Carers Australia

Submission to the Productivity Commission Inquiry on National Disability Insurance Scheme (NDIS) Costs

March 2017

AN AUSTRALIA THAT VALUES AND SUPPORTS ALL CARERS

ABOUT CARERS AUSTRALIA

Carers Australia is the national peak body representing the diversity of Australians who provide unpaid care and support to family members and friends with a:

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

Carers Australia believes all carers, regardless of their cultural and linguistic differences, age, disability, religion, socioeconomic status, gender identification and geographical location should have the same rights, choices and opportunities as other Australians.

They should be able to enjoy optimum health, social and economic wellbeing and participate in family, social and community life, employment and education.

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Questions and Answers

INTRODUCTION

Carers Australia welcomes the opportunity to respond to the Productivity Commission's Issues Paper, which has been prepared with input from State and Territory Carer associations.

Many of our responses to questions raised in the Paper reflect problems which have arisen with the implementation of the NDIS to date. We do appreciate that a major reform such as this likely to have significant teething problems which we hope and expect will be addressed over time. Carers Australia has always strongly supported the NDIS since it was first proposed and we continue to do so. However it is only through identifying shortcomings and suggesting the means to address them that the NDIS will fulfil its promise.

We have restricted our answers to questions where we believe we can contribute a degree of expertise and insight. We have made recommendations where we are able to identify some answers to problems identified. We have aligned questions and answers to the order in which they are presented in the Issues Paper.

QUESTIONS AND ANSWERS

Future estimates — some pressures emerging

Why are utilisation rates for plans so low? Are the supports not available for participants to purchase (or are there local or systemic gaps in markets)?

Do participants not require all the support in their plans? Are they having difficulty implementing their plans? Are there other reasons for the low utilisation rates?

Why is there a mismatch between benchmark package costs and actual package costs?

There are a number of factors contributing to low utilisation rates once an NDIS plan is in place.

In some cases we believe the low utilisation rate relates to inappropriate supports being included in plans – especially with the new ‘My First Plan’ process where planners develop plans over the phone with limited documentation relating to the participant and the participant may not necessarily be aware that this telephone conversation is in fact the only basis for determining the plan they receive. A pragmatic way to overcome this issue would be to allow carers and participants to review the draft plan before it is lodged. NDIA responses to carers who have requested to review the participant plan before it is submitted have been inconsistent.

Carers associations have also identified that the inclusion of supports in a plan which do not meet participants’ needs may often be a by-product of poor training and low levels of competency among some planners.

In addition, there is concern around the capacity of participants and carers who have difficulty in accessing the internet or using the internet as a necessary component of navigating the system and operationalising plans. For example, Carers Victoria report that carers are repeatedly contacting them querying how to access the NDIS My Participant Portal. The NDIA does not provide carers with any information on how to access the portal despite its use being integral to plan utilisation. Provision of the portal presumes participants and carers are computer literate and can afford access to the internet. Digital exclusion is a growing concern for carers. The Australian Digital Inclusion Index[i] illustrates that people of a low socio-economic status, older people, Indigenous people and people with disability have levels of digital exclusion significantly above the national average.[1] Carers feature prominently among the socio-economically disadvantaged. Surveys undertaken by state and territory Carer Associations reinforce the broad findings of this report in relation to carers.

Another problem relating to plan utilisation is a level of confusion among participants and family and friend carers about how to operationalise a plan and who is responsible for what. In the previous disability service system, people with a disability and their families were told which services they could have and when they were available. Service providers would provide all relevant information. The person centred nature of NDIS supports means that the initiative formally now sits with the person with a disability and/or their families and carers to initiate the implementation of the plan. In many cases, especially where people don’t have a pre-existing provider, participants don’t understand that the funding now sits under their control and it is up to them to take responsibility for organising the purchase of supports.

Even if they do understand that they must take the initiative, the task may be daunting. Support coordination and plan management assistance is technically available, however getting access to it seems to be problematic. Some participants do not know this

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[1] http://digitalinclusionindex.org.au/

coordination is available and therefore don't ask for the service in their plan. We are told that others have had it included in the plan submitted to the NDIA for approval, but funding is subsequently removed. What is clear is that the allocation of support coordination is consistently being denied to anyone who doesn't fit the NDIA's limited definition of 'complex'.

Nor, in the foreseeable future, can LACs be relied upon to assist with plan implementation. As noted elsewhere in this submission, with the fast roll-out of the NDIS the energies of LACs have been diverted into the initial planning phase.

