



A report on: “The impact of the NDIS on Carers in Tasmania - The Picture So Far”

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Executive Summary

Acknowledgement

Carers Tasmania acknowledges and thanks the Tasmanian carers who have shared their caring experience and knowledge in contributing to “The Impact of the NDIS on Carers in Tasmania - The Picture So Far”. Thanks also to Carers Tasmania’s stakeholders who have promoted and distributed the survey.

About the National Disability Insurance Scheme (NDIS)

The National Disability Insurance Scheme (NDIS) began as a trial site in Tasmania on 1 July 2013 for 15-24 year olds. The NDIS in Tasmania has now been rolled out for participants between the ages of 4-28 years old. The NDIS roll-out plan by age cohorts will be complete from 1 January 2019 and it is estimated that by that time around 10,500 people will have a plan in place.

The NDIS supports people who meet disability and early intervention eligibility criteria and who are under 65 years of age. Family members (carers) of this group of Tasmanians, already busy in their caring roles supporting their loved-one with a disability or mental illness, gave their time to respond to this survey and represent a solid cohort of responses.

Who is a carer?

A carer is a family member or friend who provides unpaid care and support to someone with a disability, mental illness, chronic or palliative condition, alcohol or other drug addiction or who are frail aged. This includes people under the age of 18.

A carer might be the mother of a child with a disability; a father caring for his son with a mental illness; a daughter who cares for her older parents, one with early-onset dementia and one with physical limitations. It might be someone whose partner has had an accident resulting in brain injury. These are caring scenarios where a person may be eligible for a support plan within the NDIS.

The role of caring can involve many aspects – from running errands, providing transport, managing doctors appointments, dispensing medication; to managing the general household including cleaning, cooking and the finances; as well as fulfilling ‘personal care’ tasks for the person being cared for. Sometimes the only source of social contact and emotional support for the care recipient is the carer.

A carer in this context is not a paid support worker – that is someone who comes into the home to undertake these tasks or fulfil such a role as part of their employed/paid work.

Caring can take an emotional, physical and financial toll on carers without the right level of support, and impact significantly on work, study and economic participation opportunities as well. Carers do not receive the benefits that come with paid employment either.

About Carers Tasmania and carers of people with a disability in Tasmania

Carers Tasmania is the main provider in Tasmania of support services to unpaid family and friend carers. See Appendix 1 for an ABS snapshot of carers in Australia (2016).

There are 84,000 carers in Tasmania – a proportion of whom care for people with a disability under the age of 65 years.

There are an estimated 10,500 people with a disability in Tasmania.

Carers underpin the disability care system and provide 74% of all community care¹. Some care for longer periods, some for shorter periods. In Tasmania, 28,300 are primary carers, 55% of whom provide care for >20 hours per week². In the 2016 ABS census 49,528 people in Tasmania reported that they provided unpaid assistance to a person with a disability³.

Other NDIS carer survey results have indicated gaps and inefficiencies in NDIS practice, sometimes providing significant challenges for most carers who responded to the survey⁴.

Survey implementation

Carers Tasmania's motivation in undertaking this survey was to test the 'outcomes so far' for Tasmanian carers – resulting from what is likely the most significant economic and social reform in Australia for more than a generation.

The NDIS and the intention of the scheme has all the makings of a positive outcome for Australians living with disability. That is, to increase their capacity to participate in society and to improve equality and fairness for the nation.

It is believed that this intention was to also include positive outcomes for carers. The rationale being, that if the care recipient has a greater level of support and is enabled to participate in society, then the carer would be able to do so as a parallel positive consequence.

Ultimately, Carer Tasmania does not want to see carers "fall through the cracks" of such consumer directed reform, occurring concurrently with aged care and mental health sector reform.

The online survey was designed to be completed by carers in less than 30 minutes. Information about the survey was promoted to carers who are already supported by Carers Tasmania, via email, through established service provider networks and via social media.

¹ Australian Bureau of Statistics (2014) Caring in the Community, Australian Summary of Findings, 2012.

² Australian Bureau of Statistics (2017) 2015 Survey of Disability, Ageing and Carers, <http://www.abs.gov.au/ausstats/abs@.nsf/mf/4430.0> accessed on 17/08/2017

³ Australian Bureau of Statistics Census 2016 http://www.censusdata.abs.gov.au/census_services/getproduct/census/2016/communityprofile/6?opendocument accessed on 21/08/2017

⁴ Carers ACT A study on the impact of the NDIS on family and friends who care for people with a disability in the ACT. Sheen et al, 2017. Canberra.

