

Submission to the Productivity Commission Inquiry into Mental Health

Submission from Mental Health Carers NSW Inc.

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Table of Acronyms

ABS	Australian Bureau of Statistics
ADAT	Adult Disability Determination Assessment
ADHC	Ageing Disability and Home Care NSW
ICSS	Integrated Carer Support Service
LHDs	Local Health Districts
MHCN	Mental Health Carers NSW
NDIS	National Disability Insurance Scheme
PC	Productivity Commission
PHNs	Primary Health Networks
SDAC	ABS Survey of Disability, Ageing and Carers

Mental Health Carers NSW

Mental Health Carers NSW (MHCN) is the peak body for mental health carers in NSW. MHCN is a community based, non-government organisation that provides systemic advocacy and education for carers, family and friends of those experiencing mental illness across NSW. MHCN works to ensure that the voices of mental health carers in NSW are represented and heard in policy and service provision reform processes to ensure that they are recognised and that their rights are upheld. We endeavour to empower mental health carers across the state to engage with mental health reform and advocacy.

Executive Summary:

Mental health carers make an immense contribution to society that often goes unnoticed and under-recognised. Nearly two-thirds of people living with severe mental illness receive care from family members or friends.¹ The total replacement cost of the care provided by mental health carers has been estimated at \$13.2 billion². Informal care also provides numerous intangible benefits which are difficult for formal services to replicate. The sense of personal connection and belonging generated by positive informal support networks is critical to the recovery process.³ Family members are a source of ongoing support which will last long after the individual has exited mental health services. Family and carers are often the first people to notice when a person is starting to become unwell and attempt to intervene and seek help before the person experiences a crisis.

As has been noted by the Productivity Commission, years of successive mental health inquiries have identified that additional funding to community mental health services is essential to ensure that people stay well. Where community mental health services are critically underfunded, the costs are often shifted onto carers. Carers will make significant personal and financial sacrifices to ensure that their family and loved ones receive care, often leaving paid employment or disengaging from education as a result. These costs are felt by society in terms of loss of carer productivity, carer participation and life potential. Many of the positive benefits of caring are lost where carers are overwhelmed, stressed, stretched to their limits or burnt out to the point that their wellbeing is impaired, or they disengage from their caring role. Ultimately, the best outcomes are achieved when caring is a choice, rather than a sacrifice made in the absence of any other satisfactory alternative to ensure that a loved one receives support.

Despite their substantial value and contribution mental health carers receive very little attention or funding within a policy context. There is not one comprehensive carer policy or strategy to guide the delivery of carer services in Australia. Other countries have implemented overarching carer policy to mandate carer needs assessment by all community service providers, by contrast, the various 'Carer Acts' passed by Australian jurisdictions are almost devoid of legal obligations on service providers other than reporting. Carer services are fragmented, receiving funding from multiple sources across all levels of government and from multiple departments including health and disability. This creates the potential for gaps in service provision to go unnoticed as well as for services to be duplicated needlessly.

Key funding and policy decisions have been made in a context where there is insufficient data and research to adequately assess the level of need for carer services, to map gaps in carer service

¹ ABS, (2015), Survey of Disability, Ageing and Carers, psychological disability tables, cat. no 4430.0.

² Diminic et al. (2017) 'The economic value of informal mental health caring in Australia', the University of Queensland, Brisbane

³ Commonwealth of Australia (2013) 'A national framework for recovery oriented mental health services: Guide for practitioners and providers' Commonwealth of Australia: Canberra, available at [http://www.health.gov.au/internet/main/publishing.nsf/content/67d17065514cf8e8ca257c1d00017a90/\\$file/recovgde.pdf](http://www.health.gov.au/internet/main/publishing.nsf/content/67d17065514cf8e8ca257c1d00017a90/$file/recovgde.pdf)

provision and to identify models of best practice in carer support. The NDIS has seen a major redesign in the way in which disability and carer services are delivered. The transition to a person-centred model of disability service delivery has shifted focus and funding away from carer services. Although a 'person-centered' model represents a huge leap forward in that it upholds the autonomy and self-determination of people living with disability, the equal need for 'carer-centered' services that recognise the carer's needs and rights as an individual have not been adequately recognised within recent reforms. Expenditure on mental health carer services is limited and total expenditure has shrunk over the past 5 years in spite of population growth. There is a need for additional services which carers can access, based on carer-need and which aim to achieve carer focused outcomes. Unsupported carers are at significant risk of developing their own physical and mental health problems.

The Productivity Commission can examine the full impact of mental illness on family and carers, to identify gaps in data, research and service provision and, to propose future directions for carer policy. These areas have not previously received detailed consideration by other inquiries of a similar nature. Positive informal relationships are invaluable to support recovery from mental illness and the care provided by mental health carers is worth billions. Improvements to policy and services which support carers is likely to have significant benefits in terms of outcomes for both carers and people living with mental illness.

The Value of Mental Health Care

- Over half a million people in Australia provide care to someone who lives with a disability due to mental ill health.⁴
- Over 240,000 people in Australia provide substantial and ongoing care to an adult living with severe mental illness.⁵
- Between 14 and 23% of children live with at least one parent with a mental illness and many of these will undertake carer responsibilities.⁶
- 21% of people living with a severe mental illness receive assistance from carers in the absence of support formal services.⁷
- The total replacement cost of the care provided by mental health carers has been estimated at \$13.2 million.⁸

⁴ ABS, (2015), Survey of Disability, Ageing and Carers, phycological disability tables, cat. no 4430.0.