The unavailability of all or some of services that are included in a plan is another key factor contributing to low utilisation rates. This is obviously the case in regional and remote areas where services needed are not currently available. It is also the case where services are complex or expensive to provide.[2] In this context many providers of services across the disability sector have complained that the benchmark prices established by the NDIS are budget-driven and too low and do not reflect the realities of service provision. The Australian National Audit Office (ANAO) has recommended independent price determination to remove a conflict of interest arising from the NDIS being both a price setter and funder.[3] At the very least, the Reasonable Cost Model (RCM) upon which the NDIA was supposed to establish prices should be revisited and independently validated.

Recommendations:

- Amend the NDIS rules to mandate the planner provide a copy of the draft plan to the participant, carer and advocate (if required) before it is submitted, to enable issues to be quickly addressed before the plan is submitted.
- Increase access to support coordination and plan management assistance under the NDIS.
- Price determination should be undertaken independently of the NDIS.
- Review the Reasonable Cost Model (RCM).

Eligibility for the NDIS

Is the ECEI approach an effective way to ensure that those children with the highest needs enter into the NDIS, while still providing appropriate information and referral services to families with children who have lesser needs?

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[2] National Disability Services, Submission to the Productivity Commission **Inquiry on National Disability Insurance Scheme (NDIS) Costs**

[3] Australian National Audit Office, 2016, 'National Disability Insurance Scheme—Management of the Transition of the Disability Services Market, ANAO, Canberra

The ECEI approach has only been piloted in two regions at this stage. The overall effectiveness of the approach with respect to supporting children with the highest needs to enter the Scheme, along with supporting those who aren't eligible for the NDIS, is not as yet tested widely enough to draw hard and fast conclusions. As the ECEI approach rolls out across Australia, the impact, outcomes and experiences of families will need to be comprehensively evaluated to ensure the ECEI approach is meeting their needs.

The experience in the Townsville ECEI trial site has not been a smooth or easy transition for families. Significant delays, confusion around planning, and the overall lack of information about the NDIS and planning have been major issues. There appears to be a staff shortage within the ECEI partner in this region. This may point to a larger workforce issue within the ECEI especially in regional and remote areas.

Early Childhood Early Intervention Approach – a family's experience in Townsville

A family with a 4 year old daughter with albinism was contacted by the ECEI partner about a plan for their child. The child is legally blind as a result of the albinism.

The family were unaware that the initial call with the ECEI partner was in fact a planning meeting and therefore all the child's needs were not included in the initial plan. This was in June 2016.

The mother has since been trying to have the plan reviewed to include the equipment that her daughter needs, particularly to start school in 2017. This revision of the plan involved a CCTV system so the little girl can participate in the classroom and have the class whiteboard projected onto her work space. A walking cane was also part of the request to help her get to school.

The family have been waiting since June 2016 to rectify these things and are frustrated with the process and the fact that their daughter has struggled to start school without the equipment she needs to help her.

Ideally, the ECEI partners will have early Intervention experience, which should mean that children get accurate and appropriate supports which may reduce plan dependence over time. The ECEI approach should also ensure that the children who access the NDIS through this pathway have plans in place that are in line with the NDIA's expectation of plan costs.

Recommendation:

The ECEI approach in the trial areas should be reviewed and evaluated fully to examine the outcomes and experiences for families. The recommendations should be shared with the new and emerging ECEI partners in each region.

The intersection with mainstream services

How has the interface between the NDIS and mainstream services been working? Can the way the NDIS interacts with mainstream services be improved?

We note that the examples of mainstream services identified in the Issues Paper are health care, aged care, education and transport. We are tempted to include services to family and friend carers in this list, as the interface between the NDIS and carer supports is particularly poor for both carers of people with packaged supports as well as those who care for a person who is not eligible for an NDIS package but who resides in an area where the NDIS has been introduced. Many carers are struggling to access supports in their own right and many are worse off in this respect than previously was the case. We deal with this issue in more detail in the section on informal carers on pages 18-20 of this submission.

With respect to those services which are identified in the Issues Paper, we note in particular the many complaints in relation to transport since the Scheme was first implemented. In some instances it was not made clear to participants and their carers that the transport services currently received would not be automatically ongoing and that their transport needs would have to be included in their plans. Where transport was included in plans, access was often sub-optimal. The recently released National Institute of Labour Studies (NILS) independent evaluation of the NDIS trials comments that:

> “While funding for transport was commonly included in participant plans, this was not consistent. For some participants funding for transport was not part of their plan (this included instances where taxi vouchers had been removed from plans). A lack of funding for transport made it difficult and costly for participants to attend activities, especially those not in the local area. “[4]

In other cases, previously available disability transport services in NDIS trial sites ceased. As National Disability Services (NDS) notes in its submission to the Inquiry:

> “The already emerging transport problems will be compounded by the fact that a growing number of service providers are considering divesting of their transport fleets. If this occurs, participants will be severely disadvantaged (or the expenditure on transport will substantially increase, with participants trading off their participation supports for transport). [5]

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[4] National Institute of Labour Studies (NILS), *Evaluation of the NDIS, Intermediate Report*, September 2016, page 35

[5] National Disability Services, Submission to the Productivity Commission *Inquiry on National Disability Insurance Scheme (NDIS) Costs*

The disappearance of these services will also affect people with disability who are not eligible for NDIS packages.