Summary of Findings

The implementation of the National Disability Insurance Scheme involves a materiel shift in the way social services are funded, to a “consumer directed care” approach. This means that the consumer or care-recipient has choice-and-control over the way services are procured and received. Nationally, this shift in thinking has been well received. However, is it a scheme that helps – or hinders – the important role of a family or friend carer, particularly given the underlying assumptions about “consumer directed care”?

The depth and significance of care provided by family members and their continued concern for the care recipient (NDIS participant) should be acknowledged at the front and centre of this survey report.

“...I have provided love, a safe and caring home for him and would like to think that this will be ongoing for him. Surely the government could provide a safe environment for our loved ones as we have done and not integrate them in to communities where you hear of instances where they are vulnerable. Governments, please pay back, appreciate the role of carers and not just take the role as a given.” (Carer Quote)

Given that the replacement value of carers in Australia is estimated at \$60.3 billion per year⁵, the NDIS should at all times take account of the unpaid family and friend carers role in supporting our community members. Informal supports are a keystone to the NDIS.

Reflective of the roll-out of the NDIS in Tasmania to this point (4-28 year olds), the majority of survey respondents care for 15 to 24 year olds.

It is difficult to judge what the broader community view of the NDIS is, but it was surprising to see such extreme views of the NDIS in survey respondents - from loving the scheme to quite frankly hating it (see quotes on p.4). Carers Tasmania believes this may be due to a number of factors:

- the point-in-time that the respondents’ (the carers’) care recipient entered the NDIS
- the assessment method used when developing the NDIS plan (whether this was face-to-face or over the phone)
- individual circumstances (level of complexity, rurality)
- level of carer knowledge and education about the NDIS
- level of carer stress/anxiety/fatigue
- local area coordinator expertise and carer awareness
- support coordinator expertise and carer awareness
- carer awareness and quality of services delivered by providers.

A clear message comes through qualitative comments that creating NDIS plans over the phone is problematic (to say the least). Carers Tasmania believes this issue may now be partly

⁵ Deloitte Access Economics’ “The economic value of informal care in Australia” (2015)

addressed by the NDIS in Tasmania, who are understood to have recruited a number of face-to-face planners and provided additional training to the Local Area Coordinators.

The quality of NDIS plans and supports is reportedly high, with 76% of carer respondents believing that the NDIS plan will meet all or some of the care recipients' needs, and 85% of respondents viewing the levels of support under the plan for the care recipient having increased or remained the same.

A key point to note is that 57% of carer respondents find it challenging or very challenging to source relevant and appropriate services for the care recipient. No direct data is available to support whether this was because of regional or remote issues in the Tasmanian context, and therefore a lack of local services, but anecdotal evidence suggests this could be the case. However, this may be a critical market issue for Tasmania. That is, while ideal supports may be listed in a plan, they may not necessarily be available in the 'marketplace'.

Almost 70% of carers responding say nothing has changed for them directly as a carer or they have less time out for themselves since the NDIS plan was activated. This is pertinent to the concerns of Carers Tasmania. The NDIS does not replace the role of the carer or support a carer in their own right, even though it *may* have excellent outcomes for the care recipient.

The NDIS is a paradigm shift in supporting Australian citizens living with a disability, and many carers are integral to the successful outcomes for those participants. It's still early days for the NDIS, and learnings are ongoing to make improvements to systems and operational guidelines.

This survey shows that, in the meantime, carers need to be informed and able to advocate for themselves and the people they care for to enable the intended outcomes.

Carers are critical to this and the success of these major changes for Australia. Let's not forget them.

"My life has become more complex, too much paperwork, and I have to fight for everything even though we have a complex high needs service co-ordinator."

Key Survey Findings

About the carers

143 carers responded to this NDIS Survey. Given the current NDIS coverage for 4-28 year olds in Tasmania, the majority of the care recipients (59%) are between 15 and 24 years, with 20% 11-14 and 21% 25-28 years. Refer to Table 1 below.

