



**National Disability Insurance Scheme Costs**

**Carers Victoria submission to the Productivity  
Commission**

**31 March 2017**

**AN AUSTRALIA THAT VALUES AND SUPPORTS ALL CARERS**

## **About Carers Victoria**

Carers Victoria is the state-wide peak organisation representing people who provide care. We represent more than 773,400 family carers across Victoria – people caring for someone with a disability, mental illness, chronic health issue or an age-related condition.

People receiving care could be a parent, child, spouse/partner, grandparent, other relative or friend. Carers Victoria is a member of the National Network of Carers Associations, and the Victorian Carer Services Network. Carers Victoria is a non-profit association which relies on public and private sector support to fulfil its mission with and on behalf of carers.

Carers Victoria is a membership based organisation. Our members are primarily family carers, who play an important role in informing our work, contributing to advocacy and strategic aims, and distributing information more widely to other carers.

This policy paper was prepared by Carers Victoria's Policy Team.

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For information contact:

Caroline Mulcahy

Chief Executive Officer

Carers Victoria

Telephone: 03 9396 9500

Facsimile: 03 9396 9555

Email: [caroline.mulcahy@carersvictoria.org.au](mailto:caroline.mulcahy@carersvictoria.org.au)

Website: [www.carersvictoria.org.au](http://www.carersvictoria.org.au)

## Contents

Recommendations .....	4
1. Introduction .....	7
2. Scheme costs .....	7
2.1 Unidentified NDIS cost drivers.....	7
2.2 Low plan utilisation rates .....	16
3. Scheme boundaries .....	19
3.1 Effect of NDIS rollout speed on eligibility of assessment process .....	19
3.2 Interface between the NDIS and mainstream services .....	20
3.3 Effect of full NDIS rollout on mental health service provision .....	23
3.4 Ensuring the intersection between the NDIS and mental health services outside the Scheme.....	27
4. Planning processes .....	28
4.1 Validity, cost effectiveness, reliability, clarity and accessibility of planning processes .....	28
4.2 Monitoring and evaluation of planner performance .....	29
4.3 Appropriateness of dispute resolution for participant supports.....	30
5. Market readiness.....	31
5.1 Effect of ageing population on the supply and demand for informal carers.....	31
5.2 Effect of assistance for informal carers on the need for formal carers and Scheme costs.....	33
5.3 Service provider readiness to move from block funding to fee-for-service .....	40
5.4 Service provider capacity to deliver supports to CALD and ATSI communities.....	41
5.5 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? .....	42
6. Conclusion .....	43
Appendixes .....	45

## Recommendations

**Recommendation 1:** The NDIA addresses factors limiting the effectiveness of primary decisions; in particular, phone-based planning; counter intuitive processes and planner competence and training adherence, to:

- ensure the delivery of a cost-effective NDIS
- ensure a more time-efficient process for participants and carers
- ensure there is no increase in administrative burden on carers
- reduce further anxiety, psychological and monetary distress on carers associated with additional effort required to navigate the review processes, and
- ensure no amendments are made to the *NDIS Act 2013* and Rules regarding current review criteria to further limit access to reviews (see ss 47–50 and ss 99–103 of the Act).

**Recommendation 2:** The NDIA develop a universally accessible ‘My Participant’ portal for participants and carers.

**Recommendation 3:** Amend the NDIS rules to mandate the planner provides a copy of the draft plan to the participant, carer and advocate before it is submitted, to enable issues to be quickly addressed before the plan is submitted.

**Recommendation 4:** The NDIA becomes the service provider of last resort in ‘thin markets’.

**Recommendation 5:** The NDIA appraises where participants and carers are likely to intersect with other government services and develops a rigorous referral framework to ensure smooth transition between government services and the NDIA, including participants who are ineligible for the NDIS.

**Recommendation 6:** The NDIA increases access to specialised care coordination and support for eligible participants and carers who require it.

**Recommendation 7:** Individual advocacy should be funded through the ILC to ensure the individual rights and support needs of participants and carers are clearly identified, articulated and acted upon.

**Recommendation 8:** The NDIA in consultation with the Victorian Government, ensures clear delineation between State and Federal community mental health services delivery, in order to reduce the risk of cost-shifting to the NDIS.

**Recommendation 9:** The Federal Government resource and ensure an adequate safety net of service provision with a similar capacity to PHaMs and PIR programs. This will reduce the risk of the worsening health of consumers resulting in a need for ongoing psychosocial disability support under the NDIS.

**Recommendation 10:** The NDIA develop a communication strategy which includes GPs, clinical mental health services, outreach and allied health services to ensure timely, appropriate access to both mainstream and NDIS supports.

**Recommendation 11:** The role of individual advocate (recommendation 7) should be recognised by law to incorporate specific powers, including monitoring and evaluation of planner performance to improve processes and reduce unnecessary costs.

**Recommendation 12:** The *NDIS Act* should include authority to delegates to make alterations to participant supports where they were omitted in the original plan; if they meet all the necessary legislative criteria for reasonable and necessary supports; and waiting for review would prolong the time of a significant need not being met, or create a significant risk to the health or wellbeing of the participant or carer.

**Recommendation 13:** The NDIA, through the ILC, invests in a multicomponent succession planning and transition support accommodation program which includes:

- psychosocial planning, including supporting broad family discussions of future needs and roles.
- Support with identifying the most appropriate supported accommodation model for the family.
- support with legal and financial planning, including wills and estate planning; special disability or family trusts; testamentary trusts; family agreements; contracts for family property management; and ongoing legal and financial representation arrangements where required
- development and promotion of NDIS operational guidelines on succession and transition planning tasks with relevance to national practice and the NDIS.

- building system capacity for emergency or sudden transitions of people with an intellectual disability and/or psychosocial disability.

**Recommendation 14:** The NDIA takes necessary action to identify care relationships at the beginning of the participant assessments, plan review and referral. This should include a screening assessment for young family carers aged 25 and under.

**Recommendation 15:** The NDIA ensures a carers statement is required for all participants with informal carers.

**Recommendation 16:** The NDIA implements a carer's assessment to ensure the sustainability of informal caring arrangements.

**Recommendation 17:** The NDIA immediately reviews the adequacy of funded transport in participant plans.

**Recommendation 18:** The NDIS includes a component of outreach advocacy, targeted engagement and culturally appropriate and tailored information for LGBTIQ, CALD and ATSI communities who may experience difficulties obtaining information on access to and navigating the Scheme.

## **1. Introduction**

Carers Victoria would like to acknowledge the work of the Productivity Commission in tackling a wicked problem, a chronically ‘underfunded, unfair, fragmented and inefficient’<sup>1</sup> disability services system, viewing it through a human rights lens and devising a fiscally pragmatic Scheme based on consumer choice to stimulate market competition and insurance principles.

Carers Victoria, together with other carer organisations, could see the life changing potential of the National Disability Insurance Scheme (NDIS) for people in care relationships. In conjunction with the disability sector the association has been active advocates for the introduction of the Scheme as envisioned by the Productivity Commission.

In a country where political bipartisanship and sector unity are uncommon; both were achieved and were integral to the establishment of the NDIS in July 2013.

As the NDIS rapidly approaches full rollout, it is now more important than ever to ensure the vision for the Scheme is realised and NDIS core values are not compromised as the National Disability Insurance Agency (NDIA) tries to keep pace with an ambitious transition schedule to achieve full rollout by 2019.

The NDIS is very new, very large and still evolving, resulting in imperfect processes. It is too important in the lives of people with a disability and their carers to depart too far from its intent. The following is Carers Victoria response to the questions posed by the Productivity Commission in its inquiry into NDIS costs.

## **2. Scheme costs**

### **2.1 Unidentified NDIS cost drivers**

Carers report a number of systemic issues which are impacting on the quality of primary decision-making. These issues are associated with the likelihood of driving NDIS costs through disproportionately high numbers of internal and external reviews and likely impact on participant capacity building. With timely and appropriate interventions, these issues can be resolved proactively before they drive costs. The Productivity Commission has identified delivery costs associated

with operating the NDIS, but Carers Victoria is keen to highlight likely long term costs if the factors affecting primary decision-making are not addressed.

## **2.1.1 Effectiveness of primary decisions**

### **2.1.1.1 Phone-based planning**

Carers and participants typically receive a phone call from either Australian Healthcare Associates (AHA) or the Local Area Coordinator (LAC), as an NDIA representative, in the first instance of phone-based planning. This initial call is intended to be for information gathering and the caller will generally have access to the participant's Individual Support Package (ISP) or Disability Support Register (DSR) documentation. However, carers have reported this initial call often develops into the planning meeting, unless the carer or participant reschedules the planning component of the phone call to a later date. Participants will generally not be offered a face-to-face meeting; although requests for one are generally honoured. It is believed this process has been developed to speed up the assessment process in light of the number of applicants going through the system.

This raises many concerns for carers and participants: limited access to supporting documentation whilst on the phone; limited time to properly consider goals and aspirations; confusion about who they are being contacted by and for what; whether the plan will be as comprehensive as it could have been if the participant had the opportunity for a face- to-face meeting; the ability for the planner to recognise opportunities for capacity building.