In terms of linking people with disability to mainstream services, LACs are intended to perform the dual role of working with participants to build their capacity and working with communities and mainstream services to increase their inclusiveness. This role is ambitious enough without the addition of planning / information gathering responsibilities given to LACs during the rollout of the NDIS. In NSW, for example, LACs are struggling to keep up with their planning quotas, let alone conduct meaningful plan implementation and other capacity building. They have no capacity to work with community and mainstream providers. (For now, this role is being conducted by Ability Links, a similar program funded by the NSW Government.) However, if LACs retain a major role in planning post full rollout, we are skeptical that they will be able to keep up with plan reviews and implementation while also performing their other functions. In the meantime, the LAC planning workload is creating a gap for people with a disability who do not receive packages.

With respect to Information, Linkages and Capacity Building (ILC), this program aims to achieve a great deal with limited funds ($132m). The effectiveness of the program in catering for the needs of people who are ineligible for packages is a major concern. We fear that people found ineligible for packages will have difficulty in accessing the supports they need through the ILC or mainstream services. The first ILC grants process recently closed for applications with decisions not yet announced, and it is difficult to assess their impact at this point. Further funding for ILC won't be made available in the jurisdictions until 2018 and 2019, creating real concern about what services and support will be available until this time.

Also of concern is the fact that funding for many services providing community support to people without packages have been folded into the NDIS. As registered providers with the NDIS, these providers are unable to apply for funding under the Information, Linkages and Capacity program. The effect is likely to be a considerable reduction in access to experienced quality providers available to non-NDIS participants.

Recommendations:

- The NDIA consider the funding disparity between the NDIS and ILC and have the flexibility to transfer funds between the NDIS and ILC as the Scheme matures.

- That ILC grants funding be implemented earlier in jurisdictions.

How will the full rollout of the NDIS affect how mental health services are provided, both for those who qualify for support under the scheme and those who do not?

What, if anything, needs to be done to ensure the intersection between the NDIS and mental health services outside the scheme remains effective?

There is considerable uncertainty around this question arising from the experience of NDIS performance to date and the capacity of the NDIS to cater for the number of people with severe mental illness who need support. The NDIS is projected to cater for only 64,000 people with mental illness and psychosocial disability who need support. The 2015 Australian government review of mental health services and programs estimated that 230,000 Australians with severe mental illness need some form of social support.[6]

NDIS package recipients

The controversy and difficulties around determining the eligibility of people with psychosocial disability for NDIS packages of support have been well canvassed. While the permanency of a disability and recognition of the continuing support needs is likely to be relatively predictable in the case of people with a physical disability, the situation can be very different for people with mental health conditions and psychosocial disability. In many cases they move in and out of periods where the severity of their illness will impair their capacity to function. In addition there may be significant variations in the ability of people with the same diagnosis to cope without support.

In 2014 the Independent Advisory Council to the NDIS noted in its advice on mental health:

> "It is apparent that consistent determinations of 'permanency' of disability are hard to arrive at under the current assessment processes. One of the objectives of the NDIS Act is to ensure the provision of a nationally consistent approach to access, planning and funding of supports. Our observation is that there are significant variations across the pilot sites in the assessment of eligibility. This lack of consistency is compounded by definitional ambiguities in the NDIS. Anecdotal reports and preliminary data indicate a higher rate of ineligibility rulings on access requests from people with psychiatric conditions compared with other participant groups."[7]

These observations and concerns have persisted. Carers Australia has received feedback from both our own associations and the mental health sector that there appears to be a degree of randomness in eligibility assessments for people with mental health disorders and psychosocial disabilities**.** The application of the NDIS access criteria to people living with a mental health condition (or, at least, those that are publicly available) are vague. They need to be made much more explicit.

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[6] Department of Health. *Australian Government Response to Contributing Lives, Thriving Communities – Review of Mental Health Programmes and Services*. 2015. Page 17

[7] (https://www.ndis.gov.au/about-us/governance/IAC/iac-advice-mental-health.html#key

The same inconsistencies apply to the planning process. As Mental Health Australia (MHA) noted in its submission to the *Joint Standing Committee into the provision of services under the NDIS for people with psychosocial disabilities related to a mental health condition* "Planning processes for people who are eligible for the NDIS are yet to mature to reflect best practice in mental health. Planning for people with psychosocial disability is a specialised task, and many people report receiving NDIS plans that are not fit for purpose or tailored for their individual needs".[8]

In areas where assessors and planners for people with mental health conditions and psychosocial disability are qualified in the field (such as in the ACT), there appears to be a higher level of satisfaction. Our view is that this model should be rolled out across all sites where the NDIS is operating.