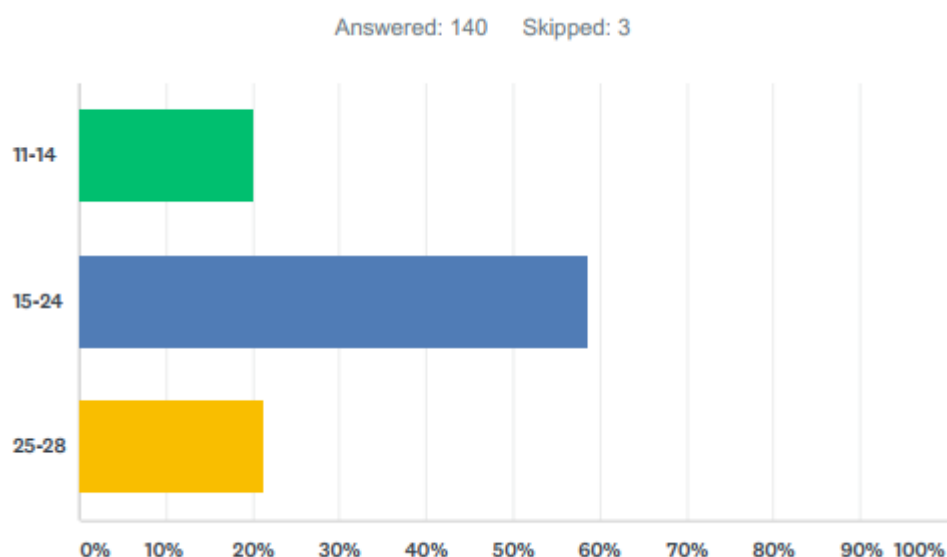


Table 1. Age of NDIS participants in Tasmania.

Positive Perspectives:

"I am just thankful for the support for my son to be himself and myself to be me."

"I feel that through the support of the NDIS we are now in a better position to give back to the community."

"We can commit to things we could not have considered before."

"NDIS has provided opportunities for my son to interact with the community and increased his lifestyle."

"I am extremely thankful for the NDIS.... Without it I wouldn't have a job, a new car and a wish list... I have more time now. Thank you for giving me my life back and improving my son's future. Thank you very very very much!"

Negative Perspectives:

"[NDIS] has created a lot more stress, uncertainty and work. Not the vision I had for NDIS."

"I have no confidence that it will provide for our child in the future."

"I became more of a coordinator of support and financial manager than a carer."

“The amount of respite for the participant has decreased drastically (by half). And the changes have made the situation tougher.”

“The whole system is shambolic.”

“The participant portal is hard to navigate and I would consider myself very computer literate and having worked in the sector, able to understand a lot of the terminology.”

About the care recipients/NDIS participants

94% of the carers that responded indicated their care recipients had passed NDIS eligibility requirements for a participant plan.

For those ineligible for NDIS, potential participants were either outside the current age cohort in Tasmania (4 to 28 years), or the illnesses presented did not meet NDIA criteria e.g. *“dyslexia, depression and anxiety”*. The responsibility to care in such circumstances, some of them with high stress and significant consequences, will continue to fall on the carer, and illustrates the need to continue to provide carer support services in their own right.

Whilst only 20 carers responded to the question about being involved in the planning process and the development of the participant plan, 85% of those carers who answered were ‘very involved’, 10% somewhat involved and only 5% were not involved at all (See Table 2). This indicates that the role of the carer in the NDIS planning process is not ‘hands-off’.

This is not surprising in some respects – given the age cohort involved in the scheme so far, many of them under 18 due to the age rollout. – Carers Tasmania would like to see this level of carer inclusion occur across all age cohorts, as the level of caring responsibility is not dependent on the age of the care recipient.

73% of carers who answered felt they had been given the choice to be involved in the plan development, and 71% of these carers felt their input was considered for inclusion in the plan. This is good news. It seems that the majority of carers in Tasmania are largely being considered and heard when included in the initial planning phase.

Some carers made comments around the needs for the person they care for as not being understood, or not being fully considered. A number of survey respondents indicated the carers need to advocate strongly on behalf of their care recipient, and this was found to be daunting and distressing.

“Their first visit was in October 27. December 14 will be the fourth visit. With all these plans and visits, including phone calls, no support for the recipient has even happened yet”.

