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Mental Health Carers and the National Disability Insurance Scheme

ISSUES PAPER – JANUARY 2016

The report was commissioned and funded by the National Disability Insurance Scheme (NDIS) Sector Development Fund as part of a capacity building project being delivered by Mental Health Australia. The report was designed to assist in identifying the needs of the disability sector, including consumers and providers, to transition to the NDIS environment. Findings from the report form the basis of the capacity building work being undertaken by the project.

The views and recommendations expressed in the report are welcomed by the Commonwealth and have been taken into consideration as the part of policy and operational design of the transition to the full NDIS. No formal response will be provided to the report.

Carers Australia is the national peak body representing the diversity of Australians who provide unpaid care and support to family members and friends with a:

- disability
- chronic condition
- mental illness or disorder
- drug or alcohol problem
- terminal illness
- or who are frail aged.

Carers Australia believes all carers, regardless of their cultural and linguistic differences, ages, disability, religion, socioeconomic status, gender identification and geographical location should have the same rights, choices and opportunities as other Australians. They should be able to enjoy optimum health, social and economic wellbeing and participate in family, social and community life, employment and education.

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Mental Health Australia is the peak, national non-government organisation representing and promoting the interests of the Australian mental health sector and committed to achieving better mental health for all Australians.

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Executive Summary

In 2013, the Australian Government introduced the National Disability Insurance Scheme (NDIS). The NDIS provides a range of supports, including individualised funding to people with disability to enable them to purchase reasonable and necessary supports.

Similar to international experiences with individual budget pilots, inconsistencies in the degree to which carers are involved in the assessment and planning of supports are emerging in Australia.[1]

This paper provides advice to the Department of Social Services (DSS) on issues arising for mental health carers in the context of the NDIS and offers recommendations to build the capacity of carers to participate in the NDIS.

This paper explores the current impact of the NDIS on carers in trial sites and the impact it may have on the sustainability of the caring role. It takes a detailed look at the role of mental health carers and young mental health carers, including the important role they play in supporting positive outcomes for people with a psychosocial disability.

Key issues are considered, including appropriate involvement of carers in the planning process; effective communication on key aspects of the NDIS, and provision for carers in participant's individually funded packages.

The paper also discusses additional issues faced by mental health carers, including stigma and lack of understanding about mental illness; issues arising due to the episodic nature of psychosocial disability and the importance of recovery focussed pre-planning support for some people with psychosocial disability.

Practical recommendations and strategies are provided, with a focus on:

- the provision of accurate, timely and definitive information to mental health carers about their involvement and rights in relation the NDIS
- building the knowledge of National Disability Insurance Agency (NDIA) staff to understand psychosocial disability[2]
- ensuring a range of supports continue to exist for mental health carers who are unable to access this through a participant's individually funded package.

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[1] Mitchell, Brooks & Glendinning, 2014

[2] Please note that there are differences between the terms used in NDIS materials and legislation and this Issues Paper. Where NDIS materials refer to impairments attributable to a psychiatric condition and reduced psychosocial functioning; Mental Health Australia and Carers Australia prefer to use the term 'psychosocial disability', which describes the experience of people with participation restrictions and impairments related to mental health conditions.

These recommendations are firmly grounded in advice provided by mental health carers to Carers Australia through the Project Advisory Group.

Supported through the Sector Development Fund, Mental Health Australia and Carers Australia continue to assist mental health carers to engage with the NDIS. We also stand ready to assist Government to implement this paper's recommendations.

Introduction

The Australian Government introduced the NDIS in 2013 to provide individualised funding to people with disability to enable them to purchase reasonable and necessary supports. The NDIS also has an Information, Linkages and Capacity Building (ILC) component, which offers broader community support. At the time of writing the NDIS was available in several trial sites across Australia.

International experiences from individual budget pilots similar to the NDIS have shown there are often inconsistencies in the degree to which carers are involved in the assessment and planning of supports.[3] As similar inconsistencies in the involvement and support of carers are beginning to arise in the Australian NDIS trial sites, it is timely to explore the role of mental health carers, the importance of their involvement in the NDIS, and how the impact of the current arrangements may affect the sustainability of the mental health caring role.

This paper was developed by Carers Australia and Mental Health Australia in consultation with a Project Advisory Group, which included mental health carers, members from the National Respite Association, Mental Health Carers ARAFMI Australia/Mind Australia, Mental Illness Fellowship Australia, Carers NSW, Carers WA and Tandem. While only one carer had direct experience in the NDIS others had ongoing links with carers with direct experience.

