including informal supports (family, friends and neighbours), community supports (sporting, social and interest groups), and mainstream supports (public transport, health and education), to help people with disability to live ordinary lives. If these supports are not available, people with disability could seek NDIS funding to fill the gap, and this could pose a risk to scheme costs.

The NDIS has simple messages on its website that leads to carers’ expectations that the NDIS will engage with them in positive ways that acknowledge their caring role:

The National Disability Insurance knows that families and carers, are partners in the support of people with disability.

We recognise that the role of families and carers is often essential in supporting people with disability to realise their goals and will include them in discussions about supports.

For many carers this has not been their experience. Responses to the *Carer Survey 2018* indicate that there has been little difference from the findings of the ACT Carer Survey in 2016 – carers still felt their input was not valued by NDIS Planners (whether through the NDIA or the LAC). They were not listened to; they had no opportunity to speak about how they supported the NDIS participant, there was no consideration of their other caring responsibilities¹⁰ or their own support needs.

2.2.2 What carers told us

Several issues emerged from the *Carer Survey 2018* responses. They echo our earlier research and our ongoing advocacy for carers and the people the care for. These are:

Lack of knowledge about carers and their caring role by NDIA Planners and LACs.

The NDIS legislation allows for carers to be involved in the NDIS assessment process if the care recipient agrees. They can provide a Carer Statement without the agreement of the care recipient, and the NDIS Planner (NDIA or LAC) should provide the carer with the opportunity to speak about their caring role and their support needs.

Carer respondents in the *Carer Survey 2018* indicated that 41% had the opportunity to provide a Carer Statement, and 51% had the opportunity to talk about the support they needed for their caring role.

⁹ Productivity Commission (2017) See footnote 2 above.

¹⁰ The 2016 Ernst & Young *Independent Review of the NDIS December 2015* identified that Clause 3.4 of Supports for Participants Rules should be amended to require the CEO to consider the extent of any other caring responsibilities in considering what a “reasonable” level of informal care is. This recommendation was endorsed by the Council of Australian Government’s response to this Review, accessible: https://www.dss.gov.au/sites/default/files/documents/04_2016/independent_review_of_the_ndis_act.pdf

https://www.dss.gov.au/sites/default/files/documents/03_2017/coag_response_to_the_independent_review_of_the_national_disability_insurance_scheme_act_2013_pdf.pdf

Legislative or policy frameworks:

There are three phases when carers and care recipients need to engage with NDIS through the NDIA Planners, and now through the Local Area Coordinators. For Planners these are the opportunities to meet new participants and their carer, if they have one, to better understand about the participant and their disability, understand their level of functionality and discuss their appropriate supports and what ‘choice and control’ the participant wants to achieve from their NDIS participant plan. It is also the opportunity for the carer to provide a Carer Statement, discuss with the Planner their other caring responsibilities and determine what is the ‘reasonable’ level of informal care¹¹ the carer can provide. It is also when the carer can discuss with the Planner their needs or be referred to information, linkages and capacity building and/or mainstream services to support their caring role.

NDIS legislation allows for this level of involvement by carers. In addition the legislation allows for carers to provide a Carer Statement without the agreement of the participant.

Carers’ experiences:

I didn't particularly understand the process and I wasn't really sure what to ask or whether I, as a carer, was entitled to any assistance or support. I didn't know anything about a Local Area Coordinator. I still haven't met one!!!

While I had the opportunity to provide input into my son's assessment my thoughts and input were clearly dismissed as soon as the NDIS rep left my premises as the completed plan bears little resemblance to what was discussed.

They don't understand what we go through day to day.

I feel there is a lot of generalisation instead of treating each person as an individual.

As a mental health carer of three family members ranging from 6 to 36 years old, I have been appalled at the lack of respect given to the carer. If I wasn't so worn out by this experience I would like to complain – but I have never felt heard.

I am a carer with my own NDIS participant plan, and my own support needs. My capacity to provide care and coordinate an NDIS participant plan should have been relevant to the development of the support plan of the person I care for.

Respite is a very needed component and the assessor made it clear, that as parents, we don't need respite.

I have had telephone conversations with staff from the NDIA telling me that it's not about me it's about what's best for the care recipient. I have been lucky in that I have been able to push my point across. I find it very stressful that there is a review each year.

¹¹ Ernst & Young (2016) See footnote 10 above.

The Productivity Report (2017) suggests that participants need to understand the planning process has changed significantly since 2013 when the NDIS began as a trial. With transition to the full Scheme dynamic processes allow the Scheme to adapt to changing circumstance, particularly being brought in line with benchmark costs, compared to the trial period¹². This is similar to the NDIS Pathways Review report¹³ that discussed the changes to the Scheme over time can cause carers, participants and organisations to think there is a lack of transparency about funding decisions being made about a participant's plan.

The Productivity Report (2017) says that Planners' limited knowledge on disability is a real concern, and that Planners should have a general understanding about different types of disability. The NDIS The Pathways report similarly discusses the importance of Planners having more knowledge of different cohorts such as psychosocial disability, younger children, Aboriginal and Torres Strait Islander communities, complex needs, culturally and linguistically diverse communities, remote and very remote communities. This is to ensure a better understanding of support needs of a participant and their family and to work with them in partnership to design individualised plans that incorporate specialised interventions leading to better engagement with the NDIS and better lifelong outcomes.¹⁴

It is important that stakeholders can access accurate and up-to-date information about planning processes. Clear messaging about how and why things are changing is also important to maintain the credibility of evolving planning practices.

There is also limited information to help scheme participants and their families, carers and advocates navigate the planning system. Scheme participants are often not aware of their rights and options, such as their entitlement to request a face-to-face meeting or have an advocate present during the planning meeting.

There needs to be greater transparency and clarity around the NDIA's planning processes. There also needs to be clear and up-to-date information about what participants should expect during the planning conversation, when it will occur, and how the information gathered during the conversation will be used.

It's encouraging to see the Productivity Commission Report (2017) and the NDIS Pathways Report Review respond to carers and participants frustrations and disappointment about the planning and review processes and are recommending measures to address these issues which are fundamental to the way the NDIS engages with its clients.

Recommendation 1. Carers ACT recommends the ACT Government should ensure that NDIS Planners have a general understanding about different types of disability. For types of disability that require specialist knowledge (such as psychosocial disability), there should be specialised planning teams and/or more use of industry knowledge and expertise.

Recommendation 2. Carers ACT recommends the ACT Government raises with the NDIS the lack of application of the legislation in relation to carers rights to participate in planning and reviews and their right to determine the level of informal support they are willing or able to provide. All NDIS Planners and decision makers should receive immediate comprehensive training in carers and in the application of the NDIS legislation.

¹² Productivity Commission (2017) See footnote 3 above

¹³ Australian Government Department of Human Services (2018) See footnote 5 above

¹⁴ Australian Government Department of Human Services (2018) See footnote 5 above

Inconsistent or reduced funding for participants NDIS plans, reduced access to services and a lack of transparency in decision-making.