*I received a telephone call from an NDIA representative and requested a face-to-face meeting to discuss the needs of my son as I had been preparing over the last twelve months through involvement in the Carers Victoria DSO project. The planner requested information regarding my son and said there were notes from his case manager which would be used to help create his plan. I inquired about the case manager, as I was not aware my son had one. The name given was of a man I had spoken to about 20 years ago. The planner said they have all his needs documented. I reiterated the need for a face-to-face meeting to discuss our changing circumstances and the support that my son needs to live independently and future support needs. I was offered a meeting three days later, 90km from my home, which was not possible for me to attend. When I received a follow up call, I thought it was to schedule another time for a meeting, instead it was to tell me that a plan had been created for my son and that I should login to the Portal to see it. A week later I received a copy of the plan in the mail.*

*The plan contained information about my son from over 20 years ago. The goals were workable, but generic and the plan included funding for home modifications we did not need. I am unsure if there is money allocated in the plan for the assistance my son needs to live more independently and for some in-home support for my son with regards to personal hygiene, as he will only let me help him at this stage. We are planning on going away for a month, but have no idea if the allocated funds can be used to support my son to live independently during that time.*

- Veronica, Victorian older parent carer of an adult son.

### 2.1.1.2 Counter intuitive processes

Carers have received formal legal correspondence for negative determinations for participants who are clearly eligible, but who have applied before their rollout date. Legally, they are not eligible before their rollout date; however, the NDIA could choose to deal with these situations pragmatically in plain English. For example: 'Dear participant, you have applied too early for the NDIS, please re-apply on x date.' Instead the following is typically sent (NDIA letter extract):

I am writing to advise that I have assessed your request to access the National Disability Insurance Scheme (NDIS) and I regret to inform you that I have determined that you do not meet the access criteria specified in section 21 of the *National Disability Insurance Scheme Act 2013* ("NDIS Act").

From the information provided I have determined that you do not meet the residence requirements for access to the NDIS which are outlined in section 23 of the NDIS Act.

I have included a fact sheet on internal review of a decision. This explains what your options are if you are unhappy with a decision.

The simple omission of a contact telephone number for one carer on her son's case notes led to the counter intuitive action of delaying his transition indefinitely, rather than using another contact method to progress his transition.

*My son has been receiving funding from the Victorian government since 2012. When the NDIS rollout was announced, we were advised that he would be in the first tranche of people to be transitioned to the NDIS because he was currently receiving services. As we reside in North East Melbourne, the roll-out in our region commenced 1 July 2016.*

*In the last year we have attended three information sessions, at each of which we have raised our concerns about not being contacted regarding transition. We have also directly approached representatives of the NDIA at information booths. At each contact we were advised not to worry, that the roll-out was just taking longer than expected.*

*Another family member contacted the Department of Health & Human Services and was advised that my son's plan was showing on their system as being 'in draft'. I then called the NDIS information line to ask for clarification.*

*The person I spoke to advised me the plan was supposed to have been prepared in May 2016. He said they had been provided with my son's details by the Department of Health & Human Services which is why we received the letter saying they would be contacting us. However, the information they were provided by the Department did not include a contact phone number.*

*He confirmed that they did not write to us to ask for a contact number, or contact the Department to ask for one, or take any other action to progress my son's transition to the NDIS. They simply put his file on hold. If I had not telephoned them it is likely it would have continued to sit on hold indefinitely, as they did not appear to have any plan to follow up and make contact.*

*We have now been 'enrolled' in the NDIS and are waiting to be advised of the date of our planning meeting. This process has caused a great deal of stress for our son, and for our family, as we have been unable to make plans for his future in the absence of knowing what support he will have access to.*

– Sarah, Victorian parent carer of an adult son with Autism.

### 2.1.1.3 Planner turnover, competence and training adherence

The role of the planner is essential in primary decision-making for the development of a quality NDIS plan for participants. Planners need to apply a person-centred approach, proactively manage a case load of participants, assess their unmet needs, informal supports, future needs and aspirations and accordingly, create plans aligned with their choices. Carers report wide variations in planners with regard to their competence, backgrounds and experience.

Information released under *Freedom of Information Act 1982* found nearly 550 coordinators were supposed to be trained by late June: only 150 had completed an online program; and just 54 had received face-to-face training.<sup>2</sup>

This lack of training is overwhelmingly consistent with reports from carers after completing a participant planning session.

*The planner told me the NDIS doesn't fund transport costs and I had to convince the planner it did. I had learnt in a Carers Victoria information session that transport was covered. The planner also had no idea about supports for community inclusion, like public transport training, which is really important for my son's independence. The planner did mention however, 'It would be good for building tolerance in the community if my son got out more'.*

- Peter, Victorian sole parent carer of an adult son with an intellectual disability.

University of Melbourne Master's program research undertaken by Nick Mann in the Barwon launch site, found staff turnover and accountability were major issues for carers '...the parent of a child with autism and epilepsy stated they had approximately seven or eight planners in three years with the NDIS, while another estimated in their three years as a participant, they had engaged with over 50 planners, coordinators and national office staff in order to obtain and enforce their plan'.<sup>3</sup>

### 2.1.2 Likely impact on numbers of internal and external reviews

NDIA's operating costs for 2015–16 were \$2.7 million.<sup>4</sup> Increased operating costs will result if there are disproportionately high numbers of internal and external reviews of primary decisions as a flow-on result of poor quality assessment and planning for NDIS participants. Presently, there is no system in place for capturing the average cost of internal reviews.<sup>5</sup> However, given the initial process is repeated by another public servant, usually at a more senior level, it is common-sense a reviewed decision is more expensive than an uncontested primary decision. Costs would be higher again when the NDIA is the respondent in an Administrative Appeals Tribunal (AAT) review. The number of internal and external reviews will naturally increase as more participants are enrolled in the NDIS; which was the case when COAG Disability Reform Council Quarterly Reports data was compared from June 2014 to June 2016 (see table 1).

Table 1: COAG Disability Reform Council Quarterly Reports data – Number of participants, internal reviews and appeals.

	June-14	Sep-14	Dec-14	Mar-15	Jun-15	Sep-15	Dec-15	Mar-16	Jun-16	Sep-16	Dec-16
Number of participants with approved plans	7,316	8,880	11,029	13,610	17,303	19,758	22,281	24,866	30,281	37,721	61,215
Internal review	82	148	*	245	302	355	435	554	772	**	**
AAT appeals	18	24	*	26	37	44	48	63	83	94	112

\* COAG Disability Reform Council Quarterly Report not available on website (likely website admin error)

\*\* Not reported in COAG Disability Reform Council Quarterly Report

Sources: National Disability Insurance Scheme, COAG Disability Reform Council Quarterly Reports.

However, the NDIA omitted reporting on the number of internal reviews in the most two recent quarters (September and December 2016); without explanation

(see table 1). The Scheme Actuary must take reasonable steps to verify the consistency, completeness and accuracy of the data provided by the Agency and resolve any discrepancies.<sup>6</sup> The reports by the Scheme Actuary on the sustainability the Scheme for the same two quarters are not currently available on the NDIA website.<sup>7</sup>

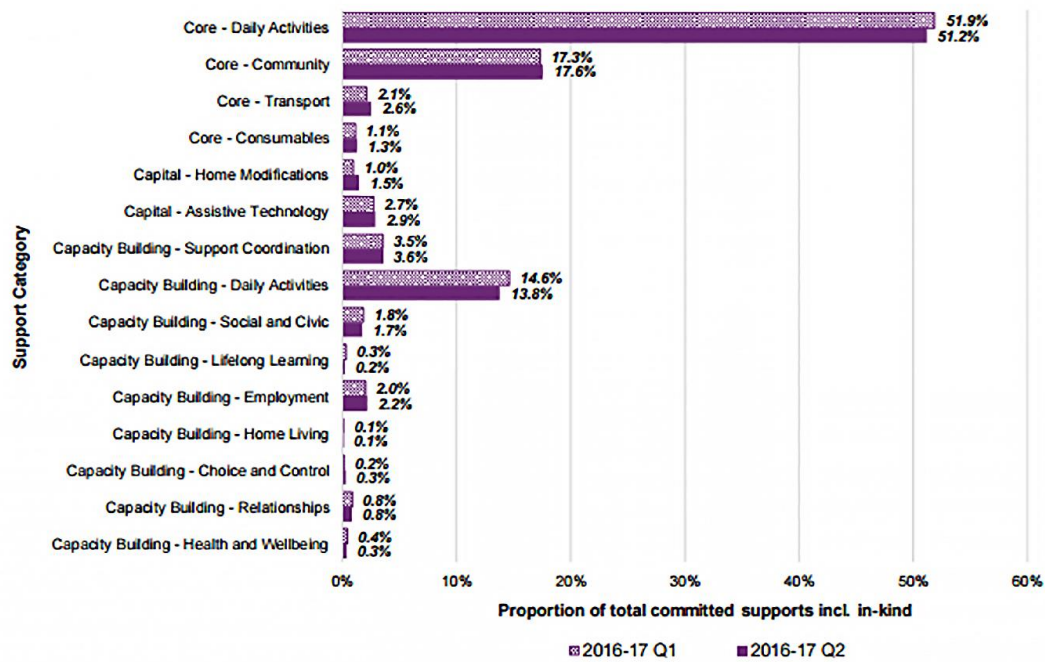
Any disproportionate current or future increase in the number of internal and external reviews will substantially increase Scheme costs. Experience with other Commonwealth legislation (for example the *Health Insurance Act 1973*) has demonstrated the passing of amendments to tighten the criteria for circumstances in which a decision can be reviewed; to limit access and thereby contain costs.