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[3] Mitchell, Brooks & Glendinning, 2014

1. Mental health carers and the NDIS

Mental health carers have told Mental Health Australia and Carers Australia that they understand and support the policy intent of the NDIS – to provide the person with a disability "more choice and control over how, when and where [their] supports are provided" and to give them "certainty over the support [they] will receive over [their] lifetime."[4]

In supporting this core aim of the NDIS, the NDIA has also acknowledged "the role of families and carers is often essential in supporting people with disability to realise these goals" and consideration should be given to including them in discussions about supports.[5] This is consistent with the aim of the NDIS to assist where there is, what the Productivity Commission referred to as, an "unreasonable reliance on family carers" to support people with a disability.[6]

The NDIS has been introduced in several trial sites across Australia with the intention of implementing changes to address lessons learned through the trials before it is rolled out nationally from 2016. Experiences of mental health carers in these trial sites offers a good indication of the implications for carers once NDIS implementation is complete.

1.1 Experiences of carers in the trial sites

Drawing on their experience in trial sites, mental health carers report many of the same issues that carers for people with other disabilities report. For example, similar to other carers, mental health carers have reported they have difficulty obtaining definitive information about:

- avenues for carer involvement in the planning process, for example the carer statement
- supports for carers, which can be included in participant plans, for example respite
- whether the programs they rely on to ensure the sustainability of their caring role will continue to exist post completion of NDIS implementation.

Despite a range of NDIS Rules and Guidelines about carer involvement in the assessment and planning process,[7] the experience of carers in the trial sites has varied significantly. These issues are outlined in more detail below.

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[4] National Disability Insurance Agency, 2014b, para. 3

[5] National Disability Insurance Agency, n.d., para 1

[6] Australian Government Productivity Commission, 2011, p. 331

[7] Carers Australia, 2015

Planning

The majority of carers of NDIS participants consulted as part of Carers Australia's NDIS Carers Capacity Building Project reported 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. This is supported by findings from an online survey conducted by Carers Australia, which found 78 per cent of carers of NDIS participants who responded to the survey (93 in total) were not aware they could provide a Carer Statement (25 per cent of respondents cared for someone with a mental illness or condition). The survey also showed 56 per cent of respondents were unaware they could ask for a separate conversation with the NDIA.

Consultation undertaken by Carers NSW in the Hunter trial site also found carers' experiences with the planning process have varied greatly depending on the planner they encounter; with some carers reporting they felt their needs had been thoroughly considered and met, while others felt excluded from the conversation.[8] There is also anecdotal evidence carers are having similar experiences in Victoria's Barwon trial site. Just over 30 per cent of respondents to the Carers Australia online survey reported they felt their caring role wasn't taken into consideration by the planner, a further 9 per cent reported they were unsure, while 36 per cent reported it was 'somewhat' taken into consideration.

In 2014 the National Respite Association reported evidence from the trial sites which suggested the (then) current Guideline lacked the clarity for a planner to understand when it is appropriate to build capacity and when it is appropriate for a carer or family to continue providing informal care.[9] The Guideline has since been updated. Unfortunately there is currently no data available to assess whether this issue has now been resolved.

Adding another layer of complexity to the planning process is the confusion around the potential for carers to submit a Carer Statement.

During his presentation at the Carers Australia National Carer Conference in November 2014, the Chair of the NDIA Board, Mr Bruce Bonyhady, stated carers have the option to provide a Carer Statement "which captures the impact and sustainability of the informal care that they provide" and which "needs to be taken into consideration in designing supports in the participant's package."[10]

A search of the NDIS website at that time did not uncover any more information about the Carer Statement, other than a brief mention in the NDIS Planning Workbook for participants.[11]

Carers Australia and Mental Health Australia have received differing advice about the Carer Statement. While these teething problems may be expected during the trials, it would benefit carers if the NDIA and DSS developed a strategy for communicating with carers and assuaging their concerns while these messages are being clarified.

In addition to NDIA-run pre-planning workshops currently underway, many organisations are providing preliminary resource materials to help carers better prepare for planning meetings. For example, through Sector Development Fund support, Mental Health Australia and Carers Australia have released a Mental Health Carers Guide and Checklist to support carers through the planning process. Carers NSW has also produced a range of fact sheets, which include

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[8] Carers NSW, 2014, p.17

[9] National Respite Association, 2014, pp. 4-6

[10] Bonyhady, 2014

[11] National Disability Insurance Agency, 2014a, p. 10

information on how to prepare for the NDIS, how carers can be involved, tips from other carers and a checklist to be used in the planning meeting.[12]

Support for carers under the NDIS

Carers' access to NDIS supports has also been mixed. While some carers report they now have access to more respite through the NDIS than previously, others state they have less, and the approach to respite by the NDIA has not prioritised the carer's own need for a break,[13] instead viewing carers' needs solely from the perspective of the participant.