⁵ Diminic et al. (2017) 'The economic value of informal mental health caring in Australia', the University of Queensland, Brisbane

⁶ Edwards, B, 2008, The Nature and Impact of caring for someone with a disability, Research Report Number 16, Australian Institute of Family Studies, available at; <https://aifs.gov.au/publications/nature-and-impact-caring-family-members-di/8-empirical-findings-mental-health-carers>

⁷ ABS, (2015), Survey of Disability, Ageing and Carers, phycological disability tables, cat. no 4430.0.

⁸ Diminic et al. (2017) 'The economic value of informal mental health caring in Australia', the University of Queensland, Brisbane

Assessing the value and cost of mental health caring

Question on assessment approach; What suggestions, if any, do you have on the Commission's proposed assessment approach for the inquiry? Please provide any data or other evidence that could be used to inform the assessment.

As the Productivity Commission has noted in the Issues Paper, 'The Social and Economic Benefits of Improving Mental Health', mental illness does not affect individuals in isolation, rather, family members and carers are also affected when an individual becomes unwell. Mental illness comes at considerable costs to the person experiencing it and all family members in terms of relationship strain, impact to the mental and physical health and often financial loss. For carers of people living with moderate-severe mental ill health, and particularly primary carers, significant caring responsibilities can interfere with a carer's paid employment, education and social relationships with others. Carers often must make hard choices concerning the level of care they provide and the need to do other things with their time, sacrificing their own employment etc., to provide care where our system won't.

The best available estimation of the replacement cost of informal care provided by the main carers of people with a mental illness is that published in 2017 by the University of Queensland. It estimated this cost at \$13.2 billion, based largely on data on the number of carers estimated in 2012. This is the estimate of the cost of providing formal services equivalent to the level of informal care provided by carers.⁹ We comment on this assessment in the table below. However, care is often provided at considerable cost, both in terms of personal cost to carers and cost to society in terms of employment. Nearly two-thirds (62.2%) of people living with a psycho- social disability receive care from informal carers and 21% of these did not receive support from formal services.¹⁰ Nearly 63.5% of mental health carers indicate that they do not feel satisfied in their caring role.¹¹ This is indicative of a mental health system in crisis, wherein mental health carers provide a substantive amount of care in the absence of support from formal services.

The limited availability of formal, funded, public mental health services in the community ultimately shifts the responsibility of care onto untrained informal carers. As a result, carers are often placed in the unenviable position where they need to make substantive personal and financial sacrifices to ensure their loved ones receive the level of support that they need or else be prepared to tolerate the consequences for themselves and their loved one of leaving them unsupported, (homelessness, prison and/or suicide). When carers are left without the 'choice not to care', this has significant consequences in terms of relationship stress, wellbeing and social and economic participation. The ultimate consequence is that carers 'burn out' and disengage from the caring role entirely, often with their own mental health issues. This opportunity cost has not been well explored, and the Productivity Commission could examine this aspect of the impact of mental illness.

The following table surmises the areas where values and costs are associated with informal care for people with a mental illness. We also suggest in this table some areas where the Productivity Commission may like to focus their inquiries.

⁹ Diminic et al. (2017) 'The economic value of informal mental health caring in Australia', the University of Queensland, Brisbane

¹⁰ ABS, (2015), Survey of Disability, Ageing and Carers, psychological disability tables, cat. no 4430.0.

¹¹ Mental Health Commission of NSW (2018), 'Mental Health Carers in NSW: A snapshot', Mental Health Commission of NSW, available at: <https://nswmentalhealthcommission.com.au/mental-health-carers-in-nsw-snapshot>,

Table 1 Suggested areas of Inquiry of the value and costs associated with caring and carers

Area of value or cost	Summary of issues	Suggestions for the Inquiry
Value of informal care	The best estimate available is the 2016 study by Diminic ¹² . This study uses the Australian Bureau of Statistics 2012 survey of Disability and Carers as the basis for the estimation of the number of carers and the hours of care they provide.	The Inquiry could use the methodology of this study to revise the estimates of the number of carers. A new estimation should use the most recent data from the available from ABS – either the 2015 or the 2018 survey. In addition, costs were based on the level of salaries paid to mental health workers in 2015. These estimates could also be updated.
The impact of caring on to mental wellbeing of carers	The study by Edwards ¹³ demonstrates that carers had significantly poorer mental health compared to their peers - 17% of carers experienced clinical levels of depression compared to about 10% in the general population	The PC may like to estimate the financial cost to the Australian community from the higher levels of mental health among carers associated with caring for a person with a mental illness.
Negative impact to physical wellbeing	The 2008 study by Edwards also found that carers had poorer physical health compared with their peers - 29.0% of carers were in poor health compared to 17.2% of the general population. ¹⁴	An estimate of the cost to the Australian community of the poorer physical health of carers, because of their caring role would also benefit the PC's enquiry.
Income support	Studies have suggested that the number of carers receiving income support is lower than those who may be entitled to it. While Diminic (2017) argues that income support is a transfer of wealth and not an overall cost to society the absence of income support may have a material impact on the lives of carers and lessen their productivity and participation.	While the PC is committed to examining whether income support 'could better meet the needs of people that are unable to work due to mental illness or caring responsibilities' the Inquiry could also examine the extent to which carers who are eligible for this benefit are missing out and the impact this loss of income has on the community.
Reduced participation in employment	Carers have lower rates of labour force participation in comparison to their non-carer peers. ¹⁵ Carers are often obliged to leave roles for which they have considerable training and expertise to be informal carers, reducing Australia's skilled workforce.	What is missing from our understanding of the costs to carers and families of the mentally ill and the cost to the community, is an accurate estimate of the number of carers who are prevented from working or working in their area of expertise, or where the number of hours of work are reduced due to their caring role, and the impact this has on the economy.