Carer respondents in the *Carer Survey 2018* were concerned about the reduction of funds in NDIS participant plans following their review, particularly for support coordination or plan management. It appears the inclusion of adequate support coordination or plan management funding relies on the interpretation of NDIS guidelines by, or the discretion of, NDIA Planners undertaking the plan assessment or a plan review. There appears to be no consistency in who receives funding and who misses out, or the number of allocated hours for these services.¹⁵ This may reflect NDIA Planners and LACs awareness of current NDIS policies.

The Productivity Commission Report 2017¹⁶ says:

... the NDIS planning process is complex and confusing, and often lacks clarity and transparency. It is difficult to access information about assessment tools that are used by the NDIA and how support allocation is determined. There is also limited information to help scheme participants and their families, carers and advocates navigate the planning system. Scheme participants are often not aware of their rights and options, such as their entitlement to request a face-to-face meeting or have an advocate present during the planning meeting.

There needs to be greater transparency and clarity around the NDIA's planning processes. There also needs to be clear and up-to-date information about what participants should expect during the planning conversation, when it will occur, and how the information gathered during the conversation will be used.

Carers' experiences:

One carer indicated the main stress point in the NDIS participant plan was the reduction from 40 hours a month case coordination to four hours a month. The carer also has a disability and found it very difficult to cope without adequate case coordination to support her caring role.

Case study: Carer of an NDIS participant with an intellectual disability, ADHA and challenging behaviours, who is unable to access their own support

Our first interview in 2016 went well. We felt that we were heard and the NDIS plan matched what was discussed in the interview, with explanations of what was funded and the level, and why decisions were made. Our second interview in 2017 was not as successful. There was a 60 per cent reduction in funding. There was no explanation for this cut, nor were we told what the funding was intended for. We were given five numbers, and no comments. This resulted in my partner and I suffering a four to six weeks debilitating depressive episode before we could move forward.

The second plan removed support coordination. We were forced to try to understand the whole NDIS process to move forward. I tried to understand the NDIS Price Guide. It had labelling and classifications inconsistencies. It was a waste of time reading the 582 row detailed price spreadsheet. I fail to understand how the NDIA's expect informal support (typically parents) to cope with the learning curve of a professional employee while trying to support their participant and carry on their own work and life duties ...

¹⁵ Author's discussion with carers, an NDIS plan manager and findings in the *Carers ACT NDIS and Carer Survey*.

¹⁶ Productivity Commission (2017) See footnote 2 above.

The loss of unused funding following an NDIS participant plan review was also of concern. Unused funds can occur because of the lack of services to meet the demand, or lack of access to services because of the care recipient's behaviour or the cessation of programs or services. This meant carers often need to increase their caring role to cover the service gap and take leave from work, or reduce the number of hours worked to do so. This can cause unnecessary financial hardship for the family. Compounding this stress is the experience of carers in having funds reduced from participant plans due to the lowered use of supports in the previous year. Carers report that this occurs without the Planner asking or understanding the circumstances that may have led to this reduced expenditure.

Changes to funding levels and coordination provides distress for caring families and results in a constant state of worry. Caring families, and people living with disability, often require routine and stability to cope with and manage the stressors in their life. The constant threat of instability through changed funding levels or funded items in NDIS participant plans, and the actuality of access to funds being frozen will reviews, scheduled or otherwise, causes undue stress to families.

Whilst changing funding levels are having an impact on caring families, perhaps more concerning is the delay in accessing the NDIS for the first time. Prior to full roll-out of the Scheme in the ACT, transition support funding was available to ensure that people living with a disability could access supports whilst waiting for funding through the Scheme. Since full roll-out the ACT Government has ceased disability and transition funding and the only services available to people living with a disability are through the health system. Carers are reporting that there are significant delays in the application process and that during this time they are unable to access funding or supports to assist with the tasks of daily living. One carer articulated the initial application process as being a nightmare for their family – no help given at all, so that a review of the original decision of non-acceptance to the NDIS was necessary. The review process was very stressful, difficult and lengthy for both client and carer. Eleven months were wasted by this process, while the client's condition worsened.

Recommendation 3. Carers ACT recommends that the ACT Government recommends the NDIA incorporates appropriate mechanisms in NDIS participant plan assessment tools to ensure that the rights of carers to be acknowledged and respected, and their right to be included as partners in the support of people with disability are an element of the NDIS participant assessment, plan development and review processes. These rights include:

- The right of carers to provide a Carer Statement during the initial NDIS participant plan assessment and subsequent NDIS participant plan reviews
- The extent of their caring responsibilities and their capacity to provide a 'reasonable' level of care is considered in the development of the NDIS participant plan and plan review processes.

Recommendation 4. Carers ACT recommends that the ACT Regulatory Body includes mechanisms for assessing the level of carer engagement in care planning and service delivery as part of the assessment of agencies and organisations in complying with the Disability Standards. This

assessment should include evidence of carers being treated with respect and acknowledgment of the role as a partner in care.

Recommendation 5. Carers ACT recommends that the ACT Government encourages the NDIA, LACs and disability provider organisations to provide carer awareness training to staff to ensure the role of carers is understood and reflected in the development of NDIS participant plan supports and Information, Linkage and Capacity Building services to assist carers maintain their caring role.

Recommendation 6. Carers ACT recommends the ACT Government advocates with the NDIS to implement the new NDIS pathways as a matter of urgency. As participants in the NDIS pilot there has been significant change and confusion that the new pathways will resolve. As an interim measure the NDIA and LAC improve communication and transparent decision making with participants and carers.

Recommendation 7. Carers ACT recommends that the NDIA reviews the processes that LACs use to assess the need for and level of support coordination to be included in NDIS participant plans to reduce the stress and time carers need to spend on coordination services.

Respite Care

The lack of respite creates difficulties for carers and caring families – they need it to have a break from their caring role, to spend time with other children who can feel neglected because their sibling with disability demands the majority of their parents time; or to look after their own health and wellbeing. Respite, or replacement care, is needed to ensure that carers maintain wellbeing, are able to participate in the workforce and can maintain and continue their caring role into the future. The NDIS needs to re-visit its policy around respite – what is its purpose is, how can we ensure that sufficient services are built into a participant’s NDIS plan to provide regular respite for carers, how much respite is enough. Regular respite is essential to maintenance of the caring role. It is not a luxury for carers nor does it disregard the needs of the participant. Caring is a relationship between the carer and the participant. The success and longevity of the relationship is dependent upon the wellbeing of both people. Without respite carers experience burnout, resentment and despair and this impacts on the quality of the caring relationship and the care provided. The longevity of the NDIS financially is dependent upon the level of informal support provided to participants. The NDIA’s refusal to provide adequate respite provisions within participant plans directly threatens the caring relationship and the viability of the Scheme. This in turn impacts the ACT Government as carers under duress will relinquish care and the ACT Government will need to fund supports whilst participant reviews are undertaken by the NDIS. This has occurred recently with the ACT Government currently paying support and accommodation costs for a participant whilst awaiting the NDIS plan following relinquishment caused by carer burnout.