Feedback from carers of NDIS participants about carer supports has been varied both across locations and over time and includes:

- Almost half of the carers of NDIS participants surveyed by Carers Australia reported there were 'respite-like supports' in the participant's plan while 16 per cent had emergency respite.[14]
- The majority of the 66 families interviewed by the Council for the Care of Children in South Australia were dissatisfied with the respite component (if any) of their child's plan in the first year. A number of families said they received some respite in their child's revised plans in the second year. One family said an NDIA planner had told them "other parents don't get respite why should you?"[15]
- 11 out of 16 carers of NDIS participants in a Western Australian survey reported the supports provided under the NDIS to give them a break from the caring role were the same as previously, and five reported they were better.[16]

It is also important to note that because it is early days for the NDIS, only a relatively small number of carers have experience of the assessment, planning, implementation and plan review stages. We therefore have a very limited perspective of the experiences of carers such as those from Aboriginal and Torres Strait Islander communities, and those from culturally and linguistically diverse backgrounds.

The mental health and disability sectors have received contradictory messages from government officials in relation to the provision of respite through NDIS plans. Carers, carer advocates and peak bodies have expressed frustration and confusion when trying to provide information to clarify where carers sit within the NDIS.

For example, when the NDIS was first set up there was a lack of clarity around how carers services would continue to be provided. There have since been a number of conflicting messages about the place of respite in the NDIS.

Carers, consumers and peak bodies continue to advise on the need for clear and consistent messaging on NDIS matters.[17] This includes information on carer supports available as a part of NDIS participant plans and through ILC and in particular respite services. More advice on the approach to information provision is provided at Section 4: Recommendations.

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[12] More information about the fact sheets is available at: www.carersnsw.org.au/NDIS

[13] Carers NSW, 2014, p. 23 and Parliamentary Joint Standing Committee on the National Disability Insurance Scheme, 2014b, pp. 11-19

[14] Out of a total of 93 respondents. Respondents were told that 'respite-like supports' included overnight assistance with self-care, short term accommodation, group-based facilities and in-home support.

[15] Council for the Care of Children, 2015, p. 41

[16] The Red Cross sent out surveys to 96 families in the WA Trial Site and to several agencies including Carers WA, Helping Minds (Arafmi) and Swan Community Services. There were 16 responses in total.

[17] Mental Health Australia, 2015

Carer support programs

Although the NDIS offers major opportunities for carers of people with psychosocial disability; as with any major reform, there are risks of unintended consequences. For mental health carers, unintended consequences include the impact of uncertainty around which (and how much of) programs for carers will be available only through NDIS individually funded support packages and whether the same level and type of carer support will be funded by the NDIS. Many mental health carers rely on the provision of adequate respite services to ensure the level of care they provide is sustainable. Accordingly, the uncertainty around which carer related services will be provided through individual packages and what will continue to be provided outside the NDIS creates anxiety for mental health carers.

At the time of writing NSW and Victoria had released bilateral agreements with the Commonwealth Government outlining arrangements for further roll out of the NDIS. However, these documents did not shed light on the abovementioned questions. Accordingly, Mental Health Australia and Carers Australia keenly await the release of more detailed NDIS planning, which is expected to include further detail. Dissemination of clear and precise information about program arrangements would help to ensure mental health carers are informed about the services they rely on to ensure the sustainability of their caring roles.

Further detail outlining information available in the public arena relating to carer programs is provided at Appendix 2.

1.2 Issues specific to mental health carers

In addition to facing the same challenges as other carers, mental health carers also experience a number of unique challenges including:

- lack of understanding of many people with a psychosocial disability about the range of supports they receive from their carer and others
- rapid changes in relation to support needs resulting from the episodic nature of mental illness and psychosocial disability and the impact this has on the caring role
- stigma and lack of understanding about mental illness; both impact the ability of NDIA planners to understand the needs of people with psychosocial disability and subsequently the impact on the caring role
- significant recovery-focussed support can be required in the pre-planning phase for people who have had no regular engagement with services or for people whose service engagement has been only treatment focussed.

