



# Mental Health Carers Australia

National Mental Health Carer Voice

Productivity Commission

Study into the National Disability Insurance Scheme (NNDIS)  
costs

A submission by Mental Health Carers Australia

March 2017



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For further information please visit [www.mentalhealthcarersaustralia.org.au](http://www.mentalhealthcarersaustralia.org.au) or contact Jenny Branton, Executive Officer, Mental Health Carers Australia

[jenny.branton@mentalhealthcarersaustralia.org.au](mailto:jenny.branton@mentalhealthcarersaustralia.org.au)



## Introduction:

Thank you for the opportunity to submit to the study into the NDIS costs. Mental Health Carers Australia (MHCA) is a member based national organisation representing people who support and/or care for a person with a mental illness. The state based member organisations have extensive connections with and understanding of families and carers of people with a mental illness. We wish to acknowledge our gratitude to those individuals and family members who have shared their personal experiences with us for the purpose of strengthening this submission. Please note that examples used have been de-identified.

MHCA supports the overarching objective of the National Disability Insurance Scheme (NDIS), however has concerns regarding the availability of supports to particular groups of people living with mental ill health and to their family, friends and others in a caring role who provide the majority of support

MHCA and its member organisations are confident that by working with mental health carers, service providers and government, the experience of carers can be better. Improving the capacity of carers in turn enhances the experience and outcomes for people with mental illness and reduces demand on the public and private mental health system and the subsequent costs to the public purse associated with that increased demand. MHCA is grateful for the opportunity to provide this submission and is keen to support the process in any way possible.

## Scheme Costs

### *Are there any cost drivers not identified that should be considered in this study?*

Mental Health Carers Australia has concerns with the overall transparency and uncertainty about how funding is being provided by governments at the federal, state and territory level to both the NDIS and state and territory community managed mental health services. This is creating difficulties in determining if spending for people with psychosocial disability is keeping in line with projections.

Mental Health Carers Australia is not aware of any additional cost driver categories, however, believes that a number of service items are currently not included within the categories.

#### *Advocacy:*

Everyone, at some time finds themselves faced with a misunderstanding or dispute. People with disabilities are no different in that respect, however, often do not have the capacity to advocate on their own behalf. Misunderstandings can arise, for example, between participants and providers, their family, utility providers such as power companies and with the NDIA. Advocacy is not included in the NDIS. Currently the expectation is family or services providers supply this support and carry the cost for it.

#### *Transport:*

Whilst transport is a service that can be funded as part of a package, planners often do not include it, making the assumption that families can provide this. The

Without engaging with the family a NDIS planner assumed they would be able to provide transport, so did not include any in the plan. Had they engaged with the carer, they would have found that she too has a disability and is unable to drive.



recent Federal Court ruling on Liam McGarrigle’s challenge to the NDIS position is a case in point.

This practice is in effect shifting the cost of an activity, essential for the participant to “live a full life”, from the NDIS to families and carers.

*Psycho social education:*

It has been established that family psycho-education has great potential to deliver improved outcomes for consumers and their families.<sup>1</sup> It is recommended in clinical practice guidelines in Australia <sup>2</sup> and yet is not provided under the NDIS.

*Translators:*

Mental Health Carer Australia member experience indicates that often translators are not included in packages. Once again, the assumption is that the family or service provider can and will provide that support.

An adult participant who can only communicate with a few family members received a package. The participant’s mother is the primary carer and translator. The carer does not speak English but the NDIS refused to fund translator for the mother.

Recommendation: That advocacy, transport, psycho social education and translators be adequately funded in individual’s packages.

*How do they impact costs in the short and long term?*

The short term impact is the immediate cost burden shifts to participants, their families and carers and providers. The long term impact, should people not receive sufficient support, will be declining health, hospital admissions and other potentially catastrophic consequences and associated costs.