¹² Diminic et al. (2017) 'The economic value of informal mental health caring in Australia', the University of Queensland, Brisbane

¹³ Edwards, B, (2008), The Nature and Impact of caring for someone with a disability, Research Report Number 16 , Australian Institute of Family Studies - <https://aifs.gov.au/publications/nature-and-impact-caring-family-members-di/8-empirical-findings-mental-health-carers> -

¹⁴ Edwards, B, 2008, The Nature and Impact of caring for someone with a disability, Research Report Number 16, Australian Institute of Family Studies - <https://aifs.gov.au/publications/nature-and-impact-caring-family-members-di/8-empirical-findings-mental-health-carers> --

¹⁵ ABS, (2015), Survey of Disability, Ageing and Carers, summary of findings, cat. no 4430.0.

Area of value or cost	Summary of issues	Suggestions for the Inquiry
Impact to superannuation	Superannuation represents a significant form of saving for working Australians and for many provides the major source of their wealth in later years. There is an impact to the Australian community of the loss of superannuation accumulation by both people with a mental illness and their carers whose capacity to earn income is impacted by their caring role.	The PC should examine the cost to the Australian community of the impact on wealth accumulation through the loss of opportunities to contribute to superannuation by carers because of their caring role. This is a hidden cost to society and one that should be estimated in this inquiry.
Reduced participation in education	One of the intangible costs to the community from mental illness is the loss of productivity and contribution caused by the inability of people with a mental illness and their carers to complete their education. It has been reported ¹⁶ that between 14 and 23% of children live with at least one parent with a mental illness and many of these will undertake carer responsibilities. However, there is little estimate of the cost to the community of the impact of the caring responsibility on the education of young carers. In addition, the children of parents with a mental illness may also have their education impacted by the influence of their parent's illness even if they don't have significant carer responsibilities.	This Inquiry could add to our knowledge of the cost of mental illness by estimating the impact that lost educational opportunities have on the carers of people with a mental illness and on the children of parents with a mental illness. While this impact may be felt most by young carers, adult carers can also have reduced opportunities to learn new skills due to their caring opportunities. The estimation of these costs would inform our understanding of the cost of mental illness and the opportunity cost of caring.
Reduced social participation	Caring responsibilities can impact the carers capacity to engage in social activities and community participation. While this may not have a direct financial impact on the community or on the carer it may have an intangible impact on Australian society by reducing the carers capacity to participate as a volunteer or other forms of community participation.	The PC could examine the cost to the community of the reduced capacity of carers to participate in the community through volunteering and other forms of community participation.
'Carer burnout' due to lack of support	Diminic (2017) reports that the Survey of High Impact Psychosis study did not find a correlation between the availability of carers	The PC could investigate the impact that having a carer makes to the likelihood of admissions and the extent that admissions are avoided by the presence of a carer in the life of

¹⁶ Maybery DJ, Reupert AE, Patrick K, Goodyear M, Crase L 2009, 'Prevalence of parental mental illness in Australian families', *BJPsych Bulletin*, 33(1): p22-6.

Area of value or cost	Summary of issues	Suggestions for the Inquiry
	<p>and the length of stay of hospital admissions of the person with the mental illness. Several reasons are offered for this explanation including the advocacy of the carer which may impact the length of stay. What is not available from the literature is an estimation of the number of admissions prevented by the existence of a carer and the savings that this represents to the health system and society.</p>	<p>the person with a mental illness. This would add to the Inquiry by better estimating the cost of mental illness to the community and the contribution that carers make.</p>

It should be noted that the experience of caring for a person living with mental illness is diverse. Some carers report that caring can be a rewarding experience and many derive a sense of pride and accomplishment from their caring role. In some circumstances, relationships between family members can be strengthened when they are able to cooperate to overcome difficult circumstances. However, the above figures point to the multiple challenging aspects of the caring role. In general, carers report higher levels of stress when compared to their peers, which impacts upon both physical and mental wellbeing. At a personal level, the financial, social and emotional sacrifices made by many carers alters their life course. For many, the caring role is associated with grief and loss; loss of their family members wellbeing, loss of finances, loss of time, loss of social network, loss of opportunities for employment and education, and loss of life potential.

Ultimately, the positive benefits of the caring role are more likely to be achieved when consumers and their families have access to services in the community so that untrained carers are not left to their own devices to manage often complex, stressful and overwhelming behaviours and care needs. This position is often untenable and can place significant strain on informal relationships which is counterproductive to recovery. Self-determination is essential to the recovery process and formal mental health services enable carers to step back from providing support and allow their loved one additional autonomy, confident their safety will be taken care of.

Emma's Story

"My life was satisfying in most areas: a healthy family, a pleasant nest to live in, a secure job, holiday projects and dreams in mind. Then I was projected into the world of mental illness, caring for my severely ill child 24/7, amidst the rest of the family, with no help whatsoever. It was a nightmare. My sole choice was to keep myself sane and my loved ones safe while enduring every aspect that strung along with the tragedy.

I am a 53yo mother and I was a full-time carer for 8 years of ongoing dramas and trauma to my child and to all our family and friends who love him. We struggled to access the NDIS but it has now been a saviour for both my son and our family. During my caring time I had to decipher not only the new reality we were plunged into but also the labyrinth of the mental health system, surviving the chronic exhaustion. I was hit with the harsh fact I had to quit my job to nurse him around the clock, while accumulating regular considerable medical expenses, losses, and property damage repairs.

It wasn't long before my health was affected. After several biopsies, I am a survivor, building up resilience thanks to the carer support connection, education and respite I used to benefit tremendously from, leading to my now volunteer advocacy position. Carers support funds have evaporated, and I am concerned that a maintainable future looks endangered for the overall health of our altruistic kind."