Supports and information sharing

Many mental health consumers are not aware of the impact of their illness and the supports they receive or require to do the things they want. In some circumstances this may only occur when people become unwell; for some people, understanding the extent to which others support them is always limited. This is challenging when the role a carer plays is crucial to the day to day living and recovery journey of a consumer.

When someone becomes unwell they may not give permission for the carer to be involved in their treatment or in conversations about their support requirements. This can be distressing for mental health carers who are involved in the ongoing support of a person with a mental illness, and can have an extensive impact on the relationships between consumers, carers and clinicians. This includes making it extremely difficult for carers to continue to provide appropriate support, if they are unaware of treatment or support arrangements that involve mental health consumers.

The National Mental Health Consumer and Carer Forum's Position Statement on privacy, confidentiality, and information sharing states:

- "Privacy of consumers is a basic human right.
- Each consumer's right to privacy should be balanced with their nominated carers' need to give and receive information relevant to their caring role.
- Nominated carers play a vital support role in a consumer's recovery and should be included in information exchanges, where appropriate and with the consumer's consent.
- Nominated carers involvement should be regularly reviewed."[18]

It is therefore vital that NDIA staff who are involved in the support of people with psychosocial disability are aware of this tension and its impacts. To ensure mental health consumers continue to receive their regular informal support, NDIA staff need to give appropriate weight to the role carers play, and consumer consent around carer involvement may need to be re-visited regularly. Staff need the skills to identify when information sharing and the type of information shared with carers is relevant to supporting the interests of the consumer. This will include balancing the consumer's right to privacy with the carers' need to give and receive information, which is relevant to their caring role. In these cases the importance of separate conversations is also highlighted.

The episodic nature of mental illness

Mental health carers have also highlighted two specific issues related to the episodic nature of some mental health conditions.

Firstly, the episodic nature of mental illness can result in unpredictable, varying needs for supports, which can be difficult to describe or accurately foreshadow in an NDIS plan. However, preparation of documents such as an emergency care plan or advance directive may aid the carer to explain the varying support needs to the NDIS planner.[19]

Secondly, the language of permanence in the NDIS Act appears to be opposed to recovery-focussed practice[20] and does not acknowledge the episodic nature of psychosocial disability. This has caused some confusion and concern amongst mental health carers due to the unintended negative consequences it causes for the person they care for. However, it should be noted that Mental Health Australia and Carers Australia understand even though some mental health conditions are episodic they can still be considered 'permanent (or likely to be permanent)' by the NDIA.[21]

Stigma and lack of understanding about mental illness

Mental health carers also face challenges in relation to the stigma around mental illness, even from health professionals.[22] Stigma comes from lack of understanding about mental illness. Mental Health Australia understands issues around communication materials and training of

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[18] National Mental Health Consumer and Carer Forum, 2011a, p. 3

[19] Mental Health Australia and Carers Australia, 2015

[20] MI Fellowship, 2015

[21] Ibid.

[22] Mental Health Council of Australia, 2011

NDIA staff in issues specific to psychosocial disability have been raised in the context of the NDIS Operational Access Review. Mental Health Australia and Carers Australia support action to address this issue and urge the NDIA to ensure mental health carers are also involved in this process.

Recovery-focussed pre-planning support

Another barrier to accessing the NDIS, which is particularly relevant to people with psychosocial disability and their carers, is the need for recovery-focussed intensive pre-planning support for people to engage proactively with the NDIS and the mental health services market. A report by Psychiatric Disability Services of Victoria highlighted that mental health consumers find it difficult to express their needs and goals and not knowing the planner causes stress and a reluctance to divulge personal issues.[23] The significant requirement for recovery-focussed pre-planning support was also identified through the Mental Health Australia NDIS Consumer and Carer Advisory Group Workshop undertaken in January 2015.[24]

The NDIA is already carrying out some pre-planning support, though it is not yet clear how well this meets the need for recovery-focussed pre-planning support, which is usually undertaken by skilled mental health workers in collaboration with both consumers and carers over a long period.

1.3 Improving the experiences of carers

Government has designed an NDIS capable of supporting the choice and control of people with a disability. It needs to bring mental health carers and their important role on this journey. To do this, NDIS communication around carer roles needs to be clarified to acknowledge and respect the role carers have to play. This is essential to achieve meaningful consideration of the sustainability of carer support.