“I (am) still the only advocate for my son. Everything achieved has been from my sole help and our determination”.

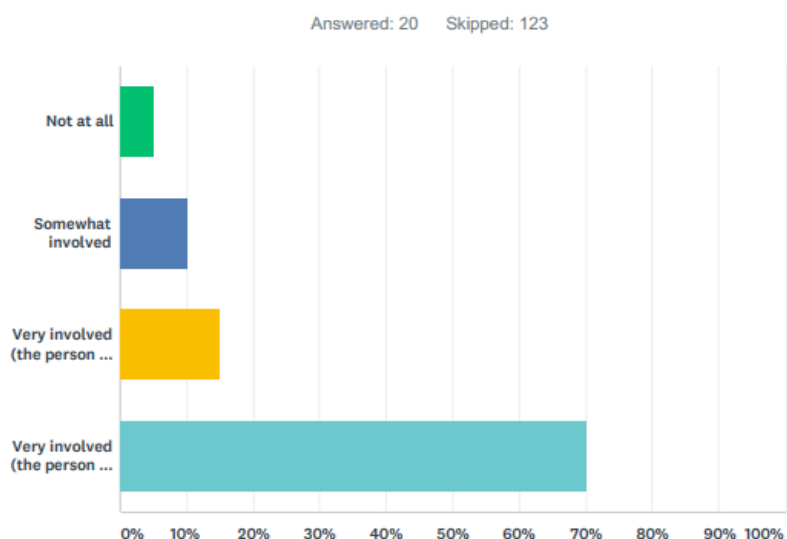


Table 2. To what extent were you involved in the development of the participant plan.

There are also the following findings:

- Only 22% and 54% of carers thought that the plan will meet all or some of the care recipients' needs, respectively.
- Levels of support under the plan have increased for 48% of participants.
- Supports for 37% have remained the same, and 15% indicated that they are receiving fewer supports.

These outcomes imply that, according to the carer, almost half of participants at this stage of the reforms see no change or that their supports have decreased as a result of the reform that is the NDIS.

Some of the anecdotes to this reflected that there can be challenges in finding service providers who understand the person requiring care, or they are unavailable. This could reflect that the market has not yet caught up with demand, or could be that services are not available in Tasmania, much of which is rural and remote.

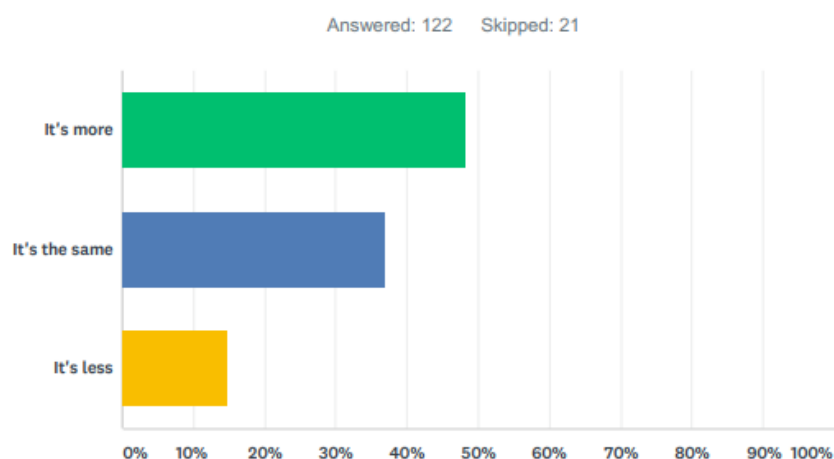


Table 6. Level of change in supports post-NDIS plan.

More supports needed for carers under the NDIS

While carers are not the focus of NDIS and not considered to be participants in the scheme there can be indirect benefits to all stakeholders through the provision of supports to the person with a disability, and there is potential for carers to receive supports in their own right.

When asked if, through the NDIS, have any services been provided to support the carers, the majority of respondents, 57%, said no, while 43% said yes (See Table 3 below).

Carers have the lowest wellbeing of all cohorts in Australia⁶ and the importance of respite (taking a short or extended break) can not be underestimated. Respite helps carers in sustaining their caring role, improving the health and wellbeing of the carer and thereby maintaining the quality of ongoing care they can provide. Caring, particularly over the longer term, can have significant negative impacts on a range of life domains including physical health, stress and anxiety, personal wellbeing, family relationships, employment, income, and disconnection from community life leading to social isolation and exclusion (See section below “Impact of the NDIS on carers’ time and lifestyle choices” for more specific survey results on lack of respite).