Internal and external reviews are a vital quality safeguard for participants and carers, enabling them to test the lawfulness and merits of NDIA decisions affecting them. Importantly, they also promote transparency in NDIA decision-making. Without a robust review system "...participants risk becoming passive and grateful recipients of assistance, rather than engaged participants and advocates. Rights such as those iterated in the CRPD can only be considered truly exercisable if the person at their centre is able to enforce them".<sup>8</sup>

### **2.1.3 Likely impact on participant capacity building**

Many people with disability will require ongoing funding for core supports; presently 72.7 per cent of all package supports are core (see figure 1). 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 per cent) and capacity building (23 per cent) 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.

Figure 1: Committed support expected to be provided by support category – proportions as at 30 September 2016 and 31 December 2016.



Source: NDIA, (2016), COAG Disability Reform Council Quarterly Report, p 70.

**Recommendation 1:** The NDIA addresses factors limiting the effectiveness of primary decisions; in particular, phone-based planning; counter intuitive processes and planner competence and training adherence, to:

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- ensure a more time-efficient process for participants and carers
- ensure there is no increase in administrative burden on carers
- reduce further anxiety, psychological and monetary distress on carers associated with additional effort required to navigate the review processes, and
- ensure no amendments are made to the *NDIS Act 2013* and Rules regarding current review criteria to further limit access to reviews (see ss 47–50 and ss 99–103 of the Act).

## **2.2 Low plan utilisation rates**

Carers Victoria has identified a number of reasons for low plan utilisation rates.

### **2.2.1 Portal access**

Carers repeatedly make contact with Carers Victoria 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.

#### **2.2.1.1 Digital exclusion**

As outlined by Carers Australia, digital exclusion is a growing concern for carers.<sup>9</sup> The Australian Digital Inclusion Index<sup>10</sup> illustrates 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. Surveys undertaken by state and territory Carers Associations reinforce the broad findings of this report in relation to carers.

The Tasmanian Council of the Ageing's recent research found only 40 per cent of the over 600 people surveyed used websites to access information. This decreased with age, with only 12 per cent of 60–74 year olds and 6 per cent of 75–84 olds using websites. Problems cited by survey participants included: lack of familiarity; and problems with online instructions and forms. Such evidence needs due consideration in future planning of service delivery.<sup>11</sup> A 2015 Carers South Australia survey found only 21 per cent of respondents used websites specifically designed for carers and 77 per cent of carers of older people had not used My Aged Care.<sup>12</sup>

#### **2.2.1.2 Internet access affordability**

Carers' incomes are 42 per cent lower than Australians who are not in a care relationship, equating to a weekly median income of \$520. This median takes into account the salaries of the 56 per cent of primary carers who participate in the workforce. Carers who do not engage in paid work are also more likely than non-carers to have a government pension or allowance as their primary source of



income.<sup>13</sup> According to the Australian Council of Social Services, this group of carers is typically on or below the poverty line.<sup>14</sup>

A recent survey of low income households found approximately 65 per cent of respondents who were receiving the Carer Payment experienced difficulty affording telecommunications technologies. This was higher than those receiving the Disability Support Pension or the Age Pension.<sup>15</sup> While income support recipients may receive the Telephone Allowance (as part of the Pension Supplement), research indicates less than half of respondents believed the Telephone Allowance was sufficient to cover their telecommunications costs.<sup>16</sup> The Telephone Allowance may assist with the ongoing costs of an internet subscription; however this allowance may not be sufficient for outright purchases of necessary computer hardware or enable connection to an internet provider in areas where connectivity is poor.

**Recommendation 2:** The NDIA develop a universally accessible 'My Participant' portal for participants and carers.

### **2.2.2 Inappropriate supports in plans**

Another reason for low plan utilisation rates is the 'my first plan' process where planners are developing plans over the phone with sometimes limited documentation and then generating inappropriate supports. A pragmatic way to overcome this issue would be to allow carers and participants to review the draft plan before it is lodged. Responses to carers who have requested to review the participant plan before it is submitted have been inconsistent.

*I'm in the process of getting a plan, but I'm not allowed to see it before approval. It doesn't make sense, if they don't get the plan right the first time, I will have to appeal.*

- Fatima, Victorian spouse carer.

*I was emailed the plan to go through it before it was finalised, this was great.*

- Phuong, Victorian parent carer.

**Recommendation 3:** Amend the NDIS rules to mandate the planner provides a copy of the draft plan to the participant, carer and advocate before it is submitted, to enable issues to be quickly addressed before the plan is submitted.

### **2.2.3 Inability to operationalise services**

For participants with complex support needs, including behaviour support, carers struggle to attain appropriate and suitable services. This significant gap in service delivery frequently results in the carer providing the majority of support without assistance. Characteristically, carers report they cannot access appropriate services at all; they have withdrawn from inappropriate formal services; or formal services withdraw due to their lack of capability and/or concerns about staff safety. This can lead to an increased likelihood of care relationships breaking down, due to the lack of support for their caring role leading to exhaustion and increases the likelihood of crisis interventions.<sup>17</sup> From feedback received by Carers Victoria, it appears similar issues may apply for participants living with psychosocial disability or those living in rural and remote areas.

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

– Leanne, NSW parent carer of an adult daughter

18

**Recommendation 4:** The NDIA becomes the service provider of last resort in 'thin markets'.

### **3. Scheme boundaries**

#### **3.1 Effect of NDIS rollout speed on eligibility of assessment process**

As outlined in section two above, a number of new processes have been developed to speed up the eligibility and assessment process to keep pace with the sheer volume of NDIS participant enrolments, according to the bilateral agreement targets. The bilateral agreements will support the transition from 35,000 participants in the Scheme trial sites (2015) to the full rollout and an estimated 460,000 eligible people in 2019.

Streamlining processes to meet volume targets compromises what should be an individualised participant package. It risks the development of generic reference packages with only the appearance of choice and control, distant from the lived experience and personal context of the participant, their carers and families.

As discussed above, these processes severely limit the effectiveness of primary decisions, which may disproportionately increase Scheme operating costs as well as increase package costs if the Scheme does not start to utilise capacity building supports for participants and carers.

## **3.2 Interface between the NDIS and mainstream services**

### **3.2.1 Better integration is required between the NDIS, ILC, existing and proposed Integrated Carer Support Services**

Carers Victoria education and counselling staff have worked with some carers who are eligible to be NDIS participants themselves. This reflects national statistics identifying 31 per cent of carers report living with a disability themselves.<sup>19</sup> Assumptions about categories of 'carers' and 'care recipients' do not accurately reflect complexities of people in care relationships. Carers Victoria is aware of many instances where support is exchanged interdependently between two people, each with a different disability.

NDIS participants who are carers need to navigate the NDIS, as well as carer support services for themselves, while at the same time support a person in their care. Meeting the needs of carers accessing the NDIS requires identification of care relationships and a thorough evaluation of care responsibilities during assessment, planning, care coordination and plan review. It also requires respectful service provision free of judgement, so carers living with disability can exercise choice and control over the appropriate mix of formal and informal support arrangements for each care relationship.

Carers Victoria advocates further analysis is undertaken to determine referral pathways between the proposed Integrated Carer Support Services (ICSS), Information, Linkages and Capacity Building (ILC) services and the NDIA, as the ICSS takes shape.

**Recommendation 5:** The NDIA appraises where participants and carers are likely to intersect with other government services and develops a rigorous referral framework to ensure smooth transition between government services and the NDIA, including participants who are ineligible for the NDIS.

### **3.2.2 Increase capacity for specialised care coordination and support**

Carers Victoria has received mixed feedback from carers regarding coordination between mainstream services and the NDIA, NDIS service providers and NDIS planners. Carers Victoria notes the importance of thorough coordination of services for people with complex needs who access multiple services. For example; a person who uses a specialist housing service, Centrelink, child support services and psychosocial services may be at greater risk of disengaging with the NDIS or at heightened vulnerability during transitions from mainstream services to NDIS supports. This may especially be the case if: a participant mistrusts the government/medical professionals, also has caring responsibility or does not have recent evidence of a diagnosis and is required to fund specialist medical reports for the NDIA.

The interface between specialist services, community services, allied health and NDIS-funded supports requires clear delineation, clarification and significant levels of coordination of service provision. This may be confusing for people who experience challenges in multiple life domains.

The Australian Association of Social Workers (AASW) has pointed out "...social workers have undertaken a key advocacy role in disability services in the past which will no longer be possible".<sup>20</sup> We note the availability of Specialist Support Coordination in the NDIS price guide;<sup>21</sup> however this funded support is time limited. While it focuses on "addressing barriers, reducing complexities in the support environment", and "encourages participants to build capacity and resilience", Carers Victoria is aware some participants and their families will require ongoing support, or specific support needs may change from one crisis to the next.

Carers Victoria is concerned complex and specialised support coordination responsibilities will fall back to carers, caring families and communities of care. Poor experiences and carer burn-out may result in some communities who seek support for particular mainstream or NDIS services. This could result in inconsistent reliance on both the NDIS and mainstream services at times of crisis, significantly lessening the predictability of disability support requirements.

**Recommendation 6:** The NDIA increases access to specialised care coordination and support for eligible participants and carers who require it.

### **3.2.3 Inclusion of independent individual advocacy services**

Carers Victoria is regularly contacted by carers seeking counselling, referral and general information regarding issues specific to eligibility, preparation and participation in the NDIS. Support requested has included: building cases for Scheme eligibility; navigation of Scheme access pathways; obtaining medical reports and medical histories; creating carer statements; pre-planning for planning processes; identifying support items which may benefit participants and their carers, support plan costs and self-management; plan reviews; and exploration of NDIS provider complaints mechanisms.