The foundation principles of the NDIS include equity of access, consumer choice and control and the assurance that no one will be worse of under the NDIS (the no disadvantage principle).[9] Evidence that these principle are not operating as would be expected for people with psychosocial disability has emerged from the National Institute of Labour Studies independent evaluation of the NDIS trials. Here it was noted that:

- Both the qualitative and quantitative data indicate that people with mental health and psychosocial disability are more likely to report less choice and control over supports since becoming NDIS participants.[10]

- The quantitative data indicates that those who report that they are worse off in terms of their choice and control over their supports are more likely to have experienced a decrease rather than an increase in the number of supports they receive since becoming NDIS participants. [11]

- Increases in social participation were limited in the case of NDIS participants with mental health problems, intellectual disabilities, or with Autism Spectrum Disorder.[12]

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[8] Mental Health Australia (MHA), *Submission to the Joint Standing Committee into the provision of services under the NDIS for people with psychosocial disabilities related to a mental health condition,* February 2017

[9] https://www.ndis.gov.au/html/sites/default/files/documents/factsheet_no_disadvantage_and_the_NDIS_easy_english_text_only.pdf

[10] National Institute of Labour Studies (NILS), *Evaluation of the NDIS, Intermediate Report*, September 2016 page xii

[11] National Institute of Labour Studies (NILS), *Evaluation of the NDIS, Intermediate Report*, September 2016 page xii

[12] National Institute of Labour Studies (NILS), *Evaluation of the NDIS, Intermediate Report*, September 2016 page xvi

People who are found to be ineligible for packages

We are apprehensive that people found ineligible for packages will have difficulty in accessing the supports they need.

Emerging gaps in the provision of services outside the NDIS

There is evidence of a contraction of existing community services providing mental health supports arising from NDIS implementation. As Mental Health Australia has commented: "There is a major risk of widening gaps in access to services for people who are not eligible for the NDIS, due to the winding down of government programs that currently deliver psychosocial services."[13]

This concern is mirrored by Vicserv in their submission to the Government's Joint Standing Committee *Inquiry into the provision of services under the NDIS for people with psychosocial disabilities related to a mental health condition*. "In Victoria, through the bilateral agreement with the Commonwealth Government, the Victorian Government has committed the majority of its mental health services funds to the NDIS (redirected from the Mental Health Community Support Services funds), leaving the NDIS as the only option for most people with mental health issues who require psychosocial support in Victoria."[14] Feedback from our network of Carer Associations confirms that this problem is not confined to Victoria, although there are variations between states. For example, mental health services in NSW are generally funded through NSW Health, and that funding is not in scope for transition to the NDIS. However some people living with a mental health condition have accessed services from Ageing, Disability and Home Care (ADHC), which will be dissolving. As ADHC clients are being transitioned into the NDIS, these people should be captured in the transition, but there is no guarantee that they will be deemed eligible for the NDIS.

From a national perspective, funding for both the Personal Helpers and Mentors Services (PHaMS) and Partners in Recovery (PIR) programs, which have proved to be very successful, is being gradually transferred to the NDIS as it rolls out. However many people who benefit from these programs, in particular the PHaMS program, may not be found eligible for the NDIS.[15]

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[13] Mental Health Australia (MHA), *Submission to the Joint Standing Committee into the provision of services under the NDIS for people with psychosocial disabilities related to a mental health condition*, February 2017

[14] Psychiatric Disability Services of Victoria (VICSERV), *Submission to the Joint Standing Committee into the provision of services under the NDIS for people with psychosocial disabilities related to mental health condition*, February 2017, pages 3-4

[15] Mental Health Australia (MHA), *Submission to the Joint Standing Committee into the provision of services under the NDIS for people with psychosocial disabilities related to a mental health condition*, February 2017

In addition, outreach services, which are very important in the mental health space, cannot be funded under the ILC. They can be provided by the LACs, but as noted above, with the rapid rollout of the NDIS the LACs are far too busy producing plans for people who are eligible for packages to focus on other aspects of the diverse roles assigned to them – at least for the next three years.

It is also worth noting that existing national government funding for the Mental Health Respite: Carer Support (MHR:CS) program is being transferred to the NDIS on the same basis as the PhaMS and PIR programs. This program not only funds respite, but also a range of other supports directed to the special needs of mental health carers, including counselling. As noted on page 20 of this Submission, carers don't have access to support services in their own right under the NDIS. Nor will this funding now be available to mental health carers who care for someone who is not eligible for NDIS supports. The transfer of this funding is particularly ill-targeted. The emotional stress of caring for someone with a mental health disorder and challenging behaviours is extremely debilitating. In 2014-15 the program supported 40,644 mental health carers.[16]

What, if anything, needs to be done to ensure the intersection between the NDIS and mental health services outside the scheme remains effective?