Children are the now the largest cohort in the NDIS, and there is also a greater than expected participants with global delay in the Scheme, according to the Productivity Commission in its 2017

NDIS Costs report. The Commission is also looking at the need for respite and asking the Planners to better inform participants and carers about how core supports in an NDIS participant plan can be used for their different respite needs. Reductions in care coordination also impact on this. Without appropriate coordination or support to implement a plan, carers are often unaware of how the plan can be used to support respite.

The implementation of the NDIS in the ACT saw a number of providers of respite accommodation close. Carers ACT was one of these providers. The funding model of the NDIS, particularly in relation to the funding for short-term accommodation, made it impossible to develop a sustainable business model for overnight respite. In 2017 the pricing guide was reviewed, and changes were made to the funding levels for short-term respite however by this time in the ACT the number of respite beds had dramatically decreased and we have yet to see these increase. As a result, there is a significant unmet need for respite beds in the ACT. Urgent planning needs to happen to replace these lost beds and project for future demand. The ACT Government could assist with increasing respite beds through the provision of low cost housing facilities to organisations to operate respite facilities.

It is worth noting that prior to the NDIS the ACT Government funded respite services through block funding. There was an expectation in transitioning this money to the NDIS that the same level of respite funding would be returned through participant plans. This is not happening and the NDIA has made numerous clear statements that they do not see that respite care is a participant need and thus is not a standard inclusion in a participant plan. They articulate that they are unable to see how respite care assists a participant to meet their goals and thus it is not a reasonable and necessary support. Carers ACT would argue that NDIS participants need and want to be supported by informal supports, they have a goal to remain part of a family unit and that respite is central to achieving this goal.

Carers' stories:

They made it worse. When NDIS services found my son too hard and refused his placement in their respite care. I was left with impossible choices for this future. The service gave me hope and left me bitterly disappointed.

Previous service had discretionary funds for alternative programs for family and sibling support.

My son was too challenging for a respite house.

Recommendation 8. Carers ACT recommends that the ACT Government encourages the NDIA to consider the evidence in the Productivity Commission Report on NDIS Costs 2017 for the need for appropriate respite with a view a to initiating this in the ACT, including the Commission’s recommendation on the provider of last resort:

- ensure planners take into account the amount of respite care that is reasonable and necessary under an individualised support package, based on the amount of informal care that is expected to be provided by informal carers
- label short-term accommodation supports and other line items within the participants’ plans in a way that makes it clear that these supports can be used for respite
- better inform participants and their informal carers that core supports provided in individualised support packages can be used to fund additional in-home care or support in shared facilities to provide respite
- include specific measures to ensure a supply of respite services in its provider of last resort policies.

Recommendation 9. Carers ACT recommends the ACT Government liaises with the NDIS and other disability and carer providers on the projected need for respite beds and, as a priority, increase respite beds in the ACT to meet the current unmet need.

Provider of last resort

The lack of a provider of last resort in the ACT is a deep concern for many carers. One carer’s response to Carer Survey 2008:

There is no organisation of last resort for people with difficult behaviour, and as participants with these difficult behaviours often live with their parent(s) this option will eventually disappear as their carers age and die.

It’s also an urgent issue that is concerning the Productivity Commission, The Commonwealth Ombudsman, the Joint Standing Committee on the National Disability Insurance Scheme, Victorian Legal Aid and others.

The Joint Standing Committee on the National Disability Insurance Scheme is investigating this issue in its Inquiry on Market Readiness. Submissions closed in February 2018.¹⁷ It’s received 95 submissions and its schedule of public hearings has begun. In its Terms of Reference the Joint Committee is to inquire into and report on market readiness for provision of services under the NDIS, and one of its Terms of Reference refers to a provider of last resort arrangements, including for crisis accommodation. It is to report by 23 August 2018.

¹⁷ Parliament of Australia (2018) Joint Standing Committee on the National Disability Insurance Scheme Inquiry into Market Readiness, Canberra. Accessible
https://www.aph.gov.au/Parliamentary_Business/Committees/Joint/National_Disability_Insurance_Scheme/MarketReadiness

Both the Productivity Commission and the Commonwealth Ombudsman¹⁸ link the need for a provider of last resort to a market fail, or a thin market, that also makes carers and the people they support vulnerable. It also wants the NDIS to include specific measures to ensure a supply of respite services in its provider of last resort policies to support carers and vulnerable families.

The Productivity Commission Report (2017) says:

The NDIA has not, to date, developed a Provider of Last Resort, or its Market Intervention Framework, and this has led to concerns about continuity of services. These policies should be published as soon as possible. (p.58)

Additionally, the Commonwealth Ombudsman is concerned that thin markets impact on an NDIS participant's ability to fully utilise their support package. The Ombudsman has no preference, but said some are arguing the NDIA should fill the gap, or that there may be a need to reinstate block funding for certain supports in difficult markets.

Recommendation 10. Carers ACT recommends the ACT Government as a matter of urgency identifies and funds a service of last resort.

3. Gaps in NDIS services

The *Carer Survey 2018* identified carer respondents found most or some services were available or easy to access. Unavailable services or those hard to access included psychologists, speech and occupational therapists and specialist pediatric health care. Some available services were overwhelmed with access requests, particularly overnight respite services and appropriate after school activities for teenagers. One carer said it had taken nearly two years to access suitable therapists for her son. Another carer said that as they can no longer get home visits from an ACT-based RDI (relationship development intervention) therapist the family was considering using Skype to access this service.

Carers indicated it was difficult to find someone who properly understood their requirements for a person with an intellectual disability, or challenging behaviour. The same was true when trying to find a suitable personal support worker or mentor.

Carers ACT research also indicated the challenges to have home modifications or assistive technology approved and funded. There is often a significant time lag between when the home modification or assistive technology (between 12 to 18 months) was approved by the NDIS.

Carers ACT continually hears stories about parents or kinship or foster carers with school-aged children with a disability, being unable to work or who need to leave work regularly as they are being called into schools to manage their child's challenging behaviour. Carers tell us that schools need training in managing challenging behaviours appropriately and to reduce their reliance on carers attending the school to respond to the needs of children in the classroom. Carers would like schools to have an increased understanding of the impact of caring on carers, particularly carers caring for children with non-physical disabilities.

¹⁸ The Commonwealth Ombudsman (2017) Submission to the Productivity Commission into the National Disability Insurance (NDIS) Costs, Canberra. Accessible https://www.ombudsman.gov.au/_data/assets/pdf_file/0024/43449/OCO-submission-to-PC-inquiry-into-NDIS-costs,-March-2017.pdf

Carers ACT is hearing reports from carers that they are providing NDIS funding to schools to assist in providing support for their child. They report that often this support is not provided directly to the child and is used for assistance to class management or is not provided at all. Carers are reporting that even when the support is not provided the school is continuing to charge the NDIS participant plan for the support.

The above comments raise questions about schools, the NDIS and participant plan funding:

- Where does the NDIS participant plan funding for students with needs go – to schools or to parents?
- Do schools incorporate NDIS funds into their own operating budgets or do they use them to fund a support person for the student attached to the funding?
- Are schools NDIS providers – do they need training for school-based management change to incorporate NDIS plans into their school environment?
- Does the school cover the insurance of the support person, or does the carer?
- Is a carer able to nominate their preferred support worker, hire them and have the worker accompany the child to school and provide assistance on the school grounds?