Carers Victoria has addressed some of these issues through NDIS-funded information sessions and the Disability Support Organisation project. However, Carers Victoria is not funded to provide individual advocacy or ongoing case management and cannot continue to respond to the high number of individual requests, as it has significantly increased demand on our Carers Advisory line, direct service staff, education teams and policy advisors. Carers Victoria strongly advocates for the implementation of an independent individual carer and consumer advocacy service, both for carers who support NDIS participants and/or who are NDIS participants themselves.

Comprehensive individual advocacy services would facilitate greater choice and control for marginalised and vulnerable participants accessing the Scheme. Advocacy services with adequate resources and mandate to support and advocate for the choice and control of marginalised participants and carers for the duration of their NDIS plans would represent value for money, and would minimise liabilities and risks to the Scheme through increased oversight.

Specialist models of advocacy need to be available for NDIS participants and carers, including those accessing ILC supports. Additional specialist knowledge and expertise (e.g. legal expertise) may be required in complex situations which

have implications for the benefit of the NDIS for some participants, carers and communities.

A NDIS-related independent individual advocacy service would require a thorough evaluation and outcomes framework, including external monitoring to measure the performance and effectiveness of advocacy services alongside participant experiences. Consultation with diverse communities such as: Culturally and Linguistically Diverse; Aboriginal and Torres Strait Islander; and Lesbian, Gay, Bisexual, Transgender, Intersex and Queers, as well as consumers, carers, and the mental health and carer peer workforce is essential to the development of any NDIS related advocacy services. This would also contribute to the integration of NDIS related advocacy services with carer support services, clinical health services, child, youth and aged care services.

**Recommendation 7:** Individual advocacy should be funded through the ILC to ensure the individual rights and support needs of participants and carers are clearly identified, articulated and acted upon.

### **3.3 Effect of full NDIS rollout on mental health service provision**

#### **3.3.1 Transfer of federal carer support services program funding to the NDIS**

In order to transition to the NDIS by 2019–20 significant funds are being directed from carer support services to the NDIS. Of particular concern is the transition of the majority of funds from the Mental Health Respite: Carer Supports (MHR: CS) program into the NDIS. The MHR: CS program provides counselling, respite and family support options for carers and families of people with a mental illness who are experiencing poor health and wellbeing, or other barriers to supporting the person they care for.

Carers of people with a mental illness face great challenges. Carers Victoria notes research which shows carers experience considerably poor mental health themselves,<sup>22</sup> can experience poor physical health, disability and chronic illness

and have considerable need for respite<sup>23</sup> and counselling<sup>24</sup> to support them in their role.

Guidelines for MHR: CS service providers require they complete a carer needs assessment, develop carer support plans and provide a broad range of support to carers and families assisting care relationships and carer wellbeing. MHR: CS guidelines also require services to coordinate carer supports and help carers navigate the mental health and community sectors, as well as liaise and work with other stakeholders to make and receive appropriate referrals for carers of people with mental illness.<sup>25</sup>

Although many carers of NDIS participants report positive experiences accessing supports for the person they care for, other feedback from carers has revealed support and recognition of carer needs is inconsistent.<sup>26</sup> These inconsistencies can present in the form of insufficient supports in plans, or the inclusion of strategies which contradict those already adopted and agreed upon by carers and the people they support. This may result in an NDIS plan compromising the independence of the participant and their carer. In addition, if a strategy is inconsistent with clinical support arrangements it may further undermine a person's recovery.

The NDIS does not include a carer assessment, nor are carers viewed as 'participants' in their own right. Therefore, carer support plans are not included in the Scheme, resulting in limited carer supports, despite the implications a plan may have for a care relationship. Carers Victoria has received feedback from carers indicating their involvement during NDIS assessments and support planning, and consideration of carer needs throughout the process, varies according to the knowledge of individual planners.

Funding for respite support is becoming increasingly uncertain for carers under the NDIS. The determination as to whether NDIS supports are reasonable and necessary is framed primarily from the participant's perspective. Despite the NDIS claim some supports may have a "...respite like effect"<sup>27</sup> for the carer, the assessment is made according to the NDIS participant's willingness to engage with a support, such as short-term accommodation assistance, or civic and social activities which also happen to provide a break for the carer.



Carers Victoria believes carers who previously accessed support under MHR: CS programs should continue to receive the same level or type of supports through the NDIS plan of the person they care for. Furthermore, the same should apply for carers who receive respite under the 'carers of young people with severe and profound disabilities' and the 'respite and information for young carers programs' which are both tagged for NDIS transition in full or part thereof.

The recently released report on the replacement cost of mental health carers, undertaken by the University of Queensland (UQ), found the proportion of the replacement cost of mental health carers to be 22% of the Deloitte replacement cost of \$60.3 billion for all carers (see appendix one). Specifically, the replacement cost for mental health carers was calculated at \$13.2 billion. The UQ methodology that they did not subtract the cost of carer respite or carer counselling funding in the cost offset estimate. Their reasoning was "This income support was subtracted from the final replacement cost model. Expenditure on other carer support services such as respite care and counselling was not included in the cost offset as many of these services would still be required for families, even under a total replacement scenario."<sup>28</sup>

### **3.3.2 Individualised focus and the impact on carers of those not eligible for the NDIS**

The Personal Helpers and Mentors (PHaMs) and Partners in Recovery (PIR) programs earmarked to have the majority of their funds transition to the NDIS are currently available to a wider group of people with mental illness and psychosocial disability than who would likely be eligible for an NDIS package. "PHaMs workers provide practical assistance to people with severe mental illness to help them achieve their personal goals, develop better relationships with family and friends, and manage their everyday tasks".<sup>29</sup> PIR offers coordinated support and flexible funding for people with severe and persistent mental illness with complex needs.<sup>30</sup>

Carer support services currently include: contact with support workers; support groups; and social gatherings to facilitate social connection with other carers. If these supports lapse, carers risk high levels of social isolation which can significantly impact their capacity to maintain the care relationship. The more

isolated carers become, the higher risk of isolation becomes for the person they care for.

Carers Victoria will continue to advocate for appropriate supports including PHaMs and PIR for those not eligible for, or do not wish to use NDIS services. Carers Victoria believes these programs are of great benefit. Although mental illness among some people may be severe and persistent, NDIS eligibility criteria of a 'permanent disability' may not be met. These are some of the ongoing and intractable barriers which exist for participants accessing psychosocial disability supports through the NDIS.

### **3.3.3 State funds transition from carer support services to the NDIS**

The transition of the Victorian Mental Health Community Support Service (MHCSS) program funds (which includes Individualised Support Packages, Supported Accommodation Services and Residential Rehabilitation Services) has implications for some carers. Participants on the MHCSS Needs Register who have not yet become a registered client of a MHCSS defined program will not automatically be eligible for the NDIS.<sup>31</sup> Clients who are deemed ineligible for the NDIS will no longer have access to these supports. Some carers now face greater uncertainty and potentially greater care responsibilities if the people they support are deemed ineligible.

The bilateral arrangement will leave a significant number of people with psychosocial disability with no other option but the NDIS.<sup>32</sup> This may exacerbate anxieties regarding their mental illness being 'permanent' and capacity to experience recovery. Carers may need to provide additional support to the participant to engage with the NDIS and meet service gaps if they do not.

Carers Victoria agrees with VICSERV and the Royal Australian and New Zealand College of Psychiatrists<sup>33</sup> with regard to the unique barriers for people under 30 years of age with moderate mental health support requirements. Some young people with experiences of moderate mental illness could potentially recover yet may not be eligible for helpful NDIS supports due to clinical decision-making.<sup>34</sup> For example, some GPs may be hesitant to diagnose young people with permanent functional impairment too early due to fears of labelling them, stigma, or being contrary to recovery-focussed practices.

This may lead to an increase in reliance on carers and subsequent loss of independence for some young people with mental illness, due to reticence to pursue NDIS plans due to stigma. If this issue is not addressed, some young people will miss opportunities to prevent further decline in their wellbeing and an increase in need for even greater NDIS support over the long term may occur.

Carers of people ineligible for the Scheme, or carers of those who refuse NDIS supports will still require assistance. It is Carers Victoria's view a well-resourced and adequately funded carer support system, which includes respite, advocacy services, counselling, material support and referral are essential.

Services such as those listed above could reach out to carers and families before crisis, thereby sustaining healthy care relationships, reducing unnecessary reliance on the NDIS and increasing independence for all parties to care relationships over the longer term.

**Recommendation 8:** The NDIA in consultation with the Victorian Government, ensures clear delineation between State and Federal community mental health services delivery, in order to reduce the risk of cost-shifting to the NDIS.

**Recommendation 9:** The Federal Government resource and ensure an adequate safety net of service provision with a similar capacity to PHaMs and PIR programs. This will reduce the risk of the worsening health of consumers resulting in a need for ongoing psychosocial disability support under the NDIS.

### **3.4 Ensuring the intersection between the NDIS and mental health services outside the Scheme**

Implementation of the NDIS is an opportunity to increase support options and improve outcomes for a significant proportion of participants and carers. However, particular policy risks remain due in part to the scale of change and speed of the NDIS implementation. NDIS reforms present many challenges to the interface between the NDIS and existing clinical mental health services which are yet to be addressed or resolved. Carers Victoria believes these challenges require

systematic and ongoing scrutiny. It is important to recognise episodic illness still requires permanent planning and ongoing management to ensure appropriate care in times of crisis.

