

SURVEY ON IMPACTS OF COVID-19 ON FAMILIES AND CARERS OF NDIS PARTICIPANTS WITH PSYCHOSOCIAL DISABILITY

1. Background

In April 2020 Mental Health Carers Australia (MHCA) was invited to talk with the National Disability Insurance Agency about impacts on families and carers of NDIS participants with psychosocial disability due to the COVID-19 pandemic.

MHCA conducted this survey in partnership with our member organisations and MHCA carer advisory group to better understand the impacts on families and carers and to identify the main challenges faced in order to inform policy responses. The survey was distributed through MHCA's member and stakeholder networks.

We would like to thank all the tireless family members and carers who completed the survey and their generosity in sharing their personal stories during these challenging times.

There were 103 completed survey responses from carers of NDIS participants from across Australia. The key themes from their responses reinforced findings from the Caring Fairly Survey in May and provided more focussed insights around the needs of NDIS carers.

2. Top three findings and recommendations

1. Provision of NDIS supports for participants, families and carers have dropped significantly

6 out of ten said lock-down has impacted the NDIS supports received to a great or a very great extent.

Eight out of ten respondents had not been in contact with the NDIA regarding their plan e.g. seeking a review.

2. Families and carers have stepped into the breach left by providers – and it is impacting their personal and family's mental health

75% are concerned about their family's mental health and 65% concerned about their own mental health.

Nearly 50% reported their caring role increased significantly or more than they can cope.

3. Carers are an at-risk cohort more vulnerable to COVID and more likely to be struggling financially on pension-level incomes

Survey respondents were aged 50 years and older (73%), and nearly all women.

Day to day expenses have increased for 6 out of 10 carers – most of whom are retired or working part-time.

OUR TOP THREE RECOMMENDATIONS

- **Proactive Outreach** – During a crisis, contact NDIS participants AND their families and carers (if nominated) to discuss any adjustments to services that may be required. This should include if a review of the NDIS plan is required, and if at-risk carers require any additional supports
- **Additional Financial Support** – Provide access to timely and adequate financial assistance for carers to supplement income when required to meet increasing or new day to day expenses, including associated with providing the support that would normally be delivered by paid providers
- **Additional Mental Health Supports** - In addition to existing supports, MHCA understands that the Federal Government funded additional mental health and carer supports in response to the impacts of the crisis. This should include dedicated and new supports designed to meet the needs of carers in a crisis

3. Executive Summary

The unexpected rapid onset and spread of the COVID-19 pandemic in early 2020 presented unprecedented challenges for policy makers and service providers across the human services sector. Decisions about service provision and appropriate safeguards for vulnerable groups had to be made quickly in a fast-changing environment. In short, we would not have expected everything to be handled perfectly given the size of the problem.

However, early on in the outbreak we started hearing that as services were reduced, altered or withdrawn that this was having severe and consequential impacts on NDIS participants with psychosocial disability, their families and carers. There were a number of themes emerging from this anecdotal evidence base that we decided to validate further by conducting a survey.

While we understand that the NDIA contacted 60,000 vulnerable NDIS participants during the height of the pandemic, our findings indicate that even based on this sample, a number of people did not have any contact from anyone at all, such as local area support coordinators and support coordinators, when they clearly had expectations of this. Added to this is the high number of people who said that they did not contact the NDIA.

It is clear from our small survey that the structural design of the NDIS has not responded adequately to the needs of families and carers. It has taken a national crisis to demonstrate that they are still providing levels of support that would be considered unreasonable by the general community. Families and carers have stepped into the breach during COVID-19 as ‘providers of last resort’ when providers have been unable to do so.

The needs of families and carers must be considered in their own right given the significant adjustments they make to their personal and economic lives in order to support the health and well-being of the participant. They have not been remunerated for this contribution, nor their contribution recognised. Our findings correlate strongly with the [Caring Fairly survey results](#) and we likewise advocate for additional financial support for families and carers of NDIS participants and the development of a national carer strategy.