Recommendation 11. Carers ACT recommends the ACT Government monitors the delivery of services provided by the growing number of ACT NDIS approved providers to ensure the services comply with standards, service gaps are identified and a market place that meets demand, including demand for supports for high need, challenging and complex participants. The ACT Government should consider recommending that the registration of providers who are not actively providing services be revoked so the true nature of the current marketplace can be determined.

Recommendation 12. Carers ACT recommends the ACT Government agencies responsible for education and disability and the NDIA work together to develop a process to improve access to schools for children with needs, including funding allocation and other responsibilities.

4. Our NDIS provider journey

Carers ACT began its NDIS journey early in 2012 when participants at the Carers ACT 2012 Supported Living Summit recommended to the then Chief Minister, Katy Gallagher, that the ACT become an NDIS trial site. We have continued to support the NDIS implementation in the ACT through representation on NDIS advisory groups and raising carer awareness about this major disability reform. Similar to other ACT organisations our main disability support income was generated by block-funded service delivery and we lost some of this funding in the transition to the NDIS.

Prior to the NDIS, Carers ACT operated respite houses that were funded by the ACT Government and enabled carers to take a break through provision of residential respite care. Financial modelling under the NDIS price guide indicated that it would not be financially viable for Carers ACT to continue to provide this service. This situation was not unique to Carers ACT and a number of other services ceased the provision of respite care under the pre 2017/18 NDIS pricing structure. There was a decision to change the pricing structure for short-term accommodation under the NDIS in 2017. This increases the financial viability of operating the service however it does not provide for the costs of obtaining and maintaining a facility. As part of the NDIS trial and the pre-2017 pricing, the ACT has lost a number of respite beds and these have yet to be replaced.

Carers report that it is becoming increasingly difficult to obtain services and supports for people with high/challenging needs or low level of functioning. Carers report that they are refused supports based on the need of the participant, are provided with supports that are then withdrawn, are excluded from services available to other people living with a disability and are often called at short

notice with advice that the services being provided will terminate within the hour or requested to attend the venue and provide additional support. These carers often carry the heaviest burden with their care role requiring upwards of 50 hours per week care. They are often overwhelmed with exhaustion, fatigue and despair. They often have their own health conditions or disability and they generally have little or no time to have a break or care for themselves. These are the carers that are more likely to relinquish care not because they want to but because they are physically and emotionally no longer able to care. There was always a promise of a service of last resort under the NDIS. A service who would provide the supports and assistance that were not available anywhere else but were reasonable and necessary. This service does not exist in the ACT and this is the most significant gap for carers and people living with a disability.

The Productivity Commission's 2017 Study into NDIS costs also considers the need for an NDIS provider of last resort policy and a market intervention framework to relay concerns about continuity of services. It said these should be published as soon as possible.

5. Unique factors impacting the ACT NDIS implementation

The NDIS offered the ACT Legislative Assembly to be part of one of the largest social reforms in Australia. There was a lot of support from the community who also saw its implementation of providing a positive future for children and adults with disability and their families. We had one level of local government and the full-scheme cohort confined in a clearly defined boundary.

There was little awareness of the impact its implementation would mean for people with disability and families who were being transitioned from block funding to a fee-for-service Scheme, or that some of block funded disability and mental health funding would also transition, along with the supports they provide, to the NDIS. Prior to the NDIS the ACT Government operated Disability ACT service was the provider of last resort people and essential therapy services were provided through the Government operated Therapy ACT. Supporting this was an experienced, accessible, user friendly disability support sector. Access to disability supports prior to the NDIS required significantly less administrative burden on carers than the NDIS currently does. Services could often be provided without the requirement for lengthy assessments, delays, reviews, funding freezes, service agreements, inoperable portals, the need to pay for the service first and be refunded later (providing you can access the portal), the need to organise your own service supports and manage staff or fill in pages of paperwork. The NDIS promised a future of choice and control. What we were not aware of was that this choice and control would come with distress, anxiety, constantly changing environments and policies, increased administration, feeling dismissed or disregarded and ultimately having little or no control. The NDIS was established to support on of the most vulnerable groups in our community. In practice the administrative processes and bureaucracy that surrounds the NDIS has prevented those most vulnerable from benefiting from the Scheme.

Reports are identifying the issues with implementing such an ambitious program in a relatively short timeframe and these highlight the difficulties for its participants – long wait times from request to meeting NDIA Planner for the first time, gaps in the market etc.

We asked respondents a closing question in the *Carer Survey 2018*: Do you think there were things about the ACT that were different to the states and the Northern Territory that influenced the NDIS

implementation in the ACT? Here's a snapshot of what they said, and it reflects the survey respondents' different experiences:

Being a trial site we had opportunity to implement and iron out issues that were relevant to people in the ACT, re services available here and in consultation and forums for preparation to NDIS. We had planners who had mental health backgrounds. However, when NDIA started to be rolled out nationally all the great steps that we had taken in the ACT to get it right and the plans that we had in place that were very good plans were not carried on by NDIA when annual reviews came up. We were not listened to and our experience and expertise were ignored by NDIA, resulting in drastic cuts in plans and people falling through the gaps and existing working programmes and funding for other services including for carers were cut.

The population size dictates budget capacity for NDIS coverage and ACT falls short in that area. The huge increase in new home and apartment builds in ACT has prevented NDIS clients to access NDIS approved builders in a timely fashion. The timing of the roll out due to NSW NDIS capacity issues with LACs and NDIS approved services impacted the ACT NDIS rollout

We have a small market. It can be hard to access specialist support and there are not many service options around.

I think the NDIS in the ACT was meant to save Local Government \$\$\$ and push therapies back onto parents and schools.

I think the ACT Government removing funding to services (and effectively shutting them down) instead of assisting programs to roll into NDIS was sort sighted and harmful.

Being a trial site with high turnover of staff, decisions are inconsistent. Planners and their supervisors often have no knowledge of the unique challenges of parenting teenagers on the ASD (Autism Spectrum Disorder) spectrum. Often they ignore clients and even professional reports by health care providers.

ATTACHMENT A:

Summary – ACT NDIS Inquiry and Carer Survey, March 2018

1. Overview

Carers ACT conducted the online *ACT NDIS Inquiry and Carer Survey* to provide carers with an opportunity to inform Carers ACT's submission to the ACT Legislative Assembly Standing Committee on Health, Ageing and Social Services Inquiry on the implementation, performance and governance of the National Disability Insurance Scheme (NDIS) in the ACT. The survey sought carer demographics, the characteristics about the people with disability they cared for, their engagement with the NDIS and if they thought unique factors about the NDIS influenced the NDIS roll out in the ACT.

1.1 Carer respondents and the people they care for

- **About carer respondents**

Carer gender: 83% were female and 17% were male.

Age of carers: the majority (56%) were aged between 45-64 years, 1 respondent was aged under 24 years, 4% were aged 25-34, 19% were aged 35-44, 13% were aged 65-74 years, and 8% were aged over 75 years.