## Scheme boundaries

### NDIS Eligibility

*Are there other aspects of the eligibility criteria of the NDIS that are affecting participation in the scheme (to a greater or lesser extent than what was expected)? If so, what changes could be made to improve the eligibility criteria?*

*Consumers:*

The draft Fifth National Mental Health Plan estimates that there are over 690,000 Australians who experience severe mental illness each year. The vast majority of these people receive assistance from their family and friends who provide support in cognitive and emotional tasks, personal and health care, mobility, household tasks, transport, and

<sup>1</sup> Family psycho-education for people with schizophrenia and other psychotic disorders and their families Carol Harvey and Brendan O’Hanlon, 2013

<sup>2</sup> Kreyenbuhl et al., 2010; McGorry, 2004; National Institute for Health and Clinical Excellence, 2009



reading and writing tasks<sup>3</sup>. The National Mental Health Consumer and Carer Forum (NMHCCF) anticipate that there are likely to be between 149,000-206,000 people who have severe or profound core activity limitations associated with mental illness. This represents a significantly larger number than the accepted figure of 64,000 used by the NDIA and will result in many people with severe mental ill health and their carers being unable to access support through the NDIS. It is estimated that only 12% of people with severe and persistent mental illness will be eligible for the NDIS<sup>4</sup>.

To be eligible for an NDIS individually funded package of support a person needs to have a 'permanent impairment' or an impairment that is likely to be permanent. Unlike many disabilities, where support needs are consistent and predictable, mental illness and the associated psychosocial disability is often episodic with the health and support needs of the individual varying enormously over a lifetime. The current assessment process for eligibility draws heavily on medical and diagnostic information, rather than assessment of functional impairment. If eligibility were tested on the basis of someone's functional impairment, then it is likely that more people with psychosocial disability would be deemed eligible, and would therefore get the support they need to participate in social and economic activities. However, people with mental ill health have not necessarily had assessments of their functional impairment.

It is not uncommon for people experiencing mental ill health to have limited comprehension that they are ill or that they need support. In this circumstance they might be eligible for a package but are unlikely to seek it out. The mental health sector also operates on a recovery model. Recovery is not synonymous with cure but rather refers to both internal conditions experienced by persons who describe themselves as being in recovery - hope, healing, empowerment and connection - and external conditions that facilitate recovery - implementation of human rights, a positive culture of healing, and recovery-oriented services<sup>5</sup>.

#### *Carers:*

Mental Health Carers Australia experience of NDIS operations in trial sites is that often the needs of the family member/s supporting an individual with severe mental ill health are not fully recognised or understood. The NDIS legislation rightfully acknowledges the important role a person's support network plays in their recovery<sup>6</sup>. However, in practice, although carers are eligible for assistance, it is often difficult to identify who the carers are and adequately assess their needs. As a consequence,

One member organisation sited a situation where a service provider made incorrect assumptions about the relationship the participant had with their family and involved themselves with issues around guardianship, causing significant distress within the family

<sup>3</sup> Australian Bureau of Statistics. 2015. Survey of Disability, Ageing and Carers: Psychological Disability, 2012 - Australia. Tables 3 and 8.

<sup>4</sup> Productivity Commission, 2011, Inquiry into Disability Care and Support Report No 54

<sup>5</sup> Jacobson and Greenley, 2001

<sup>6</sup> Supports funded by the Scheme (NDIS) <https://myplace.ndis.gov.au/ndisstorefront/families-carers/family-supports.html>



carers are less likely to receive the support they require to sustain their caring role. This places the carer, the family and the person with mental ill health at risk<sup>7</sup>.

Carers are less visible in the NDIS where the focus is, understandably, on the person with disability. A person experiencing acute mental ill health may not identify that their family member or friend is providing care. A family-centred approach is required by the assessor to ensure that family or friend carers are identified. Children in a caring role are particularly vulnerable to being overlooked yet their needs are considerable and they respond very positively to receiving support<sup>8</sup>.

Given the NDIS will be the primary avenue for people with severe mental illness and psychosocial disability it must have the flexibility to cater for the unique needs and circumstances of consumers and their families/carers.