We understand that all Australians have been asked to make sacrifices during these challenging times. We argue that the sacrifices made by mental health families and carers go well above and beyond that asked of the general community and this survey, along with Caring Fairly, provides evidence of this.

When making planning decisions, The NDIS Act (2013) requires that a participant’s plan must include a statement about the person’s informal community supports, and that the funding or provision of the support takes account of what it is reasonable to expect families, carers, informal networks and the community to provide – expecting families to undertake the role of an unpaid support worker when facing significant risks to their own and their family member’s well-being cannot be considered reasonable. It is particularly unreasonable that ageing carers are providing significant levels of service in lieu of paid supports to the detriment of their physical and mental health and well-being.

Below is a comment from a carer advisory group member when presented with the survey results:

“The majority of carers are in the older age groups and a large percentage are retired therefore both the carer and the NDIS participant also fall into the vulnerable-to-COVID-19 categories - hence increased anxiety, mental health issues and worry over the participant and family's health and well-being. Plus brings home the stark reality of not being able to provide care and what happens if the carer dies.”

We are also of the view that the social and economic impacts of the restrictions will be far reaching beyond the ‘peak’ of the crisis. Our recommendations address actions that could have been taken or done better from the outset, as well as long term strategies to ensure that people are linked to carer supports and services, including financial assistance as mentioned above.

Recommendations

1. Proactive outreach:

NDIS participants and their families and carers (if nominated) should be contacted during periods of crisis to discuss any adjustments to services needed, including if a review of the NDIS plan is required. Ideally this would also include identification of at-risk carers also requiring additional supports. Responsibilities should be identified for making contact and this should be clearly communicated to participants, their families and carers and the broader sector. Ideally it should be someone who has an existing relationship with the participant and their carer, such as a local area coordinator or support coordinator.

All participants with psychosocial disability should be deemed vulnerable (unless they ‘opt out’) and the NDIA should ensure that ongoing efforts are made to make contact and that data is recorded on contact attempts, including successful contacts with participants, families and carers. Outreach should also include capacity building support to identify alternative ways of receiving services when face to face service delivery is not possible, including access to digital technologies.

2. Additional Financial support

Consideration should be given as to how participants, their families and carers can access timely and adequate financial assistance to supplement their income when required to meet increasing or new day to day expenses, including associated with providing the support that would normally be delivered by paid providers. Many NDIS participants with psychosocial disability and their carers subsist on pension-level incomes on a long-term basis and have no savings or superannuation to draw on.

3. Additional Mental health supports

In addition to existing supports, MHCA understands that the Federal Government funded additional mental health and carer supports in response to the impacts of the crisis. This should include dedicated and new supports designed to meet the needs of carers in a crisis. There should be processes in place to ensure that NDIS participants, their families and carers are proactively linked to

these supports and that these linkages to supports are recorded and reported on. Particular attention needs to be paid to people's physical and mental well-being.

4. Plan flexibility

Flexibility of plans: COVID-19 has demonstrated that much greater flexibility is needed within plans to deal with unexpected events. In particular the ability to swap funding between core and capacity building supports would give people greater control over their plans in periods of crisis. This flexibility is also required in other circumstances that can occur for people with a psychosocial disability, for example, if a person has a relapse of their mental health.

5. Collaboration with major retailers e.g. grocers

Contingency planning and collaboration are needed to ensure that in future crises that the needs of vulnerable people and communities are catered for earlier than occurred during COVID-19 and that people with mental ill-health, their families and carers are specifically included in any response plan.

6. Business continuity

There should be a greater requirement for providers to have robust business continuity plans in place that address operational and service delivery changes required to support participants during periods of crisis.

7. Personal protective equipment (PPE)

There should be earlier and clearer guidance from the federal and state governments regarding the requirement for and access to PPE. Participants, families and carers require clear and timely information about what to expect of support workers in relation to PPE and physical distancing requirements, and measures on how to keep themselves safe during periods of service provision.