**** Names have been changed to maintain carer confidentiality***

Carer Supports:

What changes should be made to how informal carers are supported (other than financially) to carry out their role? What would be some of the benefits and costs, including in terms of the mental health, participation and productivity of informal carers and the people they care for?

Government Expenditure on Mental Health Carer Services

To MHCNs knowledge, there is no accurate account of government expenditure on mental health carer services. There are significant gaps in data with regards to;

- The portion of funding to general carer services which is used to provide services to mental health carers.
- Total expenditure at a local level by councils, PHNs and LHDs on projects & programs dedicated to mental health carer support.
- The extent to which NDIS funding has been utilised by participants to support carers of people living with psychosocial disability.
- The extent of demand for mental health carer services in Australia.

- The extent to which the level of service provision meets the demand for mental health carer services.

The introduction of the NDIS has drastically altered the funding environment for disability and carer services and this information is urgently needed to assess the success of new programs, identify arising gaps in carer supports and to inform future funding decisions. In recent years, funding to mental health carer services has been substantially reduced although there is no evidence to suggest that alternative programs will provide equivalent or better support. The concern is that some mental health carers have been left without access to services which are critical to support carers to maintain their wellbeing and be effective in their caring role.

OVERVIEW OF CHANGES TO GOVERNMENT EXPENDITURE ON SPECIALIST MENTAL HEALTH CARER SERVICES

Mental health carer services are funded by all levels of government either directly or through grants to NGOs. NGOs also fund services through private donations or a fee-for-service structure. At a local level, councils, PHNs & LHDs occasionally fund projects which are tailored to the needs of mental health carers. NDIS supports may also have positive flow on effects for carers, although this differs from carer services which carers can access in their own right based on their own needs.

The total expenditure on specialist services for mental health carers in Australia by federal and state government in 2014-15 was approximately \$90.6 million.¹⁷ Since 2014-15, the implementation of the NDIS has significantly changed the landscape of mental health carer support services as a number of carer-centred programs have been ‘transitioned’ into the person-centred scheme. Table 2 surmises changes to mental health carer expenditure by the Commonwealth and NSW government. Of note, Mental Health Carer Respite Support which previously represented 69% of total expenditure on mental health carer services Australia wide has been ‘transitioned’ into the NDIS.

Table 2 Total Expenditure on Mental Health Carer Services

Area of expenditure	2014-2015	2017-2018
COAG		
National Disability Insurance Scheme	Data on the supports accessed by participants with a psychosocial disability is collected by the NDIS. The extent to which these supports are beneficial to carers is not reflected in the data collected by the NDIS.	
Federal		
Mental Health Carer Respite Support	\$62 886 442	Defunded
Young Carer Respite and Information Services	\$2 736 928	Defunded
Integrated Carer Support Service (ICSS)	N/A	N/A. The ICSS will be implemented in 2019-2020. The percentage of funding which is allocated to specialist mental health carer supports is yet to be

17 Schess, J. G., Diminic, S. Y., Hielscher, E. A., Harris, M. G., Lee, Y. Y., Whiteford, H. A., & Kealton, J. (2018). Investment in Australian mental health carer services: How much and does it reflect evidence of effectiveness? Australian Health Review.

		determined. In total \$85,600,000 has been allocated over three years to support all types of carers.
NSW Government		
Family and Carer Mental Health Program	\$5 711 600	\$6 332 200 ¹
ADHC Disability Services	ADHC disability services provided some support to carers of people living with severe mental illness who had complex needs.	All ADHC disability services have been defunded as of June 2019. Most ADHC service recipients have been transitioned to the NDIS.

The effects of the changed funding regime on specialist mental health carer service provision have not been well understood by key decision makers. The decision to withdraw funding from Mental Health Carer Respite Services is based on several misconceptions, namely that;

- a) Most carers receiving respite prior to the NDIS will be able to access equivalent support through the Integrated Carer Support Service (ICSS), the NDIS or the aged care system.
- b) The NDIS will reduce the demands of the caring role by providing support to participants. In turn, this will reduce the need for carer services.

At present, mental health carers of non-NDIS participants under 65 years of age have very limited access to respite. The extent to which people with a psychosocial disability are likely to be able to access the NDIS has already been explored by the Productivity Commission in previous inquiries. The Productivity Commission made several recommendations which highlighted the need for mental health services to continue to be available outside of the scheme as a significant portion of people living with severe mental illness will be ineligible due to the permanency of disability requirement.¹⁸ At this stage, the extent to which the ICSS will provide specialist services to mental health carers is unclear. The ICSS will incorporate specialist carer services, however the proportion of funding allocated to specialised supports and the specific groups of carers that will be targeted is yet to be determined. Given the level of funding allocated to the program, the ICSS is unlikely to provide the same level of specialised support as the Mental Health Carer Respite program.

Concerningly, carers of NDIS participants also have limited access to carer supports through the scheme. The NDIS will not fund supports based solely on carer need, however a limited number of supports intended to increase the effectiveness of carers to carry out their caring role are funded. Other supports for participants may have a positive ‘flow on effect’ for carers, for example day activities may provide carers with a break from their caring role. Table 3. Identifies a range of carer services and their availability through the NDIS.