MHCA supports the recommendation of the National Mental Health Commission (NMHC) Review of Programs and Services recommendation to 'urgently clarify the eligibility criteria for access to the National Disability Insurance Scheme (NDIS) for people with disability arising from mental illness and ensure the provision of current funding allows for a significant Tier 2 system of community supports.

Recommendation: That carers be assessed based on their own needs as well as the needs of the person they care for.

### Young people and functional assessment

Young people with significant mental health issues may have a long history of mental ill health and have received ongoing support from their family but not have a diagnosis. Their current clinician may be unable to assess the extent of the young person's functional limitations. This has led to protracted assessment processes with Local Coordinators directing repeated requests for information to the applicant. While functional impact is a more important factor than a diagnosis, in the absence of a diagnosis that Local Coordinators understand as 'severe' for example, schizophrenia, they request additional information which the young person and/or their family may not be able to afford financially or not have the ability to organise. Many people with mental health issues are not in contact with occupational therapists, for example. Hence, while the young person may actually be eligible for NDIS support, neither they nor their family, are necessarily in the best position, financially or functionally, to fully comply with ongoing requests for information.

<sup>7</sup> O'Halloran, P. 2014. Psychosocial Disability and the NDIS.

<sup>8</sup> Cooklin, A. 'Living upside down': being a young carer of a parent with mental illness'. *Advances in Psychiatric Treatment*, vol. 16, 141-146.



*Are there other early intervention programs that could reduce long-term scheme costs while still meeting the needs of participants?*

Mental illness can escalate seriously without timely and thorough treatment and support for consumers and their carers. Without effective and accessible mental health supports more individuals will require support from the NDIS system.

There are a wide range of effective early interventions suitable for people with psychosocial disability who are participants in the NDIS which are likely to reduce future support needs including social skills training, supported employment, supported housing, illness self-management training, cognitive remediation, CBT for psychosis, individual psycho social education, family interventions, family psycho-education and support, social cognition training, health lifestyle programs and education<sup>9</sup>.

Effective early intervention highlights the importance of ensuring that families are respected and valued partners in care and feel supported to provide sustained care as needed for their family member<sup>10</sup>

Recommendation: That a wider range of early interventions be made available to NDIS participants with a mental illness.

Recommendation: Strategies to reduce the long term demand on the NDIS include:

Ensuring there are adequate treatment and support services available to people with emerging and established mental illness and their carers.

A whole of population approach to tackle stigma surrounding mental illness to increase the likelihood people will seek help.

Education and support be available for families and vulnerable communities around Mental Health 1<sup>st</sup> Aide and suicide prevention

Mechanisms are available for consumers/carers to activate when and if they have concerns about the mental health of a loved one or themselves.

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<sup>9</sup> Effective, evidence-based psychosocial interventions suitable for early intervention in the National Disability Insurance Scheme (NDIS): promoting psychosocial functioning and recovery. The Centre for Mental Health, Melbourne School of Population and Global Health. 2016

<sup>10</sup> 'Early intervention and recovery for young people with early psychosis: consensus statement', The British Journal of Psychiatry, Bertolote J & McGorry P 2005,



## The intersection with mainstream services:

*Is there any evidence of cost-shifting, duplication of services or service gaps between the NDIS and mainstream services or scope creep in relation to services provided within the NDIS? If so, how should these be resolved?*

The lack of clarity regarding the extent to which State and Territory governments will engage with and fund carer services, during and following the transition to the NDIS to support consumers and carers who are either not eligible for or not engaged with the NDIS needs to be resolved. Without support services demand for acute and crisis services will inevitably rise, as will the demand on informal carers and families at great social and economic cost to governments, communities, families and consumers.

Mental Health Carers Australia is aware of state funded services in Queensland, Victoria and New South Wales which are either discontinuing or will have altered eligibility criteria due to the transition of funding to and the implementation of the NDIS. In the other states and territories it is still unclear what the outcome will be.