4. Detailed Findings

4.1 Level of impact of the COVID-19 restrictions on NDIS supports in general

61% of respondents stated that they felt the COVID-19 lock down has impacted the NDIS support that they had normally received in general to a great or a very great extent.

Reasons given included:

“My son recently discharged from a facility into independent living 24/7 care as covid restrictions were commencing Because of limited activities he was able to participate in became non-existent he now isn't accepting of any services due to anxiety and confusion/understanding with covid - 19.”

“The support for physiotherapy is now not in person but is over Zoom, but when it happens it seems to go pretty smoothly. We have recently been able to meet with our other physiotherapist face-to-face.”



“Remote support only via Zoom. Direct support ceased during lockdown.”

“All therapies were cancelled for 3 months.”

“The support coordinator has not bothered to contact my son; the OT support person has made no contact.”

“Lack of home visits, no face to face support. Not being able to get out and visit services or groups.”

“He hasn’t had any contact with anyone at all.”

“All the planning meeting and supports for my son have stopped due to covid. I have had to have my son live with me during covid and it is pushing me to the edge.”

“It has taken extra work to ensure supports remain in place.”

“Unable to access support as providers are closed.”

“Difficult to find good support – workers don’t want to meet face to face. My son is distraught at being left on his own. He is not a risk as he has not been going out.”

“Looking after 24/7 my daughter with help of husband being in 70’s range. As parents we are in the most vulnerable age group so had to cancel all in house and outside support networks.”

“We now have her so much more due to everything shutting down and its slowly tearing our family apart.”

“It’s all by remote and if you want / need to discuss it, it’s you doing the chasing. It’s leaving both of us more isolated.”

4.2 Changes to the caring role during COVID-19

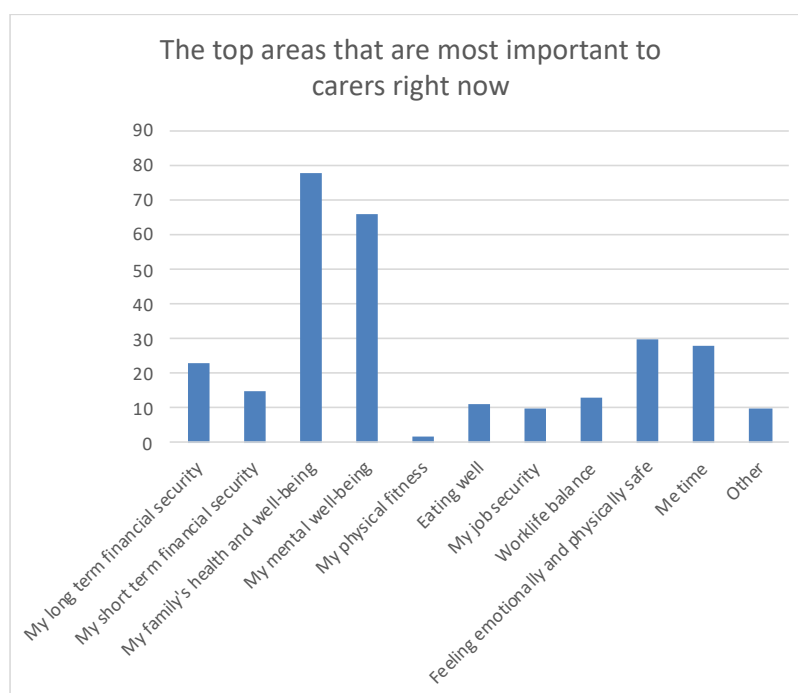
Nearly half of all survey respondents described their role as a carer of an NDIS participant as *‘increasing significantly’* or *‘more than I can cope alone’* for the following activities: acting as a support coordinator when the usual coordinator of supports isn’t available, getting the basics such as food, organising activities, additional expenses and time taken away from the carer’s usual routine – refer Table 2 below.