This is far too large and complex a question for us to respond to. However we endorse the recommendations below of Mental Health Australia.

- The NDIA should specify which tools (if any) are used to assess psychosocial disability for people making access requests, and describe in detail what safeguards it has in place around the consistent interpretation of the provisions in the Act as they relate to the assessment of psychosocial disability.

- The Australian Government should continue to fund community-based psychosocial services for people who do not enter the NDIS.

- State and Territory Governments should ensure people who do not enter the NDIS have access to community-based mental health services.

- The Australian Government should invest in capacity building activities designed to build knowledge and capability amongst mental health providers (including primary care practitioners) regarding the respective roles of PHNs, Local Hospital Networks, Local Area Coordinators and the NDIA.

- The National Mental Health Commission should take the lead in keeping governments accountable by tracking mental health expenditure, including spending within and outside the NDIS, on a regular and ongoing basis.

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[16] Department of Social Services, *Designing the new integrated carer support service, Discussion Paper 1, Appendix B, May 2016*

- Governments should develop and implement a strategy to provide assertive outreach for every person with severe mental illness and/or complex needs who may be eligible for the NDIS, building on the success of the Partners in Recovery Program.

Carers Australia's additional recommendations are that:

- The Australian Government continue funding respite and other support services for carers of people with mental illness whether are not those people are NDIS package recipients.

- NDIS assessors and planners and those providing assistance to access mainstream services should have adequate qualifications and experience when dealing specifically with people with psychosocial disability.

The intersection with the National Injury Insurance Scheme

How will the National Injury Insurance Scheme (NIIS) affect the supply and demand for disability care services?

As of 1 July 2016, the National Injury Insurance Scheme (NIIS) has been operational in each Australian State and Territory for motor vehicle accidents; but is yet to reach national coverage on workplace accidents, medical treatment or general accidents.

In relation to motor vehicle accidents; anyone who sustains a serious personal injury as a result of a motor vehicle accident is covered by this scheme. However, personal injuries are limited to permanent spinal cord injury, traumatic brain injury, multiple or high level limb amputations, permanent injury to brachial plexus, severe burns or permanent legal blindness.

The scheme provides necessary and reasonable treatment, care and support including medical and pharmaceutical services, dental treatment, rehabilitation, respite care, aids and appliances, home and transport modifications, prosthetics, educational and vocational training, and personal care and domestic services.

When and if the NIIS incorporates a wider range of disabilities resulting from accidents, it should have some impact on the supply and demand for disability care services under the NDIS.

As NIIS becomes fully operational there may be a three speed service model operating; those with NIIS funded services, those with NDIS funded services, and those without funded services relying on Information, Linkages and Capacity (ILC) funded services.

We can already see clear differences between the programs; for example NIIS makes clear commitments to support respite care and education and vocational services where the NDIS does not necessarily provide the same services. Under these circumstances, it may well be the case that the NIIS is more attractive to many people with a disability resulting from an injury and to their carers.

Planning processes

Is the planning process valid, cost effective, reliable, clear and accessible? If not, how could it be improved?

The current 'My First Plan' approach being implemented as part of the national rollout of the NDIS has some clear issues. Whilst cost and time effective for the agency, phone meetings are generally not being well received by participants and their families. Some of the issues for participants and their families are as follows.

- Participants are unaware the phone call is being treated as a planning meeting.
- The NDIS language is difficult to understand. This communication problem is accentuated in phone calls, especially for participants where English is not their first language.
- Limited capacity to assess the complete picture of someone's life. Their limitations and strengths are difficult to fully access when relying only on a phone call.
- People are unaware they can request a face to face meeting if required. This is not being promoted.
- Phone conversations are being focused primarily on the participant and the NDIA/LAC planner rather than being inclusive of families, carers or significant providers or supporters.
- Concerns about consent and privacy being maintained.
- Participants with certain disabilities may not be fully aware of the range of services and supports they currently have to inform the planner in a phone contact. Therefore their needs are unlikely to be adequately covered.

It needs to be noted that one impact of poor initial planning is the rise in future administrative costs associated with later plan reviews (and, if LACs are to be involved in this process, diversion away from their other roles). Presently, there is no system in place for capturing the average cost of internal reviews.[17] We note that the number of reviews has increased as the NDIS is rolled out, however the NDIS has stopped reporting the number of internal reviews in the most two recent quarters (September and December 2016). This may be associated with the introduction of 'My First Plan' which delays plan reviews for a year.