Length of caring: 2% had cared for less than 2 years, 8% had cared for 3-5 years, 23% for 6-10 years, 19% for 11-15 years, 11% for 16-20 years, 23% for 21-30 years and 14% had cared for over 30 years.

How many people with disability do they care for: 76% care for one person with disability, 15% care for two people, 5% care for three people and 4% care for four people.

Cultural diversity: 4% had Aboriginal or Torres Strait Islander origin and 7% were from a non-English speaking country from outside Australia.

- **About the people they care for with disability**

Age of care recipients: 5% were aged under 6 years, 12% were aged 7-11 years, 11% were aged 12-14 years, 23% were aged 15-24 years, 14% were aged 25-34 years, 11% were aged 35-44 years, 8% were aged 45-54 years and 16% were aged 55 and over.

Primary disability ranking by condition: Autism (1), Psychosocial disability (2), Intellectual disability (3), Physical disability (4), Development delay (5), Acquired brain injury (6), Dementia (including early onset and Alzheimer's) were also included. Several care recipients had more than one disability. The top five primary disabilities are also the top five primary conditions supported by the NDIS nationally.

- **NDIS engagement by care recipients**

Number of care recipients who had an NDIS participant plan: 69% had a plan, 24% didn't, and 7% were waiting for their plan assessment.

How long has the NDIS participant plan been in place: 9% had the plan in place for under 12 months, 35% for 1-2 years, 29% for 3-4 years, 6% were still waiting for plan assessment, and 21% didn't have a plan.

1.2 Carer respondent's engagement with the National Disability Insurance Agency and the Local Area Coordinator

This was an important issue for Carers ACT, particularly to discern if carer respondents' experiences and satisfaction with the National Disability Insurance Agency (NDIA) and the NDIS outcomes had shifted since our *2017 Carers ACT NDIS and Carers Survey*.¹⁹ We wanted to know their involvement in the NDIS participant plan assessment, if they were listened to, if they had an opportunity to provide a Carer Statement or to discuss their needs to maintain their caring role.

One-third of carer respondents to the question about the the NDIS plan assessment process found it easy, and 75% said it was not easy. 41% had the opportunity to provide a Carer Statement, 58% reported they didn't. Additionally, 51% had the opportunity to talk about the support they needed for their caring role, while 58% didn't.

Carer responses were mixed and included what they considered to be positive and negative engagements. Responses indicate a lack of understanding by NDIA and Local Area Coordinators (LACs) of what unpaid informal caring may involve and its impact on carers and families, and a seemingly inconsistent approach by the planners. The majority of carers indicated they had met with a LAC. The majority of respondents indicated that the LAC had understood some or all the needs of the care recipient.

Most carer respondents had been engaged with the NDIA between three to four years, depending on the care recipient's transition to the NDIS and the number of care recipients they care for. When the care recipient transitioned into the NDIS, the changing NDIS environment in the ACT, access to services and the increase in the number of ACT registered providers influenced their NDIS experience.

- **Suitability of, and access to, services included in NDIS participant plans**

Most carer respondents indicated that only some or most services were available or easy to access. Unavailable services or those hard to access included psychologists, speech and occupational therapists, specialistic paediatric health care. Some services that were available were overwhelmed with access requests, overnight respite services and appropriate after school activities for teenagers.

Carer respondents indicated that services and supports included in NDIS participant plans met some or most of the needs of Persons 1 and for Persons 2 they care for. There was more dissatisfaction with services meeting the needs of Persons 1 than for Persons 2 and Persons 3 (data for Persons 1, 2 and 3 are collated from responses of **all** carers who answered this question).

Some carer respondents indicated that NDIS service providers 'seem to only want the easy clients'.

- **Carer benefits because of the NDIS participant plan carer**

Most carer respondents identified there were benefits to care recipients from their NDIS participant plans, but some carers said that the services care recipients previously received helped support their caring role better. These included a support coordinator, with many respondents saying that the reduced hours for care coordination or plan management, along with service reduction, have increased their caring role and made their caring role more difficult.

¹⁹ Carers ACT (2017) *Is the National Disability Insurance System supporting unpaid carers of people with disability?*, Canberra. Accessible at <https://www.carersact.org.au/wp-content/uploads/2017/09/Carers-ACT-NDIS-and-Carers-Survey-Report-February-2017-Final-Version1.pdf>

Some carer respondents identified that there were several benefits to them and to the care recipients through the NDIS participant plan. These included increased independence for the care recipient, and less financial stress as services they previously paid for are now included in the NDIS participant plan.

2. Survey Findings

Carer respondents comments to questions when there was an option to provide these	
Q5	Are you from a non-English speaking country from outside Australia?
1.	Malaysia
2.	India
3.	Bangladesh
4.	Germany
Q9	What is the primary condition of the person or people with disability you care for? (Other)
1.	Functional Neurological Disorder/Chronic Regional Pain Syndrome
2.	Also has severe development delay
3.	Mental health issue – severe Obsessive Compulsive Disorder
4.	SPD, anxiety, inattentive ADHD, possible Asperger’s
5.	Depression
6.	Ageing related
7.	Alzheimer’s and Dementia
8.	Complex PTSD
9.	Parkinson’s
10.	Stroke, Early onset dementia
11.	Speech, and had failure to thrive
12.	Schizoaffective disorder. Psychosocial disability arises from this.
13.	Multiple Sclerosis
14.	Cerebral Palsy
15.	Dementia
16.	Multiple disabilities for each child
17.	Dementia
Q11	If the care recipient has an NDIS plan, how long has it been in place?
1.	2-3 years
2.	Person 2: 1 year
3.	First plans were unusable

Q12	Were services included in their NDIS plan available or easy to access?
1.	Time it takes to time to get someone from a service can be stretched out.
2.	Several were difficult to access, which made it more time consuming for me as a carer to try and manage support needs.
3.	I was a carer for five until my husband died. No NDIS for that.
4.	Psychological services could not be sourced within the ACT. We had to go outside the ACT to find a suitable person. It took several attempts to find suitable in-home support. It was difficult to find someone who properly understood our requirements for a person with an intellectual disability. The same was true when trying to find a suitable personal support and mentor.
5.	Availability for poor quality health professionals or ones trying to jump on the NDIS cash cow. Good health professionals took months to get in to see and sometimes not at all if the person being cared for could not attend that day.
6.	Some services deregistered, some were not good. Can access more with a Plan Manager. We are still finding out what services we can access and what services are available or not available or eligible within NDIS, that will assist and promote recovery focused services and activities that understand psychosocial disability and will be continuous and that will lead to employment of some sort. NDIS currently does not allow for flexibility or will provide scope to be innovative or think outside the box to gain the best outcomes for the person with psychosocial disability. such provision of a mind dog, companion dog etc.
7.	Access and flexibility has decreased over the period we have had an NDIS participant plan.
8.	Very few options in Canberra for specialist paediatric health care. So, the cost is very high for what is available and the quality is sometimes questionable.
9.	My son had his first plan in 2015. I kept telling the NDIA that they could give me a million dollars and I would still have no where to access overnight respite services in the ACT for challenging clients.
10.	It has taken some time to find the right resources. These were a multitude of services being offered but sorting through which providers were able to provide the required capability and which had just been set up to see if they could take advantage of NDIS was difficult.
11.	Psychologists are hard to get when the plan is not self-managed.
12.	Information in the plan was incorrect. It said my parents were full time live in carers. They are estranged and interstate. This year's plan is better but used most of last years plan to pay for the reports NDIS requested, to stay in the program. Pediatrician seems to think NDIS covers everything. Currently facing homelessness and Housing ACT and shelters wanted to know if plans covered accommodation. Plans are primarily for therapies. I have also found it hard to connect to services. I am at the point of feeling burnt out. I have coordination of supports however they are also unwell and haven't connected us to anything yet (into month 4 of new plan.).
13.	Not enough aba (applied behavioural analysis) therapists in Canberra.