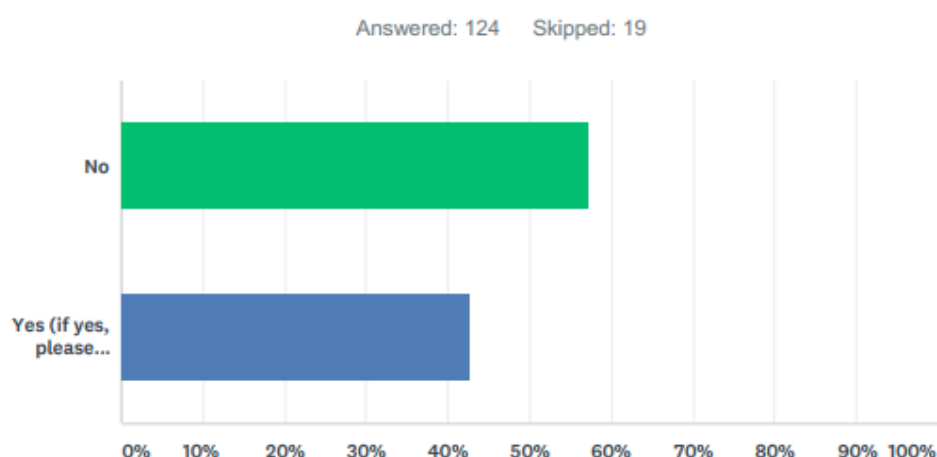


Table 3. Has the NDIA or your participants plan provided for any services to support you in your caring role?

Comments included,

“Helps me to back away from doing everything for my son and gives me a break.”

‘Respite and day support.’

“None at all.”

“Given me some respite – a tiny bit.”

“NDIS paid for a psychologist. Takes the pressure off me trying to get through to him about things.”

⁶ Australian Unity (2015) What makes us happy, Melbourne.

"This is a huge area that is lacking."

"Help around the house."

"Some school holiday care."

Plan Management – More "Work" for the Carer?

NDIS participants or their carers are given the option to self-manage or partly manage the planning and support co-ordination of the NDIS participant plan. Alternatively, participants or their carers can elect to have another organisation or individual take on this role.

33% of carers that responded said they have chosen to self-manage the participant plan, and 67% of carers chose not to.

51% who are self-managing reported they were managing it okay. The concerning finding in this section is that 40% find it fairly difficult, and 9% of carers are not coping at all (See Table 4 below).

This means a (nearly) even split of those carers who chose to self-manage are managing 'okay' and an equal balance of those who are not. Carers already have a lot 'on their plate' in being a carer. Carers who responded and were self-managing said they did so to maintain choice and control, to influence the quality of the care provided and ensure their inclusion in communication and decision making. The consequences of taking on this role can include unanticipated carer burden, including being overwhelmed with complex processes that don't always work, the learning of a whole new range of skills, and significant time investment required even for those with significant skills and sector knowledge.