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

### Personal Helpers and Mentors (PHaMs) and Partners in Recovery (PIR)

MHCA is concerned about the potential impacts on community mental health should PHaMs and PIR funding be transitioned into the NDIS. These outreach based programs enable high levels of individual and community engagement. Some of MHCA member organisations have achieved significant success with this approach, particularly with Aboriginal people in regional and remote communities with suicide prevention and family support services. By first gaining trust and engagement in a community and then a family based level, individuals can be assessed and referred to appropriate formal services. Unfortunately, the NDIS approach requires that individuals be firstly identified and diagnosed as mentally ill and only then will they and their family carers be eligible for supports. The level of stigma around mental ill health and different cultural ideas about 'caring' are likely to deter both consumers and carers from identifying themselves to service providers. As a result, it is likely that both will miss out on supports.

The case worker model supported by PHAMS has proved particularly important to assisting parents with mental health issues who require support in parenting their children and re-establishing connections with family members who have become estranged but who are potentially able to provide support if they themselves were supported. Hence we have witnessed PHaMs case workers assisting parents to enrol their children in school holiday programs and young carer peer support programs funded through Mental Health Respite: Carer Supports. PHaMs case workers are able to assist with the referral of family members to carer supports with the goal of providing the psycho-education that assists family members to re-engage and offer support to the individual who is living with mental ill health. MHCA have not witnessed a similar level of case worker support in NDIS plans.

### Mental Health Respite: Carer Support

MHCA is very concerned that should, as is proposed, funding for the *Mental Health Respite: Carer Support* continue to be transitioned to the National Disability Insurance Scheme families and carers of people experiencing severe mental ill health or psychosocial





disability, may no longer be able to access the services they need to maintain their caring role. This may occur where:

- The person with a mental illness is not eligible for the NDIS
- The person with a mental illness chooses not to engage with the NDIS. Many people with mental health issues do not seek services so it is likely, in the absence of assertive outreach, that many people with severe mental ill health will not engage with NDIS
- The person is eligible but the caring role is not fully acknowledged
- The support required by the carer is not accommodated by the activities funded through the NDIS.

The shift of funding of carer supports to NDIS will mean the eligibility of carers to receive supports will no longer be linked to an assessment of the carer and their needs. Instead it will be entirely dependent on the NDIS eligibility of the person with mental ill health. The supports then available to carers will largely be based on enabling the carer to “have a break” by engaging the person with mental illness in an activity which frees the carer to do something else<sup>11</sup>. Whilst this is a relevant way to enable respite it does not cater for the broad range of carer support needs. Consistent with the Statement for Australia’s Carers<sup>12</sup>, carers have a right to participate in activities outside of caring. There is no guarantee of a coincidence in timing of activities available for the person with psychosocial disability with the needs of a carer to participate in employment, education or other activities, or to attend, for example, to their own medical appointments. What this means in practice, for example, is that a young person caring for their parent a mental illness may no longer be eligible to participate in a school holiday program that introduces them to other young carers who offer peer support, as well as providing them with communication, coping skills, and resilience tools.

The majority of carers of NDIS participants consulted as part of the Carers Australia’s NDIS Carer Capacity Building Project reported that NDIA staff had not made them aware of the option to have a separate conversation with the planner or of the ability to submit a Carer Statement. Carers should be acknowledged as individuals with needs beyond the caring role. Carer support services should extend to facilitate a carer’s need or desire to discontinue their caring role due, for example, to concerns about the carer’s own.

MHCA strongly recommend referring to the National Carer Strategy and the Carer Recognition Act (in particular the Statement for Australia’s Carers<sup>1</sup>), to drive actions to improve carer identification and recognition, health, wellbeing and safety.