The greatest impact related to organising activities and time taken away from the carer’s usual routine.

Change in role as a carer	Acting as a support coordinator		Getting the basics such as food		Organising activities		Additional expenses		Time taken away from my routine	
	#	%	#	%	#	%	#	%	#	%
About the same	22	21%	26	25%	9	9%	23	22%	12	12%
Dropped	3	3%	0	0%	5	5%	6	6%	4	4%
Increased somewhat	16	16%	25	24%	19	18%	24	23%	24	23%
Increased significantly	29	28%	34	33%	40	39%	27	26%	36	35%
More than I can cope alone	15	15%	11	11%	24	23%	16	16%	24	23%
Not applicable	18	17%	7	7%	6	6%	7	7%	3	3%
Total	103	100%	103	100%	103	100%	103	100%	103	100%

4.3 Top concerns of survey participants

Carers were also asked about the top areas that are most important to them right now. The family's health and well-being, the carer's mental well-being and feeling emotionally and physically safe were ranked the top three areas in terms of importance – refer Table 3 below.

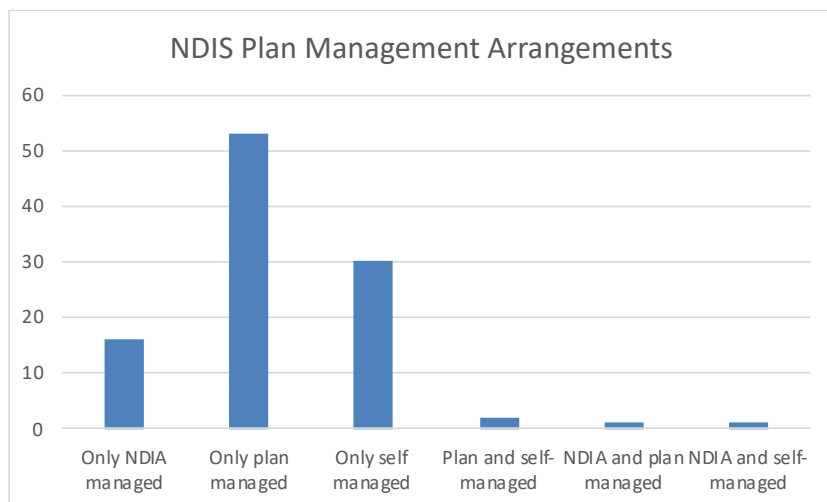


4.4 Living arrangements of survey participants

65% of respondents stated that they lived together with the person that they are supporting prior to COVID-19 and 66% lived with the participant after the COVID-19 restrictions were introduced.

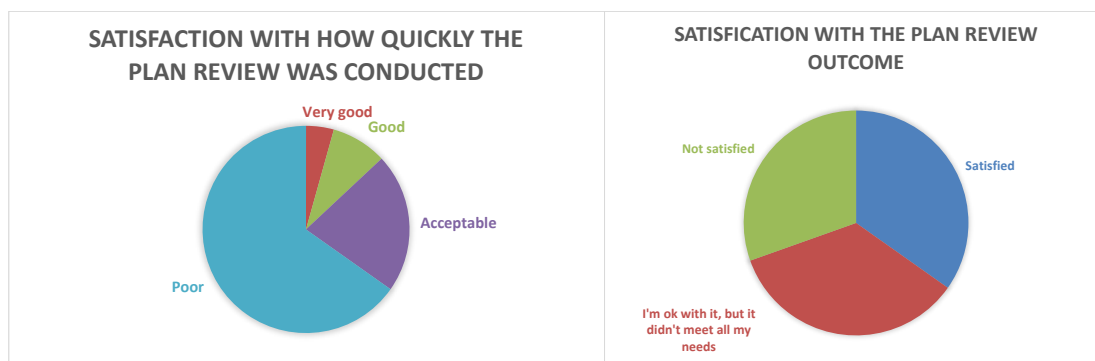
4.5 Plan management arrangements of survey participants

Of the 103 survey participants, over half (53%) have *only* plan-management arrangements in place with a further 29% have *only* self-managed plan arrangements in place (Table 1)



4.6 NDIS plan reviews during COVID-19

Of the 103 survey respondents, 23 stated that they had contacted the NDIA during the COVID-19 outbreak. Of these, 15 described how quickly the plan review was conducted as poor – refer Tables 4 and 5 below.