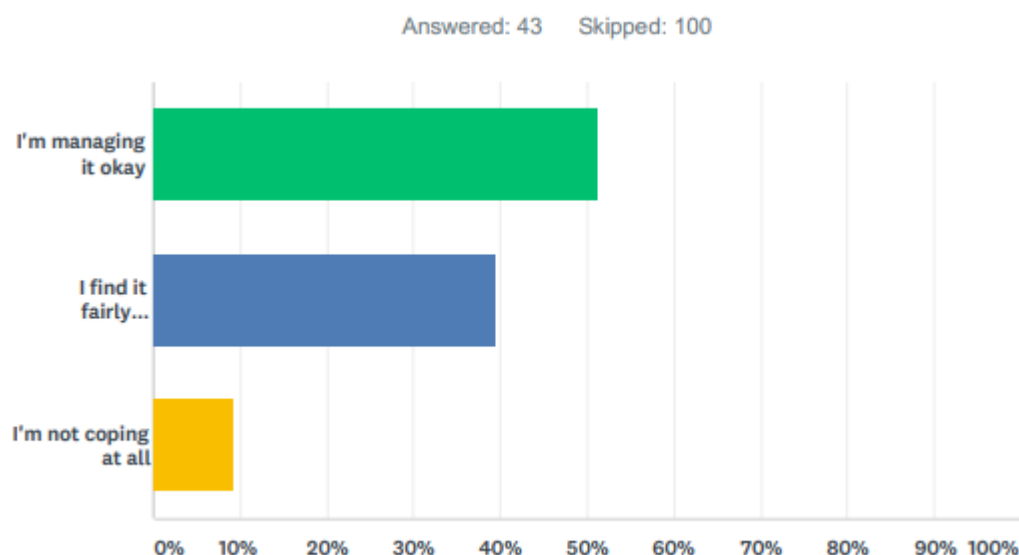


Table 4. Impact on carer of self-management of plan

Comments from those respondents who manage the care recipients plan, but are finding it difficult include,

“No help for carers.”

“I feel it gives me more control.”

“I like to be involved in decisions.”

“It seems to work better (with me managing my daughter’s plan).”

“At the moment I have the time and energy to commit to organising my daughter’s plan.”

“We self-manage part of the plan. However, because of the complexity of the plan now in place we’ve been advised to have a financial intermediary.”

“Complex and hard to manage.”

“My sister needs a lot of help and it stresses me.”

“Lack of communication between services.”

“I’m finding it difficult to find services- it’s daunting.”

There was broad feedback about how easily respondents sourced services under the plan 43% saying it was easy/somewhat easy while 57% find it challenging or very challenging (See Table 5 below). No direct data is available to support whether this was because of rurality and therefore a lack of local services, but anecdotal evidence suggests this could be the case. However, this may be a critical market issue for Tasmania – while ideal supports may be listed in a plan, they may not necessarily be available in the ‘marketplace’.

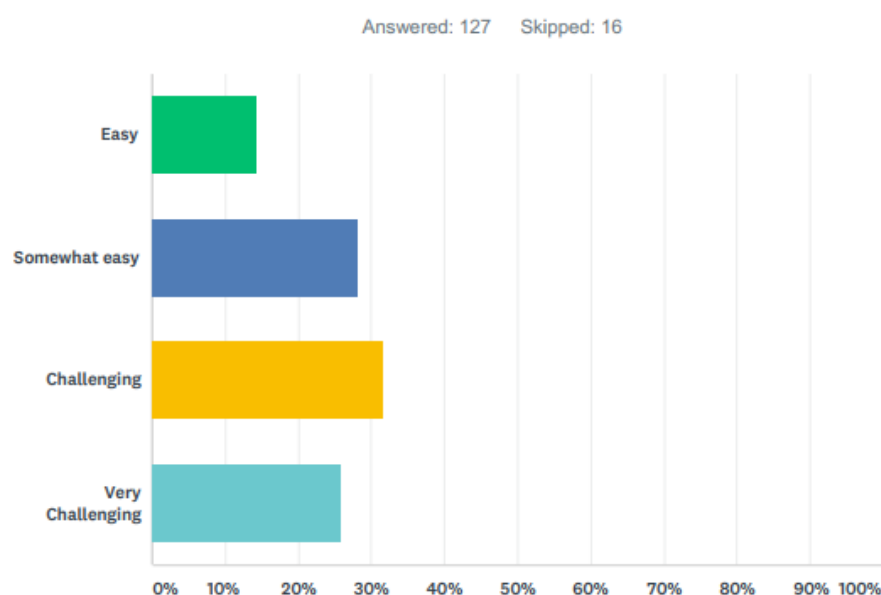


Table 5. Sourcing services funded under the plan.

Impact of the NDIS on carers' time and lifestyle choices

While there has been some presumption that the NDIS may reduce the role of a carer, and result in increased capacity for their economic and social participation, survey findings do not reflect that this is necessarily the case. This is a critical point to note.

40% of carers are spending a bit more or a lot more time managing the support needs of the participant, while 14% of respondents are saying it's too early to tell, 22% spending a little bit less or a lot less time, 24% are spending about the same amount of time.

When asked about how the NDIS plan has impacted on carers' existing work commitments, 42% responded no change, and 17% find it harder to manage (29% N/A).