14.	Appropriate after school activities for a teenager are tricky and NDIS plan does not cover transport with a support person.
15.	No coordination given.
16.	We have been with NIDS for 3 years. This FY has been dreadful. They "forgot" so many line items and it took me months the fix the "oversight" and now I have a complaint with the Ombudsman regarding a service that we had for over two years but NDIS wont fund it now. Carers ACT helped Advocate for this review. Thank you.
17.	Not sourced through NDIS.
18.	I was told less OT and no speech therapy, no swimming even though ASD children are fascinated by water and fall in plus in general they don't play sport. At all. But swimming? Yes! Even with little funding for respite, there are no support workers available. So, the stress is on me and hubby. He's already had a suspected heart attack and his first ever panic attack. Me? Another whole new story.
19.	We are currently having the plan reassessed after funding was reduced by \$27,000 which would severely curtail community based activities. We have been actively working with the in-house support provider and the NDIA to have this decision changed as it will otherwise have a profoundly negative effect on our child's community involvement.
20.	Few Listed Providers when called they happened to be plan managers/ support coordinators and not service providers for help with domestic chores not easy to find.
21.	Some services were not available yet or overwhelmed with requests.
22.	There was only one ACT-based provider of the particular autism treatment program (RDI i.e Relationship Development Intervention) that we were using, and she has now retired.
23.	The wait lists were incredibly long for speech and occupational therapy. It took me nearly two years to find therapists for my son.
24.	But quality of services was poor while it lasted. Person no longer accepts services despite being approved.
25.	Only the overnight respite service was relatively easy to access. Everything else has ranged from somewhat difficult to very difficult to access.
26.	Lack of speech therapy across.
Q14	Did the care recipient receive services before their NDIS plan began that made a difference to your role as a carer but no longer exist?
1.	Speech therapy.
2.	Everything stopped until the NDIS was rolled out in our area for over a year.
3.	Better options for support and the quality of the support has dropped. Agencies seem to only want the easy clients.

4.	Main lack in their plan was case coordination, which reduced from around 40 hours to 4 hours a month. I, the carer, also have a disability and an NDIS plan and found it very difficult to cope without the support of case coordination.
5.	Compression stocking once you go onto the NDIS.
6.	PhAMS (Personal help and mentor support)
7.	Community centres: one provided a choir, periodic excursions, weekly group visits to a gym, and a weekly social activity group. These services have all closed down, without similar services starting up.
8.	Respite/Person is no longer living at home because of the NDIS so respite is no longer needed.
9.	Before the NDIS was implemented both my boys qualified for special needs programs. These programs no longer exist. That program assisted my older boy to gain public housing and training in managing his finances and online grocery shopping. As I was still available they did not need additional services at the time and did not see the need to continue with an application for NDIS. It seemed too intrusive and difficult for them. The programs ceasing mean that I am again taking huge amounts of time off work to care full or part-time for one or both boys and one of the partners with an undiagnosed mental illness. I don't know until the day it happens when this will be needed or for how long. The last time off work was for 9 weeks and I went back to work sick without any recreation leave or sick leave left until October 2018.
10.	Service had discretionary funds for alternative programs for family and sibling support. My son was too challenging for a respite house.
11.	Much help and relief from family and friends.
12.	In-house support (in line with NDIS goals).
13.	Supports and support workers, PHaMS worker, rainbow, podiatry.
14.	When my daughter was a client of Therapy ACT, I received visits from one of their social workers, which were very helpful. There is no equivalent now. We were able to use respite services (paying out of our own pocket but government subsidised) to have a break, but now it is all couched in terms of meeting goals for the person with a disability and we have to show evidence of progress towards those goals. Also, we can no longer get home visits from an RDI (Relationship Development) consultant based in the ACT, but would have to rely on Skype (we are considering this for next year).
15.	Respite.
16.	Still continuing as needs it.
17.	Therapy ACT and ACT Government Early intervention group specifically for young children.
18.	I regularly received carers and domestic support. I don't anymore.

19.	Meaningful respite care.
Q15	Did services included in their NDIS plan make a difference to your role as carer?
1.	Support workers don't turn up and the agencies don't send replacements, so I have to take time off work and there's more.
2.	Person 3 is starting to go on it now.
3.	Having a Support Coordinator makes a big difference. She arranges support services - helps to share the load with me.
4.	The person avoided being removed from their ACT Housing property once in-home support was provided. There was less worry for us in the state of their flat, and less need for the difficult parent / child conversations about these matters. We did not need to provide regular social contacts, so we were able to have breaks from our support roles.
5.	They make a difference in that we have more peace of mind having more support than we have ever had and is leading to a better quality of life. We are still doing a lot of overseeing etc but are hopeful that when we have established key supports, services, and strategies that our caring role will be diminished and we can just be parents - provided that our person will have a lifelong NDIS plan without having to go through the rigorous, ever changing processes with an NDIA department that is much more focused in improving that lives of people with a disability rather than being focused on saving money and cutting services and supports, equipment etc only paying for cheapest options rather than looking at long term costs and benefits not only to the person with the disability and their carers, families and support persons but as an investment for future for a better Australia.
6.	They made it worse. When NDIS services found my son too hard and refused his placement in their respite care, I was left with impossible choices for his future. The services gave me hope and left me bitterly disappointed.
7.	Support Coordination and Plan Management have proven invaluable. I was quite concerned at the push to remove Support Coordination at the plan review this year and had to convince the planner that this was a must for the person I care for.
8.	We got a rest and some time to ourselves as a couple.
9.	Extra services from service provider to increase my daughter's independence. Also, I no longer have to pay for her riding lessons.
10.	After school [care] workers so I can work.
11.	Having access to money and choice of support is excellent. The opportunities that have opened up for my individual are fantastic. But my role as a carer is extensive coordinating appointments, planning for meetings, getting reports and keeping tabs on everything is a big job.
12.	Transport to cooking classes.
13.	Independency for work for my son (key thing here), time with my other family, support for me with no other care workers available now to help me.