Survey respondents told us that these are the things that it's important for the NDIA to be aware of about the impact of COVID-19 on them as a carer and the person they are supporting:

“Allow providers to continue with support and activities whilst observing social distancing rules and offering them free PPEs to carry out their work with NDIS participants.”

“The COVID-19 lockdown has placed much more stress on my son & myself. My son has been much more anxious & losing hope for his future. He has also felt very lonely. My caring role has been stretched to its limit on many occasions & I have had very little time to relax & recuperate. I know that this is not sustainable for me but there is no-one else to fill my roll. My son became suicidal & has just returned home from hospital, so now he is re-adjusting to new medications & feeling exhausted. The hospital stay was difficult for him, as visitors could only meet patients outside for half an hour. We were not allowed inside the hospital at all.”

“ALL workers - admin, planners and support workers included - need better training in mental health issues. Some have NO IDEA OR UNDERSTANDING of mental health.”

“Stopping face to face and in-home services and other centre based services has left me with no time out and severe isolation which has been incredibly draining physically, mentally, emotionally and financially. It has also put my safety at risk due to the impact this has had on the mental health of my family member.”

“The person I support has felt an increase in anxiety and other symptoms associated with anxiety which has meant they have needed more emotional support, for me to be present for them and for me to there as their main social contact. This has meant that I have had to increase my time with them and to come up with ways to support them and to help them keep their symptoms from becoming unmanageable.”

“NDIA simply do not address the family’s needs of someone with serious mental ill health. We are the 24/7 watchers. What will happen when we are no longer here? Who is interested in thinking ahead of the best plan for that time? We try our best but as the years continue the future is looking grim for my son's support. NDIS should make real effort to engage him, in turn I would be so grateful. NDIS can't fix it but there is no effort in relationship. Covid-19? It has changed nothing for us.”

“I do not worry so much for my son as I am able to advocate for him, I worry about the future when I may become less able to be there for him, I worry a great deal about others, where they receive NDIS services from people who may be unscrupulous or who may not have the skills necessary and where there are not enough checks and balances, I worry about the model that is overly complex and where for carers the onus is till on them to fix things and ensure there is quality of service.”

“The increase in Care time is quite significant and no break in sight for me.”