35% of carers that responded say the NDIS has not changed their ability to commence or continue study, while 12% say it made it harder and 7% say it's easier (46% N/A).

When asked about whether carers have more time out from their caring role since the NDIS plan has been in place, 32% responded yes, with 23% having less time out, and 45% saying nothing has changed.

That means almost 70% of carers that responded indicated that nothing has directly changed for them in terms of having more time out for themselves as a result of the NDIS plan for their care recipient – in fact some carers have less time.

The NDIS is a scheme intended to benefit the care recipient and enable the purchase of supports and services for them. It's therefore understandable that 44% of carer respondents reported that the NDIS participant (care recipient) plan provides services for the recipient that indirectly support the carer in their caring role. 34% of carers said there are no options for respite, while 21% were not sure.

The qualitative data associated with this question clearly illustrates that the majority of these services are provided to the care recipient. Examples given include things like co - ordination of supports, continence supplies being purchased, and support services provided to the participant, which free up some time for the carer. Of those carers who responded and mentioned respite, it was acknowledged that respite was provided with the focus on the care recipient and their needs. There were still a number of challenges communicated in the responses that mentioned respite, including the challenge of finding appropriate services, or respite being offered 'in home' for the recipient with the carer not being able to afford to go anywhere or have 'time off'. Alternatively the respite was provided in extenuating circumstances such as ill health for the carer (therefore not at a time to enable the carer to have a break or have some time for themselves).

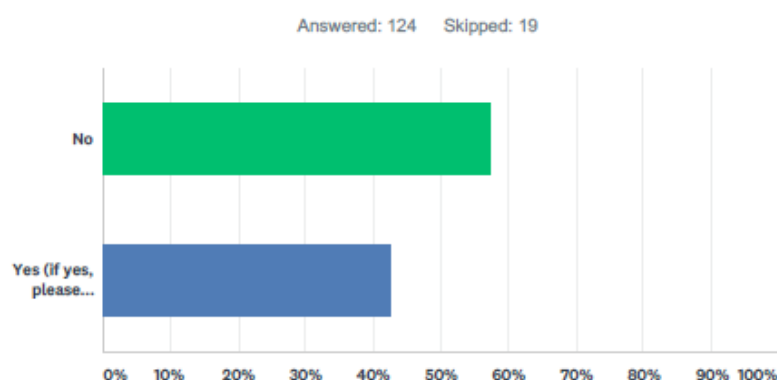


Table 6. Has the NDIA or the plan provided any services to support you in your caring role?

While supports to the NDIS provide indirect support to the carer, whether this is perceived to be helpful to respondents or indeed whether they are able to access respite at all, is dependent on a number of factors including medical needs of the person requiring care, suitability of respite options (particularly for people with autism), perceived lack of skills and knowledge of service providers, and the absence of options.

Comments were varied:

"Caring is trying and tiring".

"Tasmania has no respite suitable for a person with autism under 30."

"Having support for the participant twice a week for 3 hours each day has given me time out and peace of mind."

"Far less [respite] than was provided before."

"Yes the plan has some [respite] resources but it's trying to get them that's difficult."

"So much more time is now spent on co-ordinating the services."

"I have 2 disabled sons – 4 children in total – and a disabled husband, so a bit of money to cover one son's showering, physio and a few rides to school does not make a heap of difference!"

"NDIS is the best thing."

Some additional important comments from throughout the survey:

"It really doesn't consider me at all."

"Please make allowances for the carer."

"Stressful and frustrating."

"Waste of money."

“NDIS enrolment has provided a lot of support.”

“It took 2 years to get my son on NDIS. That’s a long time when you are a carer struggling to get help and supports put in place.”

“Still waiting for funding for a wheelchair after 4 months.”

“As a primary carer I am less fraught with worry over money.”

“Endless negotiations but no actions.”

“I think that providers make a lot of promises on what they will provide but do not deliver.”

“Has not delivered anything like it promised in 2014. It feels insecure as workers keep changing.”

“Way below average score for communication and follow-ups.”

“Thank you for the NDIS it has made a difference in our lives.”

“In our case the NDIS has proved very beneficial and my daughter’s life has been improved in many ways. We have been able to be more pro-active with her physical health and improving her communication skills.”

“Next year I will insist on a face-to-face planning meeting.”