<sup>11</sup> Anglicare, Carers doing it tough, doing it well, 2016

<sup>12</sup> Carer Recognition Act 2010



### A family's experience of PHaMs, NDIS and Mental Health Respite: Carer Support

Joanne, a 32 year old mother of three children, is an NDIS participant who has transferred from PHaMs, retaining her PHaMs service provider for one cluster of NDIS supports. Over many years, Joanne has been suicidal and has found parenting overwhelming at particular low points. Her eldest daughter, aged 14, was identified by the PHaMs case worker as being in a caring role for Joanne. With Joanne's permission, her daughter was referred to a carer service provider and received young carer counselling and participated in a young carer peer support program funded through Mental Health Carer Respite. Joanne, with the assistance of the PHaMs case worker, enrolled the children in a school holiday program funded through Mental Health Carer Respite. However, Joanne's eldest daughter became disengaged from school, and, due to a number of concerns, was formally placed in the care of Joanne's Mother. This distressed Joanne and created a level of conflict between Joanne and her Mother. Joanne's Mother was recognised as a carer by the PHAMS case worker and was also referred to carer counselling. Currently, under Joanne's NDIS plan, there are no items relating to the support of the children in their caring role, nor for Joanne's Mother. Joanne no longer has access to a case worker and has not received funding for coordination under her NDIS plan. The previous PHaMs provider continues to advocate on Joanne's behalf, arguing that Joanne and the family require additional support, particularly around coordination of access to various supports for the children and in-home parenting support for Joanne. However, it is uncertain what supports will be available for young carers in the absence of Mental Health Respite: Carer Support funding. It is also unclear whether, in the absence of a case worker (previously funded through PHaMs) whether Joanne will be well enough to source supports for herself and her children or to re-establish a more positive relationship with her Mother and her daughter, both of whom are important to Joanne's long term wellbeing.

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

We recognise that NDIS potentially offers eligible people with psychosocial disability and their carers/family great benefits. An assessment of some of our member organisations clients over the past three years indicates that only about 14 per cent of the services provided were to people caring for a family member with a diagnosis that would make them eligible for the NDIS. In a survey conducted by Carers NSW in 2012 they found that 60 per cent of mental health carers reported needing support in comparison with about 30 per cent of other carers who responded. Mental health carers also rated their health and mental health significantly lower than other respondents in different caring roles. When put together these figures suggest that channelling significant state government funding into the NDIS will leave many families caring for someone with a severe mental illness without access to any supports.

The lack of clarity regarding the extent to which State mental health services will engage with and fund carer services, during and following the transition to the NDIS, risks a nationally inconsistent outcome for carers of people living with mental health issues.



## Supports required by the carer

The shift of funding of carer supports to NDIS will mean the eligibility of carers to receive supports will no longer be linked to an assessment of the carer and their needs. Instead it will be entirely dependent on the NDIS eligibility of the person with mental ill health. The supports then available to carers will largely be based on enabling the carer to “have a break” by engaging the person with mental illness in an activity which frees the carer to do something else<sup>13</sup>. Whilst this is a relevant way to enable respite it does not cater for the broad range of carer support needs. Consistent with the Statement for Australia’s Carers<sup>14</sup>, carers have a right to participate in activities outside of caring. There is no guarantee of a coincidence in timing of activities available for the person with psychosocial disability with the needs of a carer to participate in employment, education or other activities, or to attend, for example, to their own medical appointments.

What this means in practice, for example, is that a young person caring for their parent a mental illness may no longer be eligible to participate in a school holiday program that introduces them to other young carers who offer peer support, as well as providing them with communication, coping skills, and resilience tools.

MHCA strongly recommend referring to the National Carer Strategy and the Carer Recognition Act (in particular the Statement for Australia’s Carers<sup>15</sup>), to drive actions to improve carer identification and recognition. Carers should be acknowledged as individuals with needs beyond the caring role. Carer support services should extend to facilitate a carer’s need or desire to discontinue their caring role due, for example, due to concerns about the carer’s own health, wellbeing and safety.

Further to that it is recommended that carers be assessed based on their own needs as well as the needs of the person they care for.