¹⁸ Productivity Commission (2017), ‘National Disability Insurance Scheme (NDIS) Costs’, Study Report, Canberra

Table 3 Types of mental health carer services and the availability of services through the NDIS

Types of Carer Services	Provided through the NDIS?
Counselling; Individual or family sessions with a qualified counsellor.	Yes. Family sessions which include the NDIS participant may be funded.
Support Groups; Group sessions with carers from a similar background. These can be either; peer led, peer facilitated or facilitated by a professional support worker.	No. The NDIS will not fund groups for carers.
Case Management; Collaborative planning between carer and professional worker to holistically identify and address carers needs.	No. Support coordination is available to the NDIS participant only.
Individual Advocacy for Carers; Professional advocacy to target individual carers needs.	No. Advocacy is not available through the NDIS.
Education; Individual or group sessions run by a professional facilitator intended to provide practical information and strategies to carers to help them to manage the caring role and maintain their own wellbeing.	Yes. Carer education designed to improve the capacity of carers to carry out their caring role is funded. Funding is only provided when there is a demonstrated benefit to the participant.
Coaching; One on one support by a community services professional which provides carers with practical advice, information and strategies to help them to carry out their caring role and to look after their own wellbeing	Yes. Carer coaching designed to improve the capacity of carers to carry out their caring role may be funded. Funding is only provided when there is a demonstrated benefit to the participant.
Respite; Support for the care recipient and the carer which is intended to give carers time away from the caring role to pursue life goals and improve carer wellbeing.	No. The NDIS does not use the term respite. The NDIS provide supports which may enable the carer to take a break from their caring role such as day activities. This differs from respite in that carers cannot access the support on their own terms, nor based on their preferred timing. The support is not purposefully aimed to achieve outcomes for carers.

The NDIS is designed to address the needs of people with a disability and was never intended as a source of support for carers. Carers are not able to access NDIS supports when they need it, rather the participant chooses which service they use and when. There is no requirement for carer needs assessment during application, planning or review. This is particularly problematic in the case of psychosocial disability as individuals often lack insight into their illness, the level of support that they need and their caring situation. People with a psychosocial disability may not recognise that they have a carer even where someone is providing significant amounts of care. The result is that carer support in participant’s plans are often poorly matched to the needs of carers.

Furthermore, there is no evidence to suggest that the NDIS reduces the demands of the caring role. Overseas research indicates that person centred funding models can increase the amount of time which carers dedicate to performing caring tasks.¹⁹ Rather than decrease the need for informal

¹⁹ Hamilton, M., Giuntoli, G., Johnson, K., Kayess, R., & Fisher, K. R. (2016). Transitioning Australian Respite (SPRC Report 04/16). Sydney: Social Policy Research Centre, UNSW Australia.

support, the nature of the role shifts to coordinating services with less focus on the provision of direct support. In 2018, MHCN conducted an online survey to capture carers experiences of the NDIS. Ninety four carers completed the survey; thirty one of these cared for a person receiving NDIS assistance. On average the number of hours spent caring per week decreased by 10 hours, however several carers indicated an increase in the time that they devoted to their caring role. When asked about changes to their role, multiple carers indicated that their role now included additional administrative work related to the NDIS. These comments were mirrored by carers at face to face consultations in the Hunter, Central Coast and Sydney region. As one carer commented;

“In addition to all the basic care I provide for my child, I need to coordinate, vet, contact, communicate, fill in forms (online and manual), complete questionnaires, background information. approve, attend, monitor, supervise, make payment, claim reimbursement, budget, track finances, compare level of service, price charged against recommended and follow up the service providers and in addition request a financial review, call and return calls, discuss change of circumstances, make appointments, follow up with medical professionals for referrals and most importantly disclose and discuss new service provider with recipient.”

As neither the NDIS nor the integrated carer support service is designed to comprehensively address the needs of mental health carers, it is critical that alternative avenues of support are created. In order to address emerging gaps in carer service provision, additional supports need to be funded that seek to purposefully address the needs of NDIS participants for ‘care coordination’ support (instead of this work simply being expected of them or their carers), as well as the specific support needs of mental health carers.

Change 1) Expand access to specialised ‘mental health carer-centred’ supports

In this submission ‘carer-centred’ supports refers to supports that;

1. Carers can access in their own right *without* requiring the cooperation of the care recipient;
2. Have eligibility criteria that is based on assessment of carers needs and;
3. Incorporate outcomes which purposefully address carer needs and goals.

The exact cost-benefits of the outcomes of carer services are difficult to accurately quantify, given the scarcity of high-quality research on this subject. However, in general research demonstrates that carer-centred services deliver a diverse range of outcomes. These outcomes can be grouped into; carer wellbeing, interpersonal relationships, social and economic participation, knowledge and skills related to caring and practical support.²⁰

Table 4 Outcomes of Carer Services

Carer wellbeing
<ul style="list-style-type: none"> • Improved carer scores on measures of mental health and overall wellbeing.²¹ • Reduced levels of stress and anxiety. • Carers report that their wellbeing has improved.²² • Increased confidence and recognition of personal strengths.²³
Interpersonal Relationships
<ul style="list-style-type: none"> • Social connection and support from carers in similar situations • Better quality relationships with the care recipient • Able to cope with difficult and challenging situations.^{24 25} • Improved affect regulation in young carers • Reduced sense of isolation and loneliness.²⁶
Social and Economic Participation
<ul style="list-style-type: none"> • Respite creates opportunities for participation in employment, voluntary work, education and recreational activities.²⁷ • Carers feel more confident and supported to take time for themselves.
Knowledge and skills related to caring
<ul style="list-style-type: none"> • Carers feel more confident in their caring role.²⁸

²⁰ Hamilton, M., Giuntoli, G., Johnson, K., Kayess, R., & Fisher, K. R. (2016). Transitioning Australian Respite (SPRC Report 04/16). Sydney: Social Policy Research Centre, UNSW Australia.