### **3.4.1 Engagement with GPs, clinical mental health services, assertive outreach and allied health services**

The NDIA needs to increase efforts to engage with GPs, clinical mental health services, assertive outreach and allied health services to ensure people with a mental illness are properly supported to access the Scheme. Carers Victoria would especially like to see health professionals receive information, training and resources so they may assist more people access the NDIS who may not automatically transition.

Service outreach and Clinical Mental Health service inreach for those who are newly-engaged with services would significantly improve NDIS access, participation and planning processes for people with a mental illness and their carers.

**Recommendation 10:** The NDIA develop a communication strategy which includes GPs, clinical mental health services, outreach and allied health services to ensure timely, appropriate access to both mainstream and NDIS supports.

## **4. Planning processes**

### **4.1 Validity, cost effectiveness, reliability, clarity and accessibility of planning processes**

Carers Victoria believes the planning process as they have actualised have significant issues which require immediate action. These are:

- Phone-based Planning (see section 2.1.1.1)
- Counter intuitive processes (see section 2.1.1.2)
- Planner, turnover, competence and training adherence (see section 2.1.1.3)

- Inappropriate supports in plans (see section 2.2.2)
- Effect of NDIS rollout speed on eligibility of assessment process (see section 3.1).

#### **4.2 Monitoring and evaluation of planner performance**

Carers Victoria believes, the ILC should include funding for an individual advocate for participants and/or carers where required to ensure the individual support needs of the participant and carers are clearly articulated and acted upon, as per recommendation 7. An individual advocate, who understands the types of supports available through the Scheme and has taken the necessary time to get to know the participant and their family, will be able to put a case for the most appropriate supports required for individual participants and to support care relationships. To reduce possible conflicts of interest, the individual advocate should not be a registered NDIA service provider.

The powers of the proposed individual advocate should be recognised by law and should include:

- monitoring and evaluation of planner performance
- taking every step possible to identify carers and care responsibilities
- communicating with participants, carers and families to ensure choice and control is exercised and decision-making support is provided where necessary
- identifying the support needs of participants and carers
- attending planning conversations and meetings
- observing the planners interaction with participants, carers and families
- making inquiries and inspect draft plans before they are submitted, and
- reporting back to the NDIA if the performance of the planner was unsatisfactory or to troubleshoot issues.

**Recommendation 11:** The role of individual advocate (recommendation 7) should be recognised by law to incorporate specific powers, including monitoring and evaluation of planner performance to improve processes and reduce unnecessary costs.

#### **4.3 Appropriateness of dispute resolution for participant supports**

As discussed in section 2.1.2, Carers Victoria highly values the ability for participants to make an application for internal and external review and would like to see the integrity of these processes maintained.

There are two simple processes which could reduce the need for an internal or external review and reduce the time and stress on participants and carers.

Firstly, the NDIS Rules should make it mandatory for the planner to provide a copy of the draft plan to the participant, carer and advocate before it is submitted, to enable issues to be quickly addressed before the plan is submitted, as per recommendation 3.

Secondly, the NDIS Act should give delegates the authority to make alterations to participant supports where they were omitted in the original plan; if they meet all the necessary legislative criteria for reasonable and necessary supports; and waiting for review would prolong the time of a significant need not being met, or create a significant risk to the health or wellbeing of the participant or carer.

**Recommendation 12:** The *NDIS Act* should include authority to delegates to make alterations to participant supports where they were omitted in the original plan; if they meet all the necessary legislative criteria for reasonable and necessary supports; and waiting for review would prolong the time of a significant need not being met, or create a significant risk to the health or wellbeing of the participant or carer.

## 5. Market readiness

### 5.1 Effect of ageing population on the supply and demand for informal carers

123,500 Australians living with an intellectual disability are aged over 35 years and live in the family household.<sup>35</sup> Their parent carers are ageing, with 17,700 older parent carers aged over 65 years in Australia still living in the same household as the person they care for.<sup>36</sup> Adult children with intellectual disability are still living with their ageing parents because:

- there is an undersupply of shared supported accommodation houses in Victoria (currently 914 houses), and<sup>37</sup>
- there is high unmet demand for supported accommodation places in Victoria (currently 1,671 individuals on the Disability Support Register).<sup>38</sup>

Historically, early intervention, succession planning, transition support and accommodation choices have been absent for these families. The issue is longstanding; a 2009 Victorian Parliamentary Inquiry recommended the implementation of transition planning for families in care relationships in this circumstance (see recommendation 10.14 & 10.12).<sup>39</sup> Carers Victoria has been advocating for succession planning and transition support for families in these care relationships since 2012.<sup>40</sup>

- If allocated a scarce supported accommodation place, the person living with a disability has no choice or control about who they live with and where. This can raise welfare and safety concerns.<sup>41</sup> This is especially the case where tenants exhibiting behaviours of concern are placed together in group homes, heightening risk of conflict and harm to more vulnerable residents.
- Some older parents are unaware of other housing options for their adult children e.g. social housing, in home support, outreach support, staffed housing, home-share, co residencies, or 'living nearby' arrangements.<sup>42</sup>
- Where older parent carers are aware of options other than shared supported accommodation, many significant barriers to securing safe, appropriate and affordable housing exist:
  - income and employment disadvantage<sup>43</sup>
  - critical undersupply of affordable housing in Victoria (75,000–100,000 households)<sup>44</sup>

- many existing homes require modifications to be accessible for the person living with a disability and funding for these often only covers partial costs<sup>45</sup>
- private rental is not a viable option due to requiring landlord permission for necessary modifications requirements, cost, insecurity of tenure and stigma.<sup>46, 47 & 48</sup>
- There are no long term succession planning or transition supports involving carers, to ensure a planned response to supported accommodation needs.<sup>49</sup>

Without early intervention, succession planning and transition support options, carers are often faced with:

- chronic anxiety about what will happen when they are unable able to provide care and housing due to their own ill health or after their death<sup>50</sup>
- less resilience due to fear and uncertainty of what the future holds for the person living with a disability<sup>51</sup>
- disillusionment, disappointment and a loss of faith in the system to provide viable options<sup>52</sup>
- murder–suicide ideation, and<sup>53</sup>
- not returning to collect their adult child from respite care.<sup>54</sup>

Without the above supports the person living with a disability is often faced with:

- crisis intervention when their parent becomes too unwell to continue their caring role or dies, resulting in ‘double shock’ experience of grief for the person they share a care relationship with and loss of the family home.<sup>55&56</sup>
- inappropriate accommodation arrangements as a result of allocation during crisis.

### **5.1.1 Risks of inaction for older parent carers**

This issue is projected to escalate as there are 77,800 parent carers in the 45–65 year old age group who still live in the same household as the person they share a care relationship with.<sup>57</sup> Further, independent actuarial studies have projected a 1.6 per cent decrease per annum in informal care arrangements up to the year 2036, with a consequent 7.6 per cent increase in formal service provision.<sup>58</sup>

After successive inaction, Victoria now has a crisis-driven supported disability accommodation system. Without immediate and targeted interventions, the NDIA



stands to inherit many legacy issues when the system rolls into the NDIS, initially with participants and eventually with properties.<sup>59</sup>

As a result of the highly specialised nature of this accommodation, there are concerns the market will fail to deliver specialist disability accommodation which meets the needs of individuals and families. “It stands to reason then that there would be a pressing need for the provision of specialist disability support to assist older informal carers. Equally important is the provision of more intense specialist disability support for existing service users and their informal carers as they both age, and the provision of a different mix and intensity of specialist disability support (e.g. supported accommodation) for existing service users once their informal carer can no longer continue in their caring role.” (See appendix two).

**Recommendation 13:** The NDIA, through the ILC, invests in a multicomponent succession planning and transition support accommodation program which includes:

- psychosocial planning, including supporting broad family discussions of future needs and roles.
- Support with identifying the most appropriate supported accommodation model for the family.
- support with legal and financial planning, including wills and estate planning; special disability or family trusts; testamentary trusts; family agreements; contracts for family property management; and ongoing legal and financial representation arrangements where required
- development and promotion of NDIS operational guidelines on succession and transition planning tasks with relevance to national practice and the NDIS.
- building system capacity for emergency or sudden transitions of people with an intellectual disability and/or psychosocial disability.

## **5.2 Effect of assistance for informal carers on the need for formal carers and Scheme costs**

### **5.2.1 Carer identification**

NDIS participant supports can be underestimated when carers are not identified or consulted. Over reliance on carer support can result in support plans which are not sustainable, or poorly implemented requiring early review.

Carer identification skills and screening tools need to be incorporated into training for services which play a key role detecting potentially eligible NDIS participants. Care relationships may remain undetected due to cultural context, a carer's preferred identification with family relationships over a caring role, or the age of the carer (in the case of children and young people with care responsibility).

Only through identifying hidden care relationships can professionals accurately ascertain levels of assistance a potential participant may require for daily living. At a systems level, additional work is required to clarify how Local Area Coordinators (LACs), Primary Health Networks (PHNs) and Local Health Networks (LHNs) will ensure appropriate overall inclusion of care relationships in service delivery. There also needs to be consistency in the consideration of care relationships within the mental health stepped care model recently adopted by the Australian Government.

#### **5.2.1.1 Improving planning processes by including carers of a person with a mental illness**

Access, assessment, planning and service coordination processes should be informed by evidence-based recovery models and mental health best practices to ensure plans are designed in a way which minimises participant distress and repercussions on carers and families. NDIS planning processes for people with psychosocial disability require; review and tailoring in order to be more flexible in methodology; to be undertaken over a period of time and; include an assessment of carers and care relationships.