MHCA opposes the NDIA’s move away from face-to-face assessment and planning as it will have a significant impact on all people applying for the NDIS as it creates significant difficulties for communication and diminishes the capacity to build a trusting relationship between the person and the planner. Further for mental health, which is typically episodic, having non-face-to-face assessment and planning creates difficulties in

Recommendation: NDIA collaborate with DSS, State and Territory governments to

- a) assess the likely impact of the transition of respite and other funding to the NDIS
- b) assess the likely impact of the design and implementation of proposed integrated carer support system.
- c) jointly implement a system to ensure people who care for someone with a psychosocial disability or mental illness are able to access the services they need to maintain their own health and ensure their on-going wellbeing to allow continuation of their caring role.

adequately assessing need and the person’s circumstances.

<sup>13</sup> Anglicare, Carers doing it tough, doing it well, 2016

<sup>14</sup> Carer Recognition Act 2010

<sup>15</sup> Carer Recognition Act 2010



## Planning process

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

Of particular concern for MHCA is the lack of engagement by planners with mental health carers in the planning process. Despite a strong policy framework<sup>16</sup> the common experience of mental health cares is that they are not included in the planning process. The consequence of this can be reduced carer wellbeing, care-consumer relationship damage and ultimately poorer outcomes for the consumer.

When service providers work in partnership with consumers and carers there will be improved outcomes for consumers, reduction in family and carer anxiety, improved ability and desire of family and other carers to continue in their caring role and improved satisfaction for staff<sup>17</sup>.

Current plans to 'roll in' programs including, *Mental Health Respite: Carer Support, Personal Helpers and Mentors and, Partners in Recovery*, which wholly or partly serve target groups ineligible for the NDIS are immediately put on extended hold, while the full implications for individuals and families both eligible and ineligible for the NDIS are assessed.

### *How should the performance of planners be monitored and evaluated*

The performance criteria for the NDIS needs to go beyond the number of people in the scheme and cost/usage targets. Participant and carer experience of their encounter with the NDIS should also be monitored and evaluated, including their experience of their engagement with planners. Indicators need to be established to evaluate performance against meeting reasonable and necessary supports and participant's choice and control.

Recommendation: The NDIS develop an evaluation model, including performance targets, to monitor and measure participant and carer satisfaction with their experience of the NDIS including the planning process and the resulting package and the impact on their quality of life.

### **Assessment:**

*Do NDIA assessment tools meet these criteria? What measures or evidence are available for evaluating the performance of assessment tools used by the NDIA?*

Currently there is no standardised tool to assess functional impairment resulting from a mental illness or psychosocial disability. Coupled with this, our members experience is that local area coordinators and NDIS planners do not have sufficient understanding of mental illness or psychosocial disability to adequately undertake the assessment and planning process. This is resulting in people being required by planners to return again and again, at their own expense, to private psychiatrists, occupational therapists (of which there are few with expertise in mental illness) and other practitioners to seek

<sup>16</sup> Carer Recognition Act 2010  
National Mental Health Standards 2010  
National Safety and Quality Health Service Standards 2011

<sup>17</sup> A Practical Guide to Working with Carers of People with a mental Illness, 2016



additional information to support their application. This cost is an impost on people with a mental illness not applied to other disability cohorts and will prevent those who do not have the means to pay for private assessment sessions will be disadvantaged.

Recommendation: That the NDIA investigate best practice psychosocial disability assessment tools and implement a standardised approach to assessment.

### Market Readiness:

The NDIS is not a true market as prices are set by the NDIA. Large providers with residential or transitional accommodation services have a competitive advantage over smaller agencies and those without. At discharge, after an involuntary admission, hospitals will refer directly to residential services. Given the stress associated with involuntary admission and the upheaval following discharge, it is unlikely that people will be in a position to exercise their choice and control in assessing which provider is best for them and instead will stay with the original referral.

Mental Health Carers Australia is concerned those less profitable services will not be delivered and that the need for economies of scale, particularly in large organisations, will encourage providers to pursue cost cutting approaches such as a group based rather than individually tailored programs.