14.	Cleaner, gardener, some transport.
15.	Funding pays for OT.
16.	He has a support worker for a couple of hours a week that is able to provide some mentoring.
17.	Employment funding created certainty of employment. Travel funding reduced our financial burden.
18.	Yes for both persons 3 and 4. Stupid thing doesn't allow for multiple fields to be filled. Now I can get them assessed by the necessary health professionals to help improve their lives and increase their chances of success as functioning, independent adults.
19.	Having speech therapy, but wish it was accessed earlier.
20.	It actually put more stress on me. Support coordination, paid for under the NDIS plan, is hopelessly incompetent.
21.	Transport services. It actually put more stress on me. Support coordination – paid for under the NDIS plan, is hopelessly incompetent.
22.	Cleaning, garden maintenance
23.	Community Participation Scheme
24.	Support workers
25.	It doesn't make a difference to my role, as the plan isn't to benefit me. We did have supports through community health etc previously, then lost that for over a year while applications were processed and then slowly linked in with speech, OT etc However it has been very ad hoc with therapists leaving etc. Big gaps in between it all. It has added extra stress for me ensuring needs are met, researching, advocating, attending NDIS meetings then doing the admin and accounting too - I feel very tired.
26.	It has taken some of the pressure off me to do everything.
Q17	If you were involved in their NDIS plan assessment, how were you involved?
1.	I am a carer with my own NDIS participant plan and my needs should have been relevant to the support plan of the person I care for.
2.	But once they talked to us and when we got the plan it was different than what we had discussed and wasn't good for him.
3.	The initial application process was a nightmare – no help given at all, so that a review of the original decision of non-acceptance to the NDIS was necessary. The review process was very stressful, difficult and lengthy for both client and carer. Eleven months were wasted by this process, while the client's condition worsened.
4.	The first assessment went well, and we felt that we were heard. The second time it was done (with LAC), it appeared to be rushed, and we felt that there was limited understanding of our needs.

5.	Having been involved with NDIS since inception I was quite knowledgeable and provided a carer statement and the MHA (Mental Health Australia) checklist for carers for the 1st plan and carers statement for review plan. Even though the process was still very overwhelming. The review plan process and outcome were horrendous and the plan was reduced to less than a quarter so had to go into battle to claw back funds and eventually after several plans obtained a better plan. We are dreading the next review.
6.	It is incredibly frustrating that I have to tell the same story to a different assessor every year when the plan is reviewed. There is no corporate history being kept and each assessor has a different interpretation.
7.	Support coordination seems to be tagged as something that you don't need after the first year. This is a falsehood. Support Coordination is vital given that support needs change, support workers change, and businesses/organisations providing support come and go. This is not a 'set and forget' activity.
8.	Respite is a very needed component and the assessor made it clear that we as parents don't need respite!
9.	Found the assessor rushing and not listening to me but instead answering the questions for me.
10.	It was all about my son's needs.
11.	Had to have a phone interview and it would have been easier face-to-face.
12.	All conversation was like the previous 2 cycles {reviews}.
13.	An attempt has been made to apply for an NDIS package but has stalled at obtaining the Doctor's statement due to patient load.
14.	They don't understand what we go through day to day.
15.	NDIS staff very helpful and supportive, however very difficult to contact them on phone.
16.	Still being assessed still waiting on review of decision lodged in April 2016.
17.	Very poor, have only had one initial planning meeting in 2015.
18.	The whole process was done in a screaming rush just before Christmas and pushed through.
20.	The person doing the initial assessment was a little difficult, however after a very long wait for the plan to be finished, we were happy with the outcome. The first review was a much better experience.
21.	I attended initial assessment and the one-year review. Support Coordinator turned up for final 5 minutes of the review. Review was competently, and sensitively done by NDIA assessor.
22.	The long waiting periods. Services not being aware of the correct NDIS process. Misinformation received from doctors, specialists, OT services etc.
23.	I was rushed through and told that the NDIS is moving away from face to face therapy with the client and that we will need to 'think outside the box'.

24.	I didn't particularly understand the process and I wasn't really sure what to ask or whether I, as a carer, was entitled to any assistance or support. I didn't know anything about a Local Area Coordinator. I still haven't met one!!!
25.	The assessment was done over the phone with me (the carer).
26.	The assessment process from memory was solely about my son not my role as a carer initially but only the last assessment talked about my roll and what support I needed.
27.	No to all. I felt that planners did not understand my needs as a carer, nor did they understand the children's needs.
28.	The focus seems to be on what the child needs and not at all on what the parents need in order to function to fulfil their role as a carer. For instance, respite is approved if it is considered beneficial to the child's communication and social needs. It doesn't matter that the parents are completely neglecting the rest of their family, unable to meet anyone's needs sufficiently because they are so exhausted physically and emotionally from 'caring'. I have had telephone conversations with staff from the NDIA telling me that it's not about me it's about what's best for my son. I have been lucky in that I have been able to push my point across. I find it very stressful that there is a review each year, I think it would be more time and cost effective if it was reviewed every two years.
29.	While I had the opportunity to provide input into my son's assessment my thoughts and input were clearly dismissed as soon as the NDIS rep left my premises as the completed plan bears little resemblance to what was discussed.
Q20.	Was the implementation of the NDIS in the ACT influenced by things in the ACT that are different to other states and the Northern Territory?
1.	It was implemented as a whole population trial.
2.	We were guinea pigs, and if it worked here than other states were ok with it.
3.	The ACT had for many years (more than 20 years) had the poorest services for young disabled people in Australia. For instance, despite the fact that my daughter attended a special school she had no speech therapy input for 7 years in a row. Due to low staffing issues in the ACT by government services. People with severe multiple disabilities were poorly served in the ACT for therapy services and this has resulted in adults with disabilities being more disabled than they should be, given their original diagnosis and prognosis.
4.	Being a trial site we had opportunity to implement and iron out issues that were relevant to people in ACT, re services available here and in consultation and forums for preparation to NDIS. We had planners who had mental health backgrounds. However, when NDIA started to be rolled out nationally all the great steps that we had taken in the ACT to get it right and the plans that we had in place that were very good plans were not carried on by NDIA when annual reviews came up. We were not listened to and our experience and expertise were ignored by NDIA, resulting in drastic cuts in plans and people falling through the gaps and existing working programmes and funding for other services including for carers were cut.
5.	We have a small market. It can be hard to access specialist support and there are not many service options around.

6.	Lack of therapists here really makes it difficult to see improvements in my son's speech and behaviour.
7.	PS about LAC – NDIS did not refer my sons plan to them so were not on the books to be helped.
8.	The trial period gave huge flexibility.
9.	ACT is a smaller community.
10.	Still being assessed.
11.	Insufficient services especially for housing, mentoring, household assistance, psychology and employment for ASD (Autism Spectrum Disorder) youth with a disability. Being a trial site with high turnover of staff decisions are inconsistent. Planners and their supervisors often have no knowledge of the unique challenges of parenting teenagers on the ASD spectrum. Often, they ignore clients and even professional reports by health care providers.
12.	I think ACT Government removing funding to services (and effectively shutting them down) instead of assisting programs to roll into NDIS was short sighted and harmful.
13.	I think the NDIS in the ACT was meant to save Local Government \$\$\$ and push therapies back onto parents and schools.
14.	I feel there is a lot of generalisation instead of treating each person as an individual.
15.	The population size dictates budget capacity for NDIS coverage and ACT falls short in that area. The huge increase in new home and apartment builds in ACT has prevented NDIS clients to access NDIS approved builders in a timely fashion. The timing of the roll out due to NSW NDIS capacity issues with LACs and NDIS approved services impacted the ACT NDIS rollout.
16.	It's a standard system that's been applied without consideration given to geographic requirements.