Carers Victoria has heard from some carers planners require clarification regarding what is reasonable and necessary support for families and carers. Due to inconsistencies being identified, Carers Victoria see benefits to further resourcing information and training which is targeted to NDIA staff, as well as key referral agencies and professionals working with carers and families. This training and information could explore the implications of Section 34 (1) (e) of the Act, as well as the National Disability Insurance Scheme (Supports for Participants) Rules outlining reasonable and necessary supports for NDIS participants.

Carers Victoria notes concerns the NDIS Quality and Safeguarding Framework confirms no qualification or certification requirements stipulated for workers in the

LAC and support coordination positions 60. This opens a gap of expertise between a consumer's clinical care and their individualised NDIS plan processes, which could have a dramatic impact on achieving meaningful engagement with the Scheme.

### **5.2.2 Inclusion of carer statements**

Section 3 (3)(c)(ii) of the *NDIS Act 2013* states regard is to be had to the *Carer Recognition Act 2010* (the Act). The Act includes a Statement for Australia's Carers (section 6) which recognises and respects the critical role carers have in the lives of person they share a care relationship with. It emphasises partnerships in decision-making with service providers, taking into account carers' own needs within and beyond the caring role, and providing them with timely support. As such, Carers Victoria stresses the importance of upholding the Statement for Australia's Carers and ensuring the NDIA meets their statutory obligations.

The *NDIS Act 2013* further enshrines the importance of recognising care relationships:

- section 4(12) states "the role of families, carers and other significant persons in the lives of people with disability is to be acknowledged and respected"
- section 5(e) states "the supportive relationships, friendships and connections with others of people with disability should be recognised"
- section 31(c) states "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:...consider and respect the role of family, carers and other persons who are significant in the life of the participant".

In reporting on their compliance with the *Carer Recognition Act 2010* the NDIA stated "carers can include a carer statement as part of the participant's plan development, and this statement is recorded in the plan".<sup>61</sup> Now planning and review meetings have shifted to a shorter, generally phone-based arrangement, usually conducted by a Local Area Coordinator, it is unclear whether or not carers are being given the opportunity to provide the Carer Statement to which they are entitled. Carer feedback demonstrates this opportunity is not systematically provided nor communicated when NDIA planners are conducting planning

sessions, despite continual advocacy by the National Network of Carers Associations to formalise and promote it.

### **5.2.3 Consideration of support provided by carers**

NDIS plan goals may not accurately reflect the capabilities of the participant when their carer's support is not considered, and particularly when they experience an illness with episodic fluctuations in severity.

In deciding what supports are reasonable and necessary in developing a participant plan, the planner must take account of what is reasonable to expect families, carers, informal networks and communities to provide [S34(1)(e) *NDIS Act*]. The NDIS Rules for participants reiterates this at section 2.3(e) "the funding or provision of the support takes account of what is reasonable to expect families, carers and informal networks and the community to provide". Reasonable family, carer and other supports are expanded at NDIS Rules for participants of most relevance is 3.4(b) (i) '...the extent of any risks to the wellbeing of the participant arising from the participant's reliance on the support of family members, carers, informal networks and the community' and 3.4(b) (3) 'the extent to which informal supports contribute to or reduce a participant's level of independence and other outcomes'.

Taking into account the informal provision of supports is a critical component of the sustainability of the NDIS. Three major reports have evaluated the costs of replacement care, that is, if informal support provision was withdrawn, the cost of replacing it with formal service provision. PwC estimated the replacement value of 'care of adults' at \$15.4 billion per annum;<sup>62</sup> Deloitte Access Economic valued the replacement cost of unpaid carers of people with disabilities, chronic illness, mental illness and the aged across the age spectrum at \$60.3 billion in 2015;<sup>63</sup> and the University of Queensland valued the replacement cost of mental health carers to be about 22% of the Deloitte Access Economic estimate - \$13.2 billion. The National Network of Carers Associations consider the Deloitte Access Economics evaluation of the replacement value of carers as more sophisticated, inclusive and robust than the generic PwC model (see appendix one).

#### 5.2.4 Consideration of supports provided to carers

Support line items to sustain informal support provided by carers and families are limited. Specifically:

- short term accommodation and assistance e.g. respite care, generally for no more than 28 days per year (core).
- training for carers in behaviour management strategies (capacity building \_improved relationships).
- training for carers in matters relating to caring for a person with a disability (capacity building \_ improved daily living skills).

Given only 14.6 per cent of NDIS packages (see figure 1) have capacity building support categories for improved relationships and improved daily living skills, there is a reduced likelihood carers are provided with the specific line items in these categories to sustain the level of informal support they provide. In a survey undertaken by Carers NSW, only one in four carers thought their caring role was taken into consideration by the planner.<sup>64</sup>

A recent Carers NSW survey of 1,803 carers across Australia, on behalf of the National Network of Carers found: carers want to use respite services but don't because they can't get services suitable to them, and lack of information about respite options, complicated pathways to access respite and the cost of respite prevented them from accessing these services.<sup>65</sup>

Carers not being given the opportunity to provide the Carer Statement to which they are entitled, or not receiving due consideration in the planning and assessment process due to throughput rather than quality, may affect the financial sustainability of service providers and threaten the continued provision of services. If participants are not funded to access respite services in their plans, demand for respite will decline. If carers do not have funded access to respite, bookings will decline and it will falsely appear as if carers no longer require respite and this may be inaccurately attributed to conclusion the supports provided through the NDIS to the participant are improving carer quality of life. While there are no publicly available figures on plans, including short term accommodation and assistance supports as they are core supports (respite), more than a third of carers are reporting not having any identified carer supports in the participant's plans.<sup>66</sup> '...Given that there is currently no formal requirement

for carer assessment as part of the support planning process, and that supports are considered 'reasonable and necessary' based on the goals of the NDIS participant, there is no guarantee that the level of respite required by the carer will be communicated, considered or provided'.<sup>67</sup>

*We were told no one would be worse off under the NDIS but, in actual fact, we are worse off because respite is not automatically provided for carers.*

- Cheryl, NSW carer of her 18 year old son and 17 year old daughter.

68

### **5.2.5 Effect on Scheme costs**

The greatest risk for the sustainability of the NDIS is the level of informal support provided by carers transferring to formal supports provided under the NDIS, if the NDIA does not ensure adequate support is provided to carers to ensure the sustainability of informal caring arrangements. The current estimated cost of the NDIS is \$22 billion.<sup>69</sup>

The NDIS values the economic contribution of carers; but it does little to identify the particular challenges carers face, or meet their support needs. This has occurred in spite of the carer's movement, advocating for long overdue necessary improvements to disability services and driving the introduction of the NDIS.<sup>70</sup> Carers are not only expected to maintain their current level of informal supports, with only nominal recognition, inclusion and supports to sustain the care relationship. They are also expected to provide additional high level administrative and care coordination assistance to ensure the participant can navigate the system effectively.

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

– NSW Carer.

In the UK, via the UK *Care Act* of 2014, carers have access to a formal needs assessment. Unfortunately in Australia, no formal process of carer needs assessment has been built into the NDIS.<sup>72</sup> When carers engage carer support services in Victoria and throughout the national network, they undergo a detailed assessment of their needs which is followed up with a carer support plan. The Productivity Commission recommended the implementation of a carer's assessment "...to consider the sustainability of the caring role and whether the carer would benefit from their own supports".<sup>73</sup> However, the Government did not adopt this approach for the NDIS, instead separating carer supports from participant supports through the Carer Gateway and the proposed ICSS. The rationale to separate carers and participants is flawed, since their lives are inextricably linked and each are affected in very direct ways by the capacity and support needs of the other.

**Recommendation 14:** The NDIA takes necessary action to identify care relationships at the beginning of the participant assessments, plan review and referral. This should include a screening assessment for young family carers aged 25 and under.

**Recommendation 15:** The NDIA ensures a carers statement is required for all participants with informal carers.

**Recommendation 16:** The NDIA implements a carer's assessment to ensure the sustainability of informal caring arrangements.

### **5.3 Service provider readiness to move from block funding to fee-for-service**

For many people with disability and their carers, community transport provides a valuable point-to-point transport service staffed with qualified personnel. Prior to the NDIS, people in care relationships were able to access this service at a low cost. However, under the NDIS the shift from block funding to individualised packages has placed this service in jeopardy. Providers receive transport funding per NDIS participant; however, only 2.6 per cent of participants are receiving transport as a funded support in their plans (see Figure 1: Committed support expected to be provided by support category – proportions as at 30 September 2016 and 31 December 2016). This is likely to reduce overall funding, making it difficult for service providers to cover fleet purchases and upkeep, and to adequately subsidise fares. This poses a significant barrier to the economic and social participation of people with disability and their carers.

#### **5.3.1 Potential increased financial costs to carers**

Carers already incur significant costs associated with transport, including vehicle purchase and modification; maintenance and repair; and petrol and parking. Research indicates households with a person with disability tend to have higher transport costs.<sup>74</sup> Given at least one third of carers live in low income households (defined as households within the lowest two quintiles of equivalised household income);<sup>75</sup> many cannot absorb these costs without experiencing significant economic hardship.