The environment for smaller providers, with the withdrawal of block funding before the full roll out of the scheme means they must operate with significant financial uncertainty. They are unable to commit to long term employment or other contracts. Many smaller providers are at risk of folding which will reduce competition and participant choice.

### Remote and indigenous communities:

The sustainability of delivery of services to remote communities, particularly remote indigenous communities in Western Australia and Northern Territory is a serious concern. Member organisations have investigated business models for delivery to these communities and believe it is likely to be unsustainable. In Western Australia there has been talk of alternative funding to support organisations delivering services into remote areas to allow effective business operation, however, there is no substantiation of this yet. Without a sustainable business model services are unlikely to be delivered.

Also of concern is the model of delivery in remote and indigenous communities. MHCA member experience is that in remote communities it is hard enough to get people to engage in free services where they only need to turn up to receive support (Mental Health Carer Respite, Personal Helpers and Mentors and Partners in Recovery). The actual process for NDIS application may prove too overwhelming and involved for the majority to even engage with.

Recommendation: That the NDIA investigate funding and business models and implement an alternative model that will ensure service delivery to remote communities, particularly remote indigenous communities, meet the needs of people in those communities with mental illness and psychosocial disabilities, their carers and



### Workforce:

Mental Health Carers Australia members and other providers have indicated that the prices are not sufficient to enable providers to attract and retain staff suitably qualified to support people with severe mental illness.

The financial uncertainty related to the transition between block funding to individualised packages and the uncertainty associated with state and territory mental health funding is forcing many providers to casualise their workforce which is resulting in skilled and qualified staff leaving the sector.

#### Recommendation: NDIS assessors and planners

- receiving training in family-centric assessment approaches
- understand the unique issues faces by mental health carers
- have experience working with psychosocial disability and mental ill health
- understand their obligations under the Carers Recognition Act 2004 and the Carer Recognition Act 2010.

MHCA recommends *A Practical Guide for Working with Carers of people with a Mental Illness*, 2016 to facilitate this and has the expertise and capacity to assist with this if this is considered helpful.

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

According to the 2010 Australian survey of psychosis, most people with psychotic disorders had frequent face-to-face contact with family members in the previous year: 56.5% almost daily and another 17.1% at least once a week<sup>18</sup>

Informal mental health carers in Australia are contributing \$13.2bn annually<sup>19</sup> by caring for people with mental illness. This represents 1.7 times the entire Australian mental health budget. Without supports informal carers are much more likely to burn out and be unable to continue in their caring role. If just a small portion of this work needed to be replaced by formal care it would represent an enormous increase in demand for NDIS and other publicly funded supports.

In a survey conducted by Carers NSW in 2012 they found that 60 per cent of mental health carers reported needing support in comparison with about 30 per cent of other carers who responded. Mental health carers also rated their health and mental health significantly lower than other respondents in different caring roles. When put together these figures suggest that channelling significant government funding into the NDIS will leave many families caring for someone with a severe mental illness without access to any supports.

<sup>18</sup> People living with psychotic illness in 2010. An overview of findings from the second Australian national survey of psychosis Morgan V, Waterreus A, Jablensky A, et al. (2012)

<sup>19</sup> The economic value of informal mental health Caring in Australia, University of Queensland 2016



While people who support or care for a person with a mental illness share common issues and experiences with other carers they also experience a range of factors unique to caring for someone with a mental illness. Some of these factors are outlined in appendix 1.

### Integrated Carer Support System:

The Commonwealth government through the Department of Social Services (DSS) is currently developing a model to deliver integrated support services to carers across the nation which will, in theory, cater for the needs of carers not met through the NDIS. MHCA supports this initiative to improve access to carer services, however, has significant concerns including:

- 1) Proposed regional service areas potentially being too large geographically, particularly in rural and remote areas where public transport can be poor.
- 2) The proposition that DSS will "link to but not fund"<sup>20</sup> many elements of the local service delivery system
- 3) Lack of clarity about whether funds will be distributed on assessed need or on a geographic or population formula meaning that one region area may experience a shortfall while another has underspend.
- 4) One regional hub service listed<sup>21</sup> is to assist carers to "*access planned respite and support services through collaboration with the NDIA*". As far as MHCA is aware, carer respite is not a service available through the NDIS.
- 5) Whilst there is some information on level of qualification required for different types of workers in the regional hubs, there is nothing on the broader workforce development required to competently support people caring for someone with a mental illness.