ATTACHMENT B:

Legislative and Other Frameworks

Carers ACT has contributed to ACT Government frameworks for people with disability as well as the ACT Carers' Charter. As a member of the National Network of Carers Associations, it has participated in national consultations to draft the Carer Recognition Act 2010, the National Carer Strategy 2011 and the legislation and the rules that underpin the NDIS.

Extracts below are pertinent to the support of carers within the legislation and other frameworks.

ACT

1. ACT Carers Strategy 2018-2028 (Visions, Priorities and Outcomes)

The ACT Government made a 10-year commitment to develop and implement the ACT Carers Strategy 2018-2028 commitment to 10 years. The Priority Statement was drafted during the Carers Voice Panel – as part of a deliberative democratic process.

http://www.communityservices.act.gov.au/__data/assets/pdf_file/0005/1142582/Statement-final.pdf

2. ACT Mental Health Act 2015 (ACT)

This Act replaces the *ACT Mental Health (Treatment and Care) Act 1994*. It includes provisions to provide carers and other significant people for mental health consumers rights to be considered. See Chapter 6 (ix) to (xii) and other relevant clauses.

<http://www.legislation.act.gov.au/a/2015-38/20171011-67339/pdf/2015-38.pdf>

3. ACT Carers Charter – Caring for carers

Extracts from the Charter:

The ACT Carers' Charter provides a policy framework to guide the way government and community services meet the needs of carers in the ACT:

1. Carers are engaged in matters that affect them as carers.
2. Carers are valued and treated with respect and dignity.
3. Carers are supported to sustain their caring role.
4. Carers' diverse needs are acknowledged and appropriate supports provided.

http://www.communityservices.act.gov.au/__data/assets/pdf_file/0005/1142582/Statement-final.pdf

Commonwealth

3. Carer Recognition Act 2010 Clth, and Schedule 1: Statement for Australia's Carers

Extracts from 'Part 3—Obligations of public service agencies and associated providers' of the Act:

7. Obligations of all public service agencies

- (1) Each public service agency is to take all practicable measures to ensure that its employees and agents have an awareness and understanding of the *Statement for Australia's Carers*.
- (2) Each public service agency's internal human resources policies, so far as they may significantly affect an employee's caring role, are to be developed having due regard to the *Statement for Australia's Carers*.

8. Additional obligations of public service care agencies

- (1) Each public service care agency is to take all practicable measures to ensure that it, and its employees and agents, take action to reflect the principles of the *Statement for Australia's Carers* in developing, implementing, providing or evaluating care supports.
- (2) Each public service care agency is to consult carers, or bodies that represent carers, when developing or evaluating care supports.

9. Obligations of associated providers

Each associated provider is to take all practicable measures to ensure that:

- a) its officers, employees and agents have an awareness and understanding of the *Statement for Australia's Carers*; and
- b) it, and its officers, employees and agents, take action to reflect the principles of the *Statement for Australia's Carers* in developing, implementing, providing or evaluating care supports.

***Statement for Australia's Carers* includes 10 principles:**

1. All carers should have the same rights, choices and opportunities as other Australians, regardless of age, race, sex, disability, sexuality, religious or political beliefs, Aboriginal or Torres Strait Islander heritage, cultural or linguistic differences, socioeconomic status or locality.
2. Children and young people who are carers should have the same rights as all children and young people and should be supported to reach their full potential.
3. The valuable social and economic contribution that carers make to society should be recognised and supported.
4. Carers should be supported to enjoy optimum health and social wellbeing and to participate in family, social and community life.
5. Carers should be acknowledged as individuals with their own needs within and beyond the caring role.
6. The relationship between carers and the persons for whom they care should be recognised and respected.
7. Carers should be considered as partners with other care providers in the provision of care, acknowledging the unique knowledge and experience of carers.
8. Carers should be treated with dignity and respect.
9. Carers should be supported to achieve greater economic wellbeing and sustainability and, where appropriate, should have opportunities to participate in employment and education.
10. Support for carers should be timely, responsive, appropriate and accessible.

4. National Carer Strategy 2011

Extracts from the Strategy:

'... Some carers shoulder their responsibilities alone; some share their responsibilities with others. Some do it full time, all day, every day, while others only occasionally. What they do not only makes a profound

difference to the lives of those they care for but makes an important contribution to the economic and social life of the nation.

Carers deserve the same opportunities as other Australians to participate in work and the community, and live a meaningful life. The Australian Government is determined to ensure Australia's carers get the support they deserve from the Government and the community.

We have developed the National Carer Strategy to ensure that our community values and respects carers.'

The National Carer Strategy contains six priority areas for action:

- recognition and respect
- information and access
- economic security
- services for carers
- education and training
- health and wellbeing.

5. National Disability Insurance Scheme Act 2013

Extracts from the Act:

The *National Disability Insurance Scheme Act 2013*, Part 2 Objects and Principles, 3 Objects of Act state that:

(3) In giving effect to the Objects of the Act, regard is to be had to:

(c) the broad context of disability reform provided for in:

- (i) the National Disability Strategy 2010-2020 as endorsed by COAG on 13 February 2011; and
- (ii) the *Carer Recognition Act 2010*

The 'Principles relating to the participation of people with disability'ⁱ state that:

The National Disability Insurance Scheme is to:

- s17A 3. (a) respect the interests of people with disability in exercising choice and control about matters that affect them; and
- (b) people with disability to make decisions that will affect their lives, to the extent of their capacity; and
- (c) support people with disability to participate in, and contribute to, social and economic life, to the extent of their ability.

In 'Principles relating to plans' these provisions exist for carer support under:

s31 'The preparation, review and replacement of a participant's plan, and the management of the funding for supports under a participant's plan, should so far as reasonably practicable:

- (c) where relevant, consider and respect the role of family, carers and other persons who are significant in the life of the participant; and
- (d) where possible, strengthen and build capacity of families and carers to support participants who are children; and

(da) if the participant and the participant’s carers agree—strengthen and build the capacity of families and carers to support the participant in adult life ...

s34 Reasonable and necessary supports allows that:

(e) the funding or provision of the support takes account of what it is reasonable to expect families, carers, informal networks and the community to provideⁱⁱ

Updated March 2018

Part 2 Objects and principles

4 General principles guiding actions under this Act

(12) The role of families, carers and other significant persons in the lives of people with disability is to be acknowledged and respected

ⁱ Commonwealth Government (2013) *National Disability Insurance Scheme Act 2013*. Accessible at http://www.comlaw.gov.au/Details/C2013A00020/Html/Text#_Toc352761880

ⁱⁱ There is uncertainty about what will be considered reasonable supports for families and carers are expected to provide.