²¹ Stephens, J. R., Farhall, J., Farnan, S., & Ratcliff, K. M. (2011). An Evaluation of Well Ways, a Family Education Programme for Carers of People with a Mental Illness. Australian & New Zealand Journal of Psychiatry, 45(1), 45–53. <https://doi.org/10.3109/00048674.2010.522170>

²² Carers NSW (2015) ‘Mental Health Respite: Carer Support Evaluation’, Carers NSW, Sydney

²³ Cunningham, L., Shochet, I., Smith, C. & Wurfl, A. (2017) ‘A qualitative evaluation of an innovative resilience-building camp for young carers’, Child and Family Social Work, 22, pp 700–710

²⁴ Stephens, J. R., Farhall, J., Farnan, S., & Ratcliff, K. M. (2011). An Evaluation of Well Ways, a Family Education Programme for Carers of People with a Mental Illness. Australian & New Zealand Journal of Psychiatry, 45(1), 45–53. <https://doi.org/10.3109/00048674.2010.522170>

²⁵ Cunningham, L., Shochet, I., Smith, C. & Wurfl, A. (2017) ‘A qualitative evaluation of an innovative resilience-building camp for young carers’, Child and Family Social Work, 22, pp 700–710

²⁶ Carers NSW (2015) ‘Mental Health Respite: Carer Support Evaluation’, Carers NSW, Sydney

²⁷ Hamilton, M., Giuntoli, G., Johnson, K., Kayess, R., & Fisher, K. R. (2016). Transitioning Australian Respite (SPRC Report 04/16). Sydney: Social Policy Research Centre, UNSW Australia.

²⁸ Carers NSW (2015) ‘Mental Health Respite: Carer Support Evaluation’, Carers NSW, Sydney

- Carers ability to perform caring tasks improved.²⁹
- Carers ability to access services and information improved.³⁰

Practical Support;

- Carers receive practical support which meets their needs;
 - Housing support
 - Employment support
 - Assistance navigating the mental health system including referrals to relevant services
 - Individual advocacy
- Respite gives carers time away from their caring role and creates time to focus on other life goals.³¹

‘Carer centered’ supports can be categorised according to the type of support delivered, level of intervention and area of specialty (see table 5).

Table 5 Categories of carer supports

Table 5 Categories of carer supports		
<p>Types of Carer supports:</p> <ul style="list-style-type: none"> • Counselling • Support Groups • Case Management • Individual Advocacy • Education • Coaching • Respite 	<p>Level of intervention:</p> <ul style="list-style-type: none"> • Early Intervention • Crisis Intervention <p>Level of need addressed:</p> <ul style="list-style-type: none"> • Low • Moderate • High and Complex Needs 	<p>Area of specialty:</p> <p>Supports which are targeted to:</p> <ul style="list-style-type: none"> • Mental health carers • Young Carers • Parents • Aboriginal and Torres Strait Islander Carers • Culturally and Linguistically Diverse (‘CALD’) Carers

There is no one single best type of carer-centered support which is likely to give the highest value for cost. There is a lack of high quality evidence to draw accurate cost-benefit comparisons between different types of carer supports. Furthermore, such comparisons are unlikely to be useful as each type of carer support addresses a separate set of specific needs and outcomes. Future planning of carer services should attempt to incorporate a range of carer supports in order to comprehensively address the variety of needs of carers. Attention needs to specifically be given to specialised services for mental health carers as general carer services often lack the capacity to support this cohort of carers.

²⁹ Carers NSW (2015) ‘Mental Health Respite: Carer Support Evaluation’, Carers NSW, Sydney

³⁰ Carers NSW (2015) ‘Mental Health Respite: Carer Support Evaluation’, Carers NSW, Sydney

³¹ Hamilton, M., Giuntoli, G., Johnson, K., Kayess, R., & Fisher, K. R. (2016). Transitioning Australian Respite (SPRC Report 04/16). Sydney: Social Policy Research Centre, UNSW Australia.

Mental health carers require specialised mental health carer services due to the unique nature of mental health caring. Mental health care involves a high level of emotional support, care planning and behaviour management. Due to the fluctuating nature of mental illness, mental health carers need to manage a high level of unpredictability in their caring role and this can interfere with carers ability to meet other life commitments. Mental illness is a chronic health condition which typically has an early age of onset. This lengthens the caring role and extends the social and economic impacts of caring.

The symptoms of mental illness can interfere with individuals' ability to engage with formal mental health support. Mental health carers often act as the link between formal services and the person that they care for by encouraging help seeking behaviour, arranging appointments with services, contacting emergency services in crisis situations and ensuring that the person has support even where formal services are not available. The complexity of the mental health system also poses challenges for mental health carers when they assist the person that they care for to navigate complex systems (including health, disability, social services and housing). General carer services often lack the detailed knowledge around mental health supports, eligibility criteria, policy and law which mental health carers need to navigate their caring role.

The stigma associated with mental illness is also a significant barrier which prevents access to generalist carer services. Many mental health carers report that they feel uncomfortable seeking support from general carer services especially in group settings. There are a number of options for funding or expanding programs or service models that provide specialised mental health carer-centered supports.

Option 1: Fund the development of a specialised mental health carer gateway and a suite of specialised mental health carer supports to be incorporated into the ICSS model.

The Commonwealth funded ICSS is designed to provide access to a range of carer supports along a continuum ranging from early intervention and low level supports to individualised funding packages for carers with complex and high-level needs. The concept is promising; however, the concern is that the program has not been allocated the funding required to successfully achieve these goals. There are no specific plans to incorporate specialised mental health services in the 'ICSS Service Blueprint' so at present the extent to which mental health carers are supported through the program will depend on the types of specialised services offered by regional delivery partners.³² Formalising a pathway for mental health carers to receive specialised supports through the ICSS will ensure that this program addresses some of the gaps that have arisen from the transition to the NDIS and changes to mental health carer service funding.