### Conclusion:

MHCA recognises that the National Disability Insurance Scheme (NDIS) has the potential to offer eligible people with psychosocial disability, their carers and families the supports they require. Also recognised is the enormous task involved in implementing such comprehensive reform and acknowledges the efforts of the people involved in the implementation process. MHCA's goal in making this submission and the recommendations is to assist the Government to honour the commitment to the principle of no disadvantage by highlighting where unintentional disadvantage might occur without intervention.

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<sup>20</sup> Delivering an integrated carer support service, Department of Social Services, 2016

<sup>21</sup> Delivering an integrated carer support service, Department of Social Services, 2016





## Appendix 1: Mental Health Carers:

While people who support or care for a person with a mental illness share common issues and experiences with other carers they also experience a range of factors unique to caring for someone with a mental illness, including:

- The stigma, guilt and isolation experienced are greater than for most other carers and create significant barriers to people asking for or receiving help from both formal and informal sources. Cultural factors may intensify these experiences. Carers are often deeply affected by adverse responses by neighbours, friends, school communities and extended family members<sup>22</sup>. The stigma experienced by carers and consumers in the mental health sector is also exhibited by mental health and other health professionals<sup>23</sup>.
- It is not uncommon for a person with a mental illness to have limited comprehension that they are ill and to resent attempts by family members to encourage them to seek treatment or support. It is also not uncommon for symptomology of mental illness to manifest as paranoia at acute stages with the person turning against the people who have been supporting them most.
- Families have always occupied an ambiguous space in mental health research and practice. They are seen either as burdened carers, as causing the mental illness in a family member, as acting to sustain the mental illness, or as contributing to relapse<sup>24</sup>. However, utilising a person's natural support network has also been shown to promote recovery and reduce acute episodes requiring hospitalisation<sup>25</sup>.
- The experience and nature of a mental illness is obscure and difficult to understand. The state of mind of a person with a mental illness is hidden. Carers and family members see behaviour and personality changes and emotional swings but cannot necessarily comprehend the internal experience which drives these changes. Unlike other carers who can more readily interpret and understand the experience of their family member, carers and families of people with mental illness experience great stress and confusion because they cannot see what is happening, don't know what to do or how to help. When difficult behaviour occurs, family functioning may be significantly disrupted and become crisis-oriented, sometimes resulting in conflict and breakdown. In some circumstances the behaviour can be frightening and bewildering for the carer and can impact on the carer's physical, emotional and financial wellbeing<sup>26</sup>.
- The unpredictable and episodic nature of some mental illness, often with sudden onset accompanied by abusive behaviour, variability of treatment compliance, and potential involvement with the police and judicial system all contribute to the stress experienced by mental health carers.
- The high prevalence of substance misuse among people with mental illness compounds the grief and difficulties families face.

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<sup>22</sup> The Network for carers of people with mental illness, Differences and similarities, 2001

<sup>23</sup> Mental Health Council of Australia. 2011. Consumer and Carer experiences of stigma from mental health and other health professionals. MHCA, Canberra

<sup>24</sup> Wydera and Bland, The recovery framework as a way of understanding families' responses to mental illness: Balancing different needs and recovery journeys, 2014

<sup>25</sup> Amir, N, Freshman, M, and Foa, E. B. (2000). 'Family distress and involvement in relatives of obsessive-compulsive disorder patients'. *Journal of Anxiety Disorder.*, 14, pp209-217

<sup>26</sup> The Network for carers of people with mental illness, Differences and similarities, 2001