#### **5.3.2 Opportunity costs for carers**

The time involved in transporting someone to a medical appointment, to work or participate in the community can represent an opportunity cost for carers, especially with regard to carers' workforce participation<sup>76</sup> and social participation.<sup>77</sup> The workforce participation rate for primary carers is only 56.3 per cent; whereas the workforce participation rate for Australians who are not carers is 80.3 per cent.<sup>78</sup> With regard to social participation, 175,000 primary carers did not participate in leisure activities away from home in the last year.<sup>79</sup>

**Recommendation 17:** The NDIA immediately reviews the adequacy of funded transport in participant plans.



#### **5.4 Service provider capacity to deliver supports to CALD and ATSI communities**

Carers Victoria welcomes recent activity by the NDIA to create CALD, ATSI, Rural and Remote and LGBTIQ strategies. We also note the number of disability advocacy and other organisations providing information and education to marginalised groups.

The Information, Linkages and Capacity Building (ILC) Framework also has potential to offer some assistance to people from CALD or ATSI backgrounds to navigate the system via the Community Inclusion and Capacity Development (CICD) Program. However, the ILC however is unlikely to meet its goals without input of significantly increased investment.

Enabling marginalised communities to better access and understand the goals and purpose of the NDIS is only part of the challenge to creating consistency and continuity in service provision. Positive NDIS planning outcomes will always depend on the cultural competencies of Local Area Coordination services and mainstream NDIS providers to identify and work with CALD or ATSI participants and carers where specifically targeted programs and services do not exist. In addition, ensuring all consumers and carers can be proactive self-advocates, assert their rights, and efficiently use existing complaint mechanisms is important.

We are pleased to see instruments built into the Safeguarding and Quality Framework such as whistle-blower protections, service reporting and staff training requirements. Carers Victoria has expressed a desire to introduce independent advocacy services, see recommendation 7. This is particularly vital for cohorts with barriers to Scheme access, who are at risk of disengaging with service providers, or require high risk supports.

**Recommendation 18:** The NDIS includes a component of outreach advocacy, targeted engagement and culturally appropriate and tailored information for LGBTIQ, CALD and ATSI communities who may experience difficulties obtaining information on access to and navigating the Scheme.

## **5.5 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?**

Many carers and people with disability accessing the NDIS have long histories negotiating with services to find and receive support. Their experiences are varied and impact them positively and negatively. For those with negative experiences it can be challenging to find a voice, or have the confidence that their voice will be heard when negotiating supports. Many individuals care relationships have lived experiences of state interventions in disability services e.g. institutionalisation and deinstitutionalisation. These experiences may have negatively impacted upon their skills and confidence. Gill Pierce, the first policy advisor at Carers Victoria, commented on carer reticence in light of historical experiences back in 1993; her comments are still as relevant today, especially since the largest number of NDIS packages are for participants living with an intellectual disability (32.5 per cent).<sup>80</sup>

“Can we wonder that ageing carers are fiercely self-reliant and reluctant to request help from the state? Can we question their distrust of field change? Many have worked and waited for every basic service needed by their child, in an environment where universal service provision excluded those with an intellectual disability. Should we be surprised if ageing carers are protective and cautious, and reluctant to choose new service options? Their life experience involved successive exclusions from generic community services and facilities. Can we question a carer’s wish to maintain her adult child at home as long as possible when the residential alternatives offered have been frequently of poor standard, and inappropriate? Can we be surprised if ageing carers are reluctant to request help from outside agencies, and to make long-term care plans when the state and commonwealth governments have provided them with so little? When there is such a gap between rhetoric and reality? Public policy may indeed mould carer’s lives, attitudes, values and coping strategies”.<sup>81</sup>

The NDIS is underpinned by the presumption participants and carers will have the capacity to act independently, make choices and advocate for themselves and have a clear idea for how their needs should be met.

Please see section 3.2.3 on the need for individual advocacy and how such advocacy will assist with planner monitoring and review section 4.2.

## **6. Conclusion**

The hopes of people with a disability, their families and carers and their aspirations for a good life are pinned on the successful implementation of the NDIS. The Scheme is too important in the lives of millions of Australians to go off track due to unforeseen costs. In this submission Carers Victoria has addressed key cost drivers that must be identified and addressed in order to improve the experience of participants and carers and reduce Scheme costs over time. Carers Victoria has identified the need for upfront investment in NDIS planning processes to ensure the long term sustainability of the Scheme. Carers Victoria believes this preventative approach is preferable to containing costs through altering eligibility criteria or access to internal and external reviews.

The transition support Carers Victoria has been funded to provide to carers is currently assisting the NDIS to reduce costs through improving carer readiness for planning. However, the current approach of the Agency to planning processes and the emphasis on through-put can negate the value of this preparation, increasing the risk of inappropriate plans and subsequent reviews and appeals.

People with a disability, their families and carers have experienced many shifts in disability policy and practice over time. This can contribute to feelings of disempowerment, cynicism and reluctance to engage with the NDIA. Many prospective participants have past negative experiences with disability supports and/or complex psychosocial needs. Carers Victoria has recommended the provision of individual advocacy support as a necessary investment to improve the match between participant and carer needs, their individual plans and service delivery. Carers Victoria has also suggested advocates are legally recognised in order to provide independent monitoring of the planners as they engage with participants, carers and families.

The role of an independent advocate would also ensure the appropriate match is made between support needs, funded supports and areas for capacity building. This will ensure the single largest costs of the NDIS – funded supports – are

directly commensurate with participant needs, promoting participant independence, sustaining care relationships and reducing funded supports in the very long term.

Specialist Disability Accommodation (SDA) will be necessary for some of the most vulnerable participants in the NDIS. Carers Victoria has made a series of recommendations to improve planning for and access to this critical feature of the NDIS. Those ineligible for SDA support also require access to specialist planning for their future accommodation needs as recommended by Carers Victoria.

Carers Victoria would welcome the opportunity to discuss these issues further with the Productivity Commission.

## Appendices

### Appendix One: Differences between evaluations of the replacement costs of carers.

Brief prepared by Sue Elderton, Carers Australia, 15 March 2017.

Differences between the PwC approach and the Deloitte Access Economics approach to identifying the value of unpaid care:

- PwC estimated the replacement value of 'care of adults' at \$15.4 billion p.a
- Deloitte Access Economic values the replacement cost of unpaid carers of people with disabilities, chronic illness, mental illness and the aged across the age spectrum at \$60.3 billion in 2015.

Identifying the number of unpaid carers:

- PwC uses the 2011 Census. The Census only identifies the number of people who provided unpaid care, help or assistance to family members or others because of a disability, a long term illness or problems related to old age in the last two weeks
- Deloitte Access Economics used projections to 2015 on the 2012 Australian Bureau of Statistics Survey of Ageing, Disability and Carers (SDAC), the second biggest survey undertaken by the ABS after the Census and one which has a dedicated focus. The SDAC identifies the number of people who provided care over the previous three months.
- Hence the difference between the 2011 Census identification of 1.9 million carers as opposed to 2.7 million in the SDAC.
- The SDAC also identifies the hours of care provided by primary carers which is factored into the equation of replacement costs. While the SDAC does not provide hours of care for non-primary carers, the replacement costs of their care in the DAE modelling was estimated on the basis each provided an average of five hours of care per week, given non-primary carers, by definition, do not provide the majority of informal care. The point is PwC has no basis for estimating hours of care 'of adults' at all as far as we can tell from their report.
- PwC confines its analysis to carers of adults. Deloitte Access Economics, using the SDAC, includes carers of people across the age spectrum.
- The SDAC also specifically identifies mental health carers, many of whom may well have been missed in the Census because the people who answered the question may not have identified the term 'disability' with mental health conditions. Based on analysis of the ABS 2015 SDAC, there were 194,000 primary carers caring for someone who had a psychosocial

condition as their main disabling condition. This represents about a quarter of the primary carer population

- In addition, PwC based its analysis on the top 20 locations for unpaid work in Australia. The SDAC covers people in both urban and rural areas in all states and territories (although it does miss smaller populations in remote areas).

Identification of the value of unpaid care:

- Both PwC and Deloitte Access Economics use the ABS Employee Earnings and Hours from the ABS to calculate the replacement cost of unpaid care
- It is not clear from the PwC report which of the occupation groups identified it uses to calculate the hourly costs of 'care of adults' except it is likely to be average ordinary time earnings of Personal Carers and Assistant.
- Deloitte Access Economics uses a unit cost based on the wages of moderately skilled formal sector carers (supervised employees based on the Australian and New Zealand Standard Classification of Occupations). This is inclusive of personal income tax and superannuation, and includes payment of overtime for after-hours work. However, the hourly rate received by employees does not account for on-costs such as the wages of supervisors, managers or administrative support staff, or other capital overheads. Deloitte Access Economics has incorporated into its model loadings for capital and administrative overheads were based on the relative shares of capital expenditure and administrative costs to other areas of recurrent spending in Australia's formal health sector (taken from the Australian Institute of Health and Welfare's Australia's health 2014). The loading for on-costs was sourced from the ABS' report on labour costs in 2011 (Australian Bureau of Statistics, Labour costs, Australia, 2010–11.).

The University of Queensland approach to identifying the value of unpaid mental health carers

- Their methodology is similar to the Deloitte's Access Economics report except they used slightly different data sources.
- UQ used the 2009 and 2012 SDAC (whereas DAE did 2015 projections on the SDAC).
- UQ did their own survey.
- UQ used more mental health specific replacement worker data and awards.
- UQ deducted Centrelink costs and national and state and territory service contributions to mental health carers support. DAE didn't deduct carer supports and payments in its model.