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[17] Confier, D. & McKinnon, M, (12/3/2017), National Disability Scheme rollout plagued with problems, FOI documents reveal, ABS.

However, this approach is likely to simply delay a large future administrative burden arising from high demand for reviews which will have cost consequences for the NDIS.

We also note that the administrative impact on families, carers and people with a disability in applying for and preparing for planning for the NDIS is significant. Collating reports and evidence of the disability and functional capacity of the person with the disability, contacting the agency and preparing for the planning meeting takes a large number of hours for participants, families and carers. This administrative burden for families is supported in the findings of the National Institute of Labour Studies, Interim NDIS Evaluation report.[18] The report also highlighted the negative impact of the ongoing administrative burden of the NDIS. It was a new source of stress; some carers felt the added paperwork consumed time that was in the past usually spent as a family.

Recommendations:

- The performance of planners should be monitored and evaluated not only on the numbers of plans finalised or the package cost, but also on the quality, outcomes and experience of the planning process for participants.

- As mentioned above under Future Cost Pressures, amend the NDIS rules to mandate that the planner provide a copy of the draft plan to the participant, carer and advocate (if required) before it is submitted, to enable issues to be quickly addressed before the plan is submitted.

- The NDIS should address factors limiting the effectiveness of primary decisions. In particular it should address the following issues.
    - Flaws identified in relation to phone based planning;
    - The high administrative burden placed on participants and carers in initially navigating the process, implementing plans and navigating review processes
    - Ensure no amendments are made to the National Disability Insurance (NDIS) Act 2013 Rules regarding current review criteria to further limit access to reviews (sections 47-50 and 99-103 of the Act).

What implications do the criteria and processes for determining supports have for the sustainability of scheme costs?

While we do not have detailed knowledge of the criteria and processes for determining supports (and as noted elsewhere in this submission there are inconsistencies in the criteria applied) we do note that there is to date a disproportionate emphasis on the provision of

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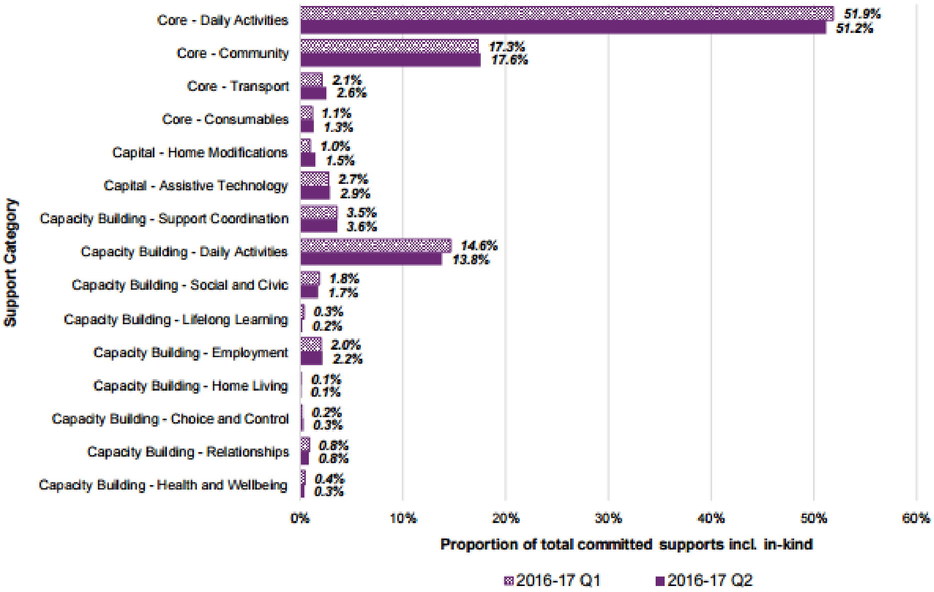
[18] National Institute of Labour Studies (NILS), *Evaluation of the NDIS, Intermediate Report*, September 2016 page xv

core supports, especially in relation to activities of daily living and community participation. Indeed, 72.7% of all package supports are core supports.



Source: 2016 COAG Disability Reform Council Quarterly Report, p 70

The emphasis on core supports is likely to be even more pronounced with the new fast planning approach.

We understand the reasons why the provision of core supports has been the overriding focus to date. The NDIS has replaced a chronically underfunded, ration based system and many participants transitioning to the Scheme from state based programs have significant support needs which require core supports. However, the low rate of capital (4.4%) and capacity building (23%) will need to be monitored. This will ensure broader goals of the Scheme in supporting the independence and social and economic participation of people with disability and their carers are achieved, and costs are contained to ensure the ongoing sustainability of the Scheme. Again, the role of the planner is critical to promoting the capacity building features of the NDIS to carers and participants.