“The last few days this has been all I thought about, I have sat down and cried and asked myself “what can I do?”

Transition Issues

Carers also talked about being let down by service providers, being told that if a support worker is coming in to care for the recipient and doesn’t arrive, it’s because the portal has gone down and the service provider can’t see its bookings.

“We find there is a lot of confusion regarding what is available for the participant.”

“It has actually made life harder because all I seem to do is fix things for the service providers because the NDIS has not completed his plan properly.”

“The number of meetings and time wasted on the phone (the NDIS 1800 number is a joke) has been draining and so far pointless.”

“This is so positive for us as a family.”

Like any major reform or change, Carers Tasmania acknowledges there will be ‘teething problems’. It’s important that these are addressed early so the NDIS does not end up in market failure and more important – failure to adequately assist some of the most vulnerable people in our community.

Conclusions

The outcomes of the survey indicate that the transition for some people living with disability to the National Disability Insurance Scheme in Tasmania has provided positive outcomes. However, these outcomes do not always translate to the carer and many are facing significant the challenges. Ultimately the NDIS will not be available to all and it will not replace the role of the carer. Sustaining the carer will require continued carer focused support (including respite).

It is evident that carers need clear and accurate information about NDIS; how they can be involved; and what supports they can access through the scheme. Those carers who take on the role of plan self management need to understand what this involves and be provided with training and support.

According to the survey responses, those carers most challenged by NDIS report facing the following challenges:

- Not feeling heard or included and needing to advocate for involvement.
- Limited availability of adequate supports.
- Communication and process issues.
- The difference between reality and “what looks good on paper”, and their continued need to provide significant care, and navigate a complex system.
- The time consuming nature of finding and accessing supports for the recipient.
- Any respite being counterbalanced by increasing administrative responsibilities.
- Lack of confidence that their loved one will receive adequate high quality support into the future as the carer themselves age.

It appears that so far, the jury is out as to whether the NDIS as an ‘insurance’ scheme it provides any significant benefit to carers in Tasmania.

Summary & Recommendations

The survey informing this report “The impact of the NDIS on Carers in Tasmania - the Picture So Far” has provided a snapshot of carers’ views on the NDIS as it has rolled out to 4 to 28 year olds across Tasmania.

As a result of these survey findings, and the impact of the NDIS on carers in this state, Carers Tasmania proposes:

- Increased carer awareness and inclusion in the NDIS planning process so that it is routine practice;
- That carers continue to be provided with their own support, independent and separate to the needs of the person requiring care, whether the care recipients are NDIS participants; eligible but unwilling to engage; or ineligible;
- That service providers relating to the NDIS specifically are trained in carer inclusion;

- That the carer need for respite is acknowledged in its own right, and should be tailored to suit the needs of the carer to sustain them in their role;
- A collaborative approach across funding agencies specific to social services reform is needed to ensure no-one 'falls through the cracks' – in particular carers.

All reforms currently occurring in the social services sector rely, to some extent, on the support of the closest family members or friends – the carer.

Our country does not have the economic capacity to replace this care (valued at \$60.3 billion per annum). So let's not forget them. We have to continue to support carers.

A profile of carers in Australia



Informal carers make a significant contribution to the lives of others. Caring can be very rewarding, however the time taken to care can impact on a carer's ability to work and their opportunities to study and participate in the community.

The results of the 2015 Survey of Disability, Ageing and Carers provide a profile of carers in Australia.



2.7 million Australians provided informal care in **2015**



272,000 carers were under the age of 25, this equates to around **1 in 10**



Around **856,000** Australians were a **primary carer** — the carer who provided the most assistance to a person with disability



Almost all **primary carers** cared for a **family member**



The average age of a **primary carer** was **55**



More than **two thirds** of **primary carers** were **female**



More than **half** (55%) of **primary carers** provided care for at least **20 hours** per week



56% of **primary carers** participated in the workforce*, compared to **80%** of **non-carers**



The weekly median income* of a **primary carer** was **\$520**, which was **42% lower** than **non-carers**

* Labour force and income figures are for persons aged between 15 and 64 living in households.

Further information is available in *Disability, Ageing and Carers, Australia: Summary of Findings, 2015* (cat. no. 4430.0) available from the ABS website (www.abs.gov.au). A pdf version of the information sheet is available from the Downloads tab of this publication.