Option 2: Expand state run specialised mental health carer services

The NSW government funds a combination of NGOs and Local Area Health Districts to deliver the state wide Family and Carer Mental Health Program. The Family and Carer Mental Health Program provides;

- Individual advocacy and support for carers;
 - Support groups for carers;
 - Information and referrals to general carer services;
 - Education and training for carers intended to teach coping strategies and build resilience;
- and,

³² Department of Social Services (2018), 'ICSS Service Blueprint', Commonwealth of Australia, Canberra

-
- Education and training for professional mental health staff to effectively engage with carers and respond to their needs.³³

The program is one of the sole reliable sources of individual carer advocacy and one on one support in NSW and MHCN routinely refers carers to the program for support. Although the program has not been comprehensively evaluated, the feedback which we have received from carers is that the support provided by the program is highly valued. Small scale research indicates that peer support groups run through the program facilitates learning, validates carers experiences and expertise and provides information on and referrals to other local carer supports.³⁴

Change 2) Prioritise research and data collection on mental health carer supports

There is a dearth of quality evidence on the effectiveness of various types of carer supports, both nationally and internationally. There is insufficient data to accurately determine the extent of mental health carer service provision in Australia, yet alone whether this is matched to the level of demand for services. It is difficult to make sound policy decisions on carer services in this context. The risk is that the value of mental health carer services are underestimated and inadequately supported in strategic reform. There is an urgent need to address critical gaps in our knowledge of carer-centred supports which can be achieved by;

- Prioritising research which seeks to evaluate ‘carer-centred’ services and supports;
- Developing methods to capture data on the carer experience of NDIS supports;
- Enhancing the understanding of the scale of currently funded mental health and all related services in Australia and the precise quantity of unmet need for these services (and then funding them as a human rights priority), and so stop *forcing* untrained carers to take on extensive caring roles;
- Conduct formal evaluations of government funded mental health carer services such as the family and carer mental health program and fund enough services to meet the community’s objectively calculated needs.

³³ NSW Health (2018) ‘Family and Mental Health Carer Program Framework’ NSW Health, Sydney, available at <https://www.health.nsw.gov.au/mentalhealth/services/carers/Pages/support-framework.aspx>

³⁴ Green, M., Dawes, K. and Pai, N. (2013) ‘Family and Carer Mental Health Program: Reflections on gaps in educational needs’, poster presentation from the ACMHN 39th International Mental Health Nursing Conference 2013, available at: <http://ro.uow.edu.au/cgi/viewcontent.cgi?article=2224&context=smhpapers>

Social Security Payments for Carers

Do the carer payment and carer allowance provide income support to carers who need it most? If not, what changes are needed?

The carer allowance and carer payment provide key support to carers who have made significant financial sacrifices to care for a loved one. Carer income support enables carers to continue in their caring role where it would otherwise be financially unfeasible. For carers from low income backgrounds, social security can help to mitigate some of the effects of socio-economic disadvantage. Carers on MHCN's Peak Advisory Committee have raised several issues with regards to carer income support;

1. There are a number of barriers which limit carers' access to income support. These include; knowledge and awareness of income supports, assessment processes tailored to physical disability and the complexity of the application process.
2. The carer payment places restriction on the number of hours which carers can engage in employment and education before the payment is stopped. The re-application process is complex, lengthy and time consuming. This can disincentive carers from engaging in periods of paid employment or education.
3. The maximum rate of the carer payment for a single carer is \$843.60 per fortnight which sits below the internationally accepted poverty line.

Access to Carer Income Payments

There may be considerable discrepancy between the number of mental health carers eligible for carer income support and the number who apply, however, this is difficult to quantify using publicly available data sources. The latest DSS Payment data from September 2018 indicates that 212,248 mental health carers receive the carer allowance and 73,875 receive the carer payment.³⁵ Changes to the disability assessment in late 2018, may have reduced the number of eligible carers. By contrast, the SDAC indicates that 512,600 people provide informal care for someone living with psychological disability in Australia.³⁶ The SDAC definition of an 'informal carer' is broad, including any type of ongoing informal care. Conservative definitions have produced numbers closer to the number of carer allowance and carer payment recipients. For instance, Diminic et al., estimated that there are 240,000 mental health carers in Australia who provide, "regular and sustained informal care to a care recipient whose main health condition is a mental illness, where the care recipient is aged 16 years or over."³⁷

Access Barrier 1) Knowledge and Awareness of Income Supports

It is critical that carers eligible for income support have access to information on eligibility criteria and application processes. Anecdotally, mental health carers sitting on MHCN's Peak Advisory Committee have indicated that carers' level of awareness around the social security system is an issue with regards to access to income support. MHCN is aware of multiple carers, who prior to their contact with our organisation, did not know that they were eligible income support based on their caring role, some of whom, had undertaken substantial caring responsibilities at significant personal cost for extended periods of time.

³⁵ Department of Social Services (September 2018) 'demographic payment data', available at: data.gov.au

³⁶ ABS, (2015), Survey of Disability, Ageing and Carers, summary of findings, cat. no 4430.0.

³⁷ Diminic et al. (2017) 'The economic value of informal mental health caring in Australia', the University of Queensland, Brisbane

Access Barrier 2) The Adult Disability Determination Assessment:

The Adult Disability Determination Assessment (ADAT), which is used by Centrelink to assess level of care provided, is currently weighted towards physical disability. The Department of Social Services is field testing a new assessment form which, if implemented appropriately, is likely to better capture the level of care provided by mental health carers.