Market readiness

What factors affect the supply and demand for disability care and support workers, including allied health professionals?

How will competition from other sectors affect demand (and wages) for carers? What evidence is there from the NDIS trial sites about these issues?

How will an ageing population affect the supply and demand for disability carers (including informal carers)?

To what extent is the supply of disability care and support services lessened by the perception that caring jobs are poorly valued? If such a perception does exist, how might it best be overcome?

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Formal Disability Care Workforce

The anticipated growth in demand for supports and services across both aged and disability care and a very large projected inter-related workforce shortfall in both these areas are well-documented.

As National Disability Services (NDS) commented in their *2016 State of the Sector* report, the majority of providers who responded to their survey reported that they also provided services in aged care, mental health and/or homelessness, with only 43% reporting that all their activities related to the provision of disability services. Seventy five percent of providers for whom disability services is half or less than half of their business are planning to move into new markets.[19] Providers also reported that about 38% of their staff were casual and projected that, while they anticipated increasing employment in 2016-17, the highest predicted areas of employment growth were for part-time casual workers and, to a lesser extent, part-time permanent workers. There is a very high turnover of casual staff – about 30% per year compared to 20% per year for full-time or part-time staff. Allied health workers are the most difficult to recruit followed by disability support workers.

As noted in the National Institute of Labour Studies' (NILS) evaluation of the NDIS trials, one consequence of this workforce shortage is its impact on the quality of services delivered. They found that the low hourly rate for supports funded by the NDIS had led to increased staff turnover and agency staff being employed without appropriate qualifications or experience.[20]

The reasons for the difficulty associated with attracting and retaining staff is clearly identified in the NDS report:

> "Compared to the Australian labour force as a whole, jobs in disability are less likely to offer either a living wage or job security. Jobs in the disability sector are more likely to include fewer hours with the average at 22 hours per week. Across all industries the Australian average is 35 hours per week. A significant proportion of disability workers earn a living by combining two or more short-hours jobs together. This can adversely affect the quality of service, with a worker's commitment and focus split and their responsiveness to each individual employer constrained. For people with disability, being supported by the same person(s) tends to correlate with high-quality care."[21]

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[19] National Disability Services (NDS), *State of the Disability Sector*, 2016, page 10

[20] National Institute of Labour Studies (NILS), *Evaluation of the NDIS, Intermediate Report*, September 2016, page 50

[21] National Disability Services (NDS), *State of the Disability Sector*, 2016,page 29

Recommendation:

If the sector is to attract and retain a more stable and higher quality workforce; wages, conditions, job security and training will need to be improved. This is likely to push up NDIS costs, but the alternative is a failure to provide the services both promised under the Scheme and expected by participants.

How might assistance for informal carers affect the need for formal carers supplied by the NDIS and affect scheme costs?

As acknowledged in the Productivity Commission Issues Paper, the Deloitte Access Economics (DAE) report on *The economic value of informal care in Australia in 2015* identified a decline in the propensity to care based on historical Australian Bureau of Statistics (ABS) surveys, government reports and academic research.[22] A number of reasons why such a decline is projected to increase were explored in the DAE report. These included: smaller family sizes; changing generational attitudes towards providing informal care; changes in family mobility and dispersion; rates of relationship breakdown; the proportion of the population living in single person households; and an increase in the number of women choosing workforce participation over caring. However, the "carer gap" was calculated based on the number of people over 65 with a profound or severe disability who were not living in cared accommodation, and the forecast number of co-resident primary carers in that year. Whether the ratio of carers to people with a life-long and significant disability under the aged of 65 might also be expected to decline is less clear, although it seems entirely likely in circumstances where carers are ageing and unable to sustain a high level of care.

What is clear is that to date there has not been a significant decline in the number of carers who provide a very significant amount of care with the introduction of the NDIS. According to the National Institute of Labour Studies, family and friend carers continue to provide the most care to NDIS participants.[23] These findings are echoed in a Carers ACT 2016 survey of carers and the NDIS which found that most carers of package recipients (92%) who answered a question related to time out from caring as a result of the NDIS reported time out had not increased. In addition, the majority (63%) of respondents felt that the time spent managing the support needs of the person they cared for had in fact increased.[24]

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[22] http://www.carersaustralia.com.au/storage/access-economics-report-2015.pdf

[23] National Institute of Labour Studies (NILS), *Evaluation of the NDIS, Intermediate Report*, September 2016 page xiv

[24] Carers ACT, *Is the National Disability Insurance Scheme supporting unpaid carers of people with a disability?*, 2017

Importantly, the NILS evaluation found that access to support services for carers in their own right has diminished since the NDIS roll-out:

- Both the quantitative and qualitative data indicate that many family members and/or carers of NDIS participants are unable to take adequate breaks from providing support and they cannot access carer support in a consistent manner.[25]

- The qualitative evidence also suggests that support for carers (within and outside of the NDIS) has diminished since the NDIS roll-out.[26]

Where funding supports for families have been included in packages, the NILS report notes on the basis of qualitative evidence that: "Funding for family supports was inconsistently included in plans and limited in scope". [27]

In this context it is of note that one reason a number of carers are not able to access supports is that, not only does the NDIS not provide supports to carers in their own right to assist their wellbeing and sustain them in their caring role, but funding from dedicated carers support programs established prior to the NDIS is being transitioned into the NDIS as it rolls out. This includes existing carer support programs for young carers and, as noted above, mental health carers.

To the extent that the affordability of the NDIS is (and is likely to continue to be) predicated on the support of informal carers, continuity of supports for carers in their own right is an important dimension of NDIS affordability.

While both the NILS survey and the Carers ACT survey found that carers have benefited from the NDIS, the benefit has come largely from the sense of satisfaction and relief that the person they care for is much better off, some assistance with caring and, for about 50% of carers surveyed by NILS, decreased anxiety about future supports available to the person they cared for. However this doesn't mean that support for the person they care for removes all major stresses related to the caring role or that carers themselves are suddenly freed from their own social isolation and the impact caring has on their mental and physical health. In particular, it doesn't mean that they no longer need breaks from caring from time to time (over and above the short breaks they may have if some degree of paid care is included in plans). What is needed is a proper break to recharge batteries, similar to how most people who work a significant number of hours get through weekends and other holiday breaks. It also doesn't mean that carers no longer need peer support or counselling.

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[25] National Institute of Labour Studies (NILS), *Evaluation of the NDIS, Intermediate Report*, September 2016 page xii

[26] National Institute of Labour Studies (NILS*), Evaluation of the NDIS, Intermediate Report*, September 2016 page 19

[27] National Institute of Labour Studies (NILS), *Evaluation of the NDIS, Intermediate Report*, September 2016 page 28

Assisting carers to sustain care should be of central concern in the context of addressing NDIS sustainability, especially in the context where there is a shortage of formal care workers and no solution yet in sight.

Against this background there would seem to be two obvious options for providing a higher level of support to carers in the interests of both recognising and sustaining their contribution to the NDIS. Either carer supports which are currently excluded from the NDIS under the operational guidelines are incorporated into it, along with the required funding, or improved carer support service provision and funding outside the NDIS (including restoration of funding currently being transferred to the NDIS). The government is currently exploring the latter option in the context of a Department of Social Services Integrated Carer Support Services project which would support carers of people both over and under the age of 65. (One big advantage of this approach is that carers who provide support to someone who is aged and also to someone under the age of 65 – which will be a growing cohort with the ageing of the population - would not have to navigate their way through two support systems and different eligibility and access criteria.)

Recommendation:

That the national government implement an Integrated Carer Support Services model which will be adequately resourced to meet the needs of carers (whatever the age of the person they care for) and which will improve the quality of supports provided to carers in their own right (including to carers of NDIS package recipients and those who are not NDIS eligible).

Will participants be ready?

How well-equipped are NDIS-eligible individuals (and their families and carers) to understand and interact with the scheme, negotiate plans, and find and negotiate supports with providers?

Families and carers are finding the Scheme difficult to understand and engage with. There is a significant lack of general understanding and knowledge in communities about the NDIS. Participants, carers and families are very anxious about the NDIS and there is a genuine fear that people will lose services and be worse off under the NDIS. In communities where the NDIS is about to rollout, there is a lack of understanding about access, eligibility, the process, what to expect and being prepared.

Carers have anecdotally expressed confusion over the NDIS language and the administrative tasks associated with the NDIS. A large number of hours are being spent trying to find information and navigate the NDIS to establish what it means for the individual.

The sector as a whole is implementing enormous reform under the NDIS to provide support and services to people with a disability and their families. Some anxiety and uncertainty is likely as the Scheme matures to full roll out, however more work needs to be funded to build the sector's capacity to engage with the NDIS as well as individual people's capacity in regards to the NDIS.

Recommendation:

If anything has characterised the NDIS to date it is poor communications performance. It has failed to communicate changes in the Scheme as it has been rolled out to potential participants. Its communications have frequently been heavily jargonised and pitched at a very high level. Even people whose job it is to understand NDIS developments and operations often struggle with exactly what is being communicated. In some cases the NDIA has been successful in making elements of the Scheme intelligible to consumers; for example, in a number of their plain English guidelines to supports available under the NDIS. This approach needs to be incorporated into all communications with participants, their carers and providers.