**Appendix Two: Specialist disability service users with an informal carer extract taken from National Disability Strategy 2010–20, Evidence base, November 2011.**

As the AIHW (2009b) explains, '[NDA] service users with an informal carer are a group with very high support needs, who typically require a combination of informal and formal care to enable them to live in the community.'<sup>82</sup>

Among the 295 024 people who received specialist disability services in 2009–10, 39.9 per cent (117 754) had an informal carer. This figure rises to 43.1 per cent when the group whose informal care arrangements were not known are excluded from the calculation.

In the vast majority (71.4 per cent) of cases where informal care arrangements existed, parents were providing the care. Additionally, just under half (41.4 per cent) of all informal carers were aged 45 years or older, comprising 31.3 per cent aged 45–64 years and 10.1 per cent aged 65 years and older. See [Table 9](#) for further details.

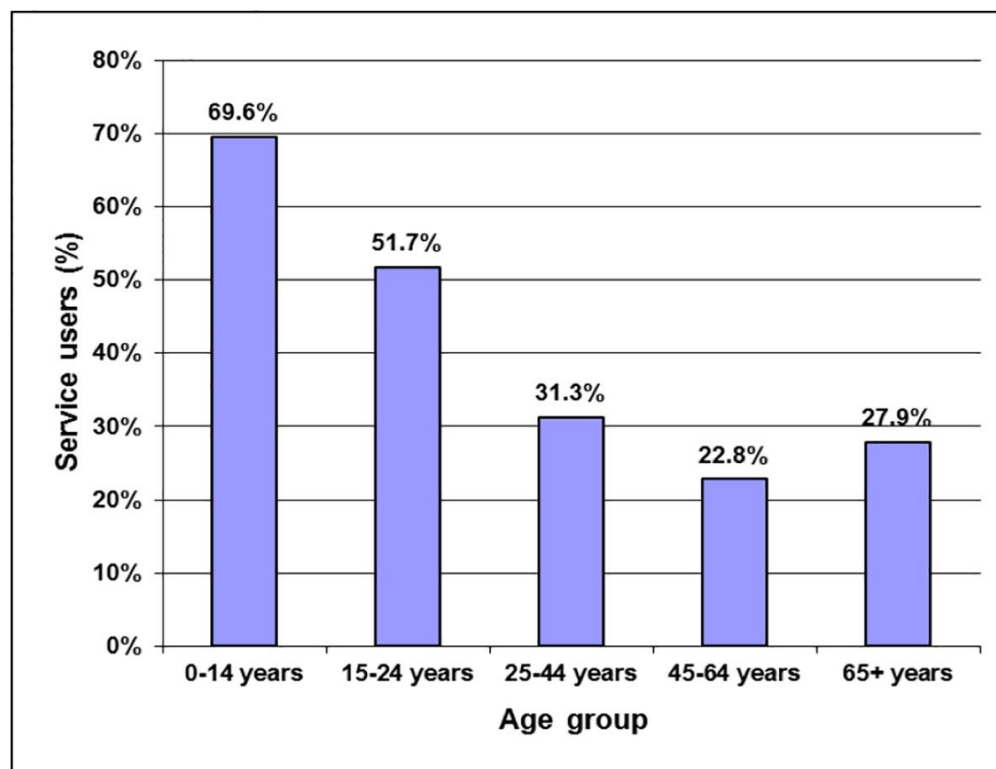
Table 9: Characteristics of informal carers, 2009–10

Relationship of informal carer to service user	%	Age of informal carer	%
Parent	71.4%	0–14 years	0.3%
Spouse/partner	7.9%	15–24 years	1.9%
Child	1.9%	25–44 years	38.3%
Other family member	5.5%	45–64 years	31.3%
Friend/neighbour	1.9%	65+ years	10.1%
Not stated	11.4%	Not stated/not collected	18.1%
Total	100%	Total	100%

Source: AIHW 2011, *Disability support services 2009–10*, Tables 5.4 & 5.5, p. 38 & 39.

Worthy of mention also is that the likelihood of specialist disability service users having an informal carer declines with their age. Understandably, the presence of an informal carer is greatest when the service user is a child aged 0–14 years (69.6%). It then declines for service users aged 15–24 years (51.7%) and then declines steadily for those aged 25 years and older (31.3% for those aged 25–44, 22.8% or those aged 45–64, and 27.9% for those aged 65 and above) (see Figure 14).

**Figure 14: Service users with an informal carer, by age group, 2009-10**



Source: AIHW 2011, *Disability support services 2009-10*, Tables 5.4 & A2.12, p. 38 & 74.

These differences largely reflect changes in the family circumstances of older service users with the ageing of their informal carer. As informal carers age, so does their capacity to continue in their caring role. It is most likely to be the onset of diminished health or death marking the end of their caring role.<sup>83, 84</sup> It stands to reason there would be a pressing need for the provision of specialist disability

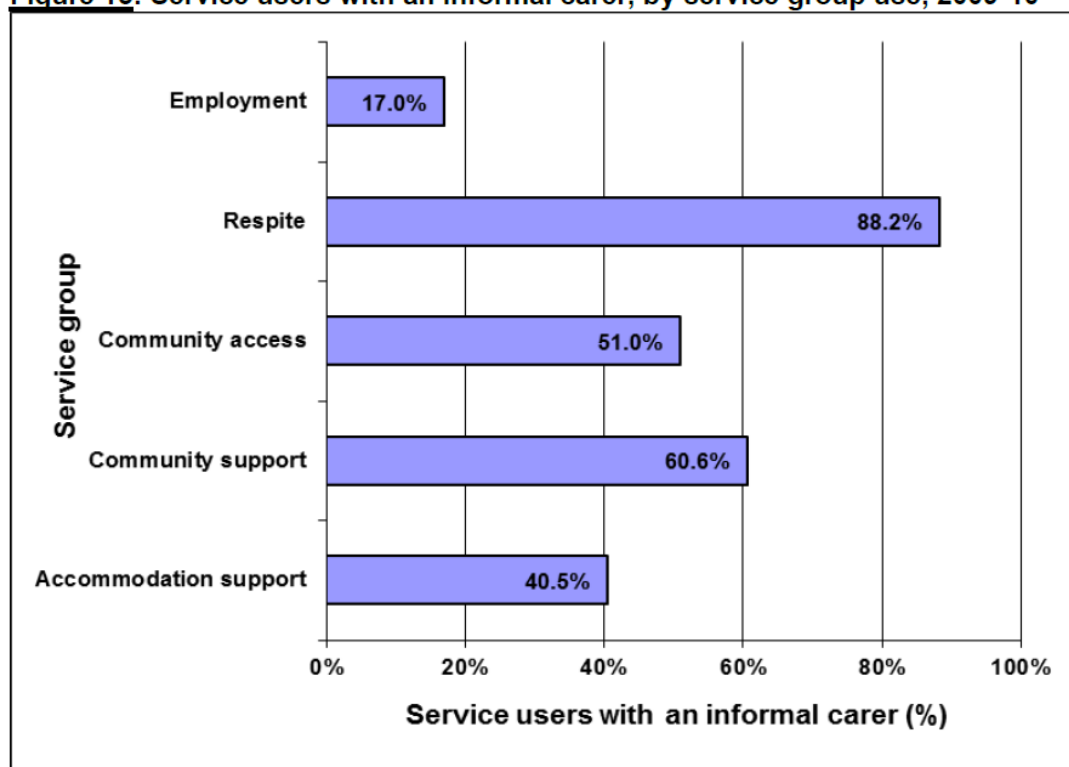


support to assist older informal carers. Equally important is the provision of more intense specialist disability support for existing service users and their informal carers as they both age, and the provision of a different mix and intensity of specialist disability support (e.g. supported accommodation) for existing service users once their informal carer can no longer continue in their caring role. Importantly, under the NDA, older carers are a priority area for reform.

In August 2011, the Australian Government launched the National Carer Strategy. The National Carer Strategy strengthens the commitment to recognise and respond to the needs of carers so they have rights, choices, opportunities and capabilities to participate in economic, social and community life. The National Carer Strategy recognises older informal carers as a target group requiring particular support services.

Moving on to the pattern of specialist disability service use among those with informal care arrangements in place, service users receiving respite were most likely to have a carer (88.2 per cent), followed by those receiving community support (60.6%), community access (51%), and accommodation support (40.5%). Those receiving employment services were least likely to have a carer (17.0 per cent). (See [Figure 15](#)).

**Figure 15: Service users with an informal carer, by service group use, 2009-10**



Source: AIHW 2011, *Disability support services 2009-10*, Table 5.2, p. 35.

<sup>1</sup> Productivity Commission, (2011), *Disability care and support*, Inquiry report volume 1, p 2

<sup>2</sup> Confier, D. & McKinnon, M, (12/3/2017), *National Disability Scheme rollout plagued with problems*, FOI documents reveal, ABS.

<sup>3</sup> Mann, N. (2017), *Fighting for the right to choose: the National Disability Insurance Scheme and participant experiences of choice and control*, p 66.

<sup>4</sup> NDIA, (2016), *Annual report*, P 122.

<sup>5</sup> NDIA, (2016), *11th quarterly report to COAG Council on Disability Reform*, P 68.

<sup>6</sup> R6(2) Rules for the Scheme Actuary 2013

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<sup>14</sup> ACOSS, (2016), Poverty in Australia, Social Policy Research Centre, p.25.

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<sup>19</sup> ABS, (2015), Disability, Ageing and Carers, Australia, Victoria, Catalogue # 4430.0

<sup>20</sup> AASW, 2015, AASW Submission on the National Disability Advocacy Framework, p.2

<sup>21</sup> NDIA, 2016, Vic/NSW/QLD/TAS NDIS Price Guide, p. 38

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