About the ADAT

Most the questions used in the current assessment either directly relate to physical or intellectual disability only, or otherwise are described in terms which are not relevant to mental health. In particular, questions on self-care and daily living activities are often couched in terms of physical impairments and do not represent the level of coaching and emotional support which mental health carers must often provide with self-care tasks (e.g. 'cannot walk' in comparison to 'needs emotional support to get out of bed'). Although there is a small note on the form to explain that help means any physical assistance, supervision or guidance provided, this is not necessarily well understood by professionals and carers alike. As such, the assessment may fail to accurately capture extent of the caring role for many mental health carers.

Table 6. surmises the scoring in the ADAT. Part 1 of the questionnaire is filled out by carers and part 2 of the questionnaire by a health professional.

Table 6.1 ADAT Scoring

Division	Score for questions directly related to physical or intellectual disability only	Score for questions which are framed in terms relevant to physical or intellectual disability only	Score for questions related to mental illness which are described using relevant terminology
Part 1 Division A	27.5	33	12
Part 1 Division B	0	15	4.5
Part 1 Division C	0	6	34
Part 2 Division A	25	23.5	0
Part 2 Division B*	0	10.5	8.5
Part 2 Division C	0	0	21
Total Score	52.5	88	80

* For Division B either question 2 or 3 is scored. The maximum score for question 2 is 10.5 and for question 3 is 8.5.

Part 1 Division C: The questions in Part 1 division C pertain to mental illness or intellectual disability. These questions describe a small set of very specific symptoms which relate to some mental health conditions. The broad range of symptoms associated with mental ill health are not covered by the assessment. People who experience severe symptoms in one or two domains are likely to receive a low score for this division. For instance, it would be possible for a person who experiences psychosis 'most of the time' to score as low as 4 out of a possible total of 40 in this division.

- Highest score for aggression: 18
- Highest score for depression/anxiety: 4
- Highest score for self-harm: 6
- Highest score for unusual/inappropriate behaviour: 8

Part 2 Division C: As with Part 1, Part 2 Division C relates directly to mental illness or intellectual disability. The questions pertain to specific symptoms, namely; depression, memory loss, withdrawal from social contact, aggression and disinhibited behaviour. As with Part 1, it is possible for people who experience severe symptoms in a single domain to receive a low score.

Assessment of fluctuating care needs: For episodic conditions the ADAT form asks carers to answer questions based on the persons condition when they are 'not experiencing an episode or flare-up'.

About the Carer Allowance Field Test

The Carer Payment and Carer Allowance Field Test includes an additional explanation which states that 'help' includes prompting the person to do daily activities such as taking medication. The carer section is divided into the following fields;

- Mobility
- Self-Care
- Communication
- Learning and thinking
- Getting along with others and behaving appropriately
- Community Participation

There are additional questions which relate to mental health caring and the range of symptoms/conditions included is broader compared to the ADAT. The addition of a community participation field is particularly pertinent, as mental health carers typically provided extensive assistance in this area. Compared to the ADAT the field test questionnaire is better suited to assess the care responsibilities of mental health carers.

Restriction on Education and Work Hours for the Carer Payment

The eligibility criteria for the carer payment requires the carer to provide 'constant care' within a private residence to a person with a disability. Constant care is defined as care on a 'daily basis' which equates to at least a normal working day. Carers are restricted to 25 hours of paid employment, education or voluntary work, including travel time. Participation in education or employment for an excess of 25 hours per week results in the cessation of the carer payment, even where the carer still provides care 40+ hours of care each week.

The hours restriction on work and education acts as a disincentive for carers seeking to enter the workforce and limits available options. Carers who have been out of the workforce for an extended period may understandably feel apprehensive about the likelihood of success in their first new role. Carers may fear loss of income where the first job is not a success and they need to undergo a complex and lengthy application process to resecure the carer payment. Carers who are seeking to upskill and retrain in order to be competitive in the job market may need to undertake part time study as a result

of the hours restriction. This can add additional years to achieving their degree. Carers already experience significant barriers to entry including; limited prior work experience, level of educational attainment, gap in employment history so there is a mismatch between skills and workforce demand, loss of confidence and a lack of flexible work options which accommodate caring responsibilities.

The hour restriction is especially problematic for school-aged carers whose education responsibilities typically extend beyond 25-hours per week. Young carers may fear reprisals from child-protective services if they report taking time out of school to provide care.³⁸ The hour restriction also generates a barrier to young adult carers (aged 18-25) seeking to complete higher education. These impacts are exacerbated for young carers from low-income backgrounds, who are reliant on the carer payment to provide for the basic needs of their family and may choose to disengage from study as a result. Young carers experience significant educational disadvantage due to the challenges involved with juggling caring responsibilities and schooling. As a cohort, young carers are statistically less likely to complete high school, less likely to engage in higher education, and receive poorer results in schooling compared to their peers.³⁹ This has significant implications for future employment prospects and ultimately for life course.

There are numerous economic benefits where carers engage in some form of employment and education through the duration of their caring role and this can be encouraged by relaxing the 25 hour restriction on the carer payment. Carers with work experience prior to exiting the carer payment are less likely to receive a different type of social security payment once the caring role has ended.⁴⁰ Similarly, carers who have a higher level of educational attainment are less likely to continue onto a different type of payment.⁴¹ Employment and education can provide an opportunity for carers to spend time away from the caring role and to focus on other aspects of their identity and wellbeing.

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³⁸ Cass, B., Brennan, D., Thomson, C., Hill, T., Purcal, C., Hamilton, M., and Adamson, E. (2011), Young carers: Social policy impacts of the caring responsibilities of children and young adults, Report prepared for ARC Linkage Partners

³⁹ Ibid.

⁴⁰ Department of Social Services (2015), A New System for Better Employment and Social Outcomes - Interim Report of the Reference Group on Welfare Reform to the Minister for Social Services, Commonwealth of Australia

⁴¹ Ibid.