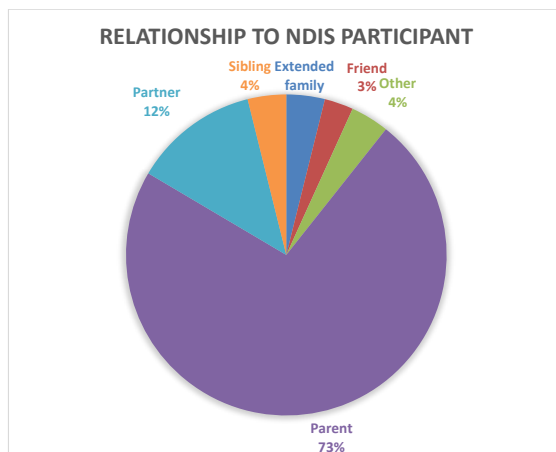
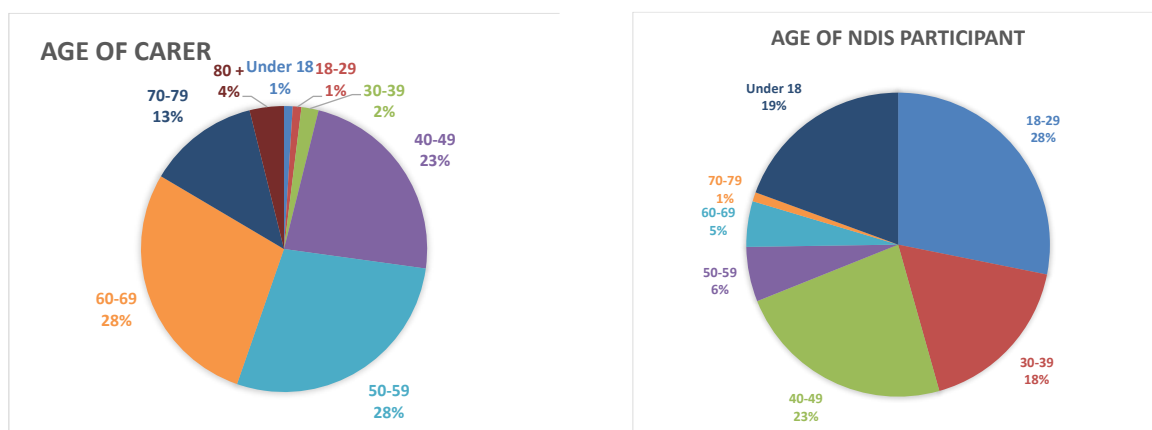
“If the support co-ordinator doesn't bother, that's yet another person who falls through the cracks.”

5. Demographic information

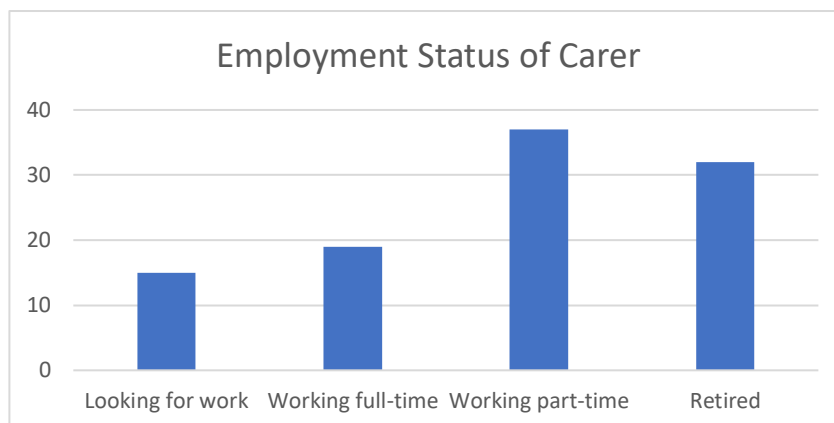
82% of the respondents identified as female, 10% male and one person responded that they would prefer not to disclose.

The vast majority (89%) of survey participants stated that they are immediate family members or partners of NDIS participants with psychosocial disability with the majority of NDIS participants supported (65%) aged under 39 years – refer Tables 6 and 7 below.

Survey respondents were aged 50 years and older (73%).



Most survey respondents were working full or part-time (54%) with a further 31% being retired and 15% of people looking for work at the time the survey was conducted.



Additional survey comments

“The person I support was in a good mental health space for the first time in a long time - about to start using more community supports - for groups, education and work supported activities - none of these new supports have started due to COVID 19 leaving the person more isolated and more reliant on me for social and emotional support.”

“My son has heard nothing from the support coordinator; nor his one therapist.”

“My dad has his plan review a few weeks ago. It was difficult as it was done online, and I was excluded from this process as his primary carer. We were only given 48 hours-notice that the review was happening. I was able to send a letter of support but unable to attend due to work commitments that I did not have time to re-arrange. Since the plan review dad's supports have been increased. It seems that COVID-19 has helped increase the understanding of isolation and loneliness, which he already experienced prior to COVID-19 and has increased as a result of COVID-19.”