This change to NDIS communications needs to be understood by service staff so they can demonstrate regard for the role of carers in supporting people with psychosocial disability. Tangible suggestions on next steps to achieve this change are provided under Section 4: Recommendations.

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[23] Psychiatric Disability Services of Victoria, 2015

[24] Mental Health Australia, 2015

2. Young mental health carers and the NDIS

A young mental health carer is someone under the age of 25 years who cares for a family member or friend with a mental illness.

Young mental health carers are a significant proportion of the young carer population. There has been little research into the role of young carers for people with a psychosocial disability, but given the significant number of young carers caring for someone with a mental illness, the research on the latter is relevant to consider here.

Research into young carers who are in receipt of income support has shown around 30 per cent provide care for someone with mental or behavioural conditions.[25] The latest figures from the Young Carers Respite and Information Services Activity delivered by the network of Carers Associations shows similar findings, with 29.8 per cent of young carers accessing the program caring for someone with a mental illness.[26]

The impact on a young person of caring for someone with a mental illness can be significant. For example, a young carer may or may not be recognised by the person with a mental illness as a carer either due to their age or a lack of awareness by the person with a mental illness of the responsibilities placed on the young carer.

Forty two per cent of surveyed young mental health carers report their physical or mental health had become worse as a direct result of their caring role, and 77 per cent said their caring role had affected their studies to some extent.[27] Research undertaken by the Wesley Mission in 2012 into carers of people with mental health issues also found young people who are exposed to the caring role under 16 years of age are at greatest risk of negative consequences.[28] Of particular significance for this group is the impact of the caring role on their own mental health, with 67 per cent of those exposed to the caring role under 16 years reporting this had been affected, compared to 49 per cent of all other mental health carers.[29]

In addition to these facts above, many of the issues faced by young mental health carers are similar to those faced by all young carers. They include:

- stigma, social isolation and bullying

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[25] Bray, 2012, p. 67

[26] Data from 1 July 2014-June 2015, Carers Australia Twelve Month Progress Report 2014-15, Young Carers Respite and Information Services Activity

[27] Mental Health Council of Australia, 2012, p. 30

[28] Wesley Mission, 2012, p. 6

[29] Wesley Mission, 2012, p. 50

- difficulty concentrating when at school due to worrying about the person they care for
- increased absences from school due to caring responsibilities
- reduced participation in extra-curricular activities.

2.1 How will the NDIS affect young mental health carers?

One of the carer programs identified to transition in part into the NDIS is the Young Carers Respite and Information Services Activity. This program assists young carers who need support to complete their secondary education (or the vocational equivalent) due to the demands of their caring role. In 2013-14, the Young Carer program assisted 4,520 young carers with respite services across Australia.[30]

The activity has two components:

- Information, referral and advice services (delivered by Carers Australia and the Network of Carers Associations), which provides access to information, advice and referral services, including referral to counselling for students with a significant caring role up to and including 25 years of age.
- Respite and Education support services (delivered by the national network of 54 Commonwealth Respite and Carelink Centres), which assists students 18 years of age and under with a significant caring role to access respite and age appropriate educational support.

According to the DSS website, the direct respite component of the Young Carers program is being transferred into the NDIS as it rolls out. Direct respite services for young carers in NDIS trial sites must be accessed by their care recipients through the NDIS.[31]

With previous evaluations of the program showing some 34 per cent of young carers who access this support care for someone with a mental illness (with 61 per cent caring for a parent)[32] this change in program funding may have a particularly negative impact on young mental health carers.

According to the NDIA, providers of respite for young carers are to elect either to 'cash out' their Young Carers funding for NDIS participants or to provide these services 'in-kind'. For those who elect to 'cash out' their funding, DSS would reduce their funding 'by the amount required to service participants of the NDIS', and they would then directly invoice the Agency for supports provided to participants in the NDIS.

For providers who elect to provide 'in-kind' support, they are required to quarantine a portion of their Young Carers funding for the exclusive use of providing Young Carer services to NDIS participants in trial sites.[33] (NB: The longer-term funding arrangements for this program are yet to be determined).

The transfer of the respite component of the Young Carers Respite and Information Services Activity into the NDIS is of particular concern in the context that:

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[30] Australian Government Department of Social Services, 2014a, p. 75

[31] More information is available at: https://www.dss.gov.au/disability-and-carers/programmes-services/young-carers-respite-and-information-services

[32] ARTD Consultants, 2008, p. 34

[33] More information is available at: http://www.ndis.gov.au/sites/default/files/documents/young_carers_respite.pdf

- This program is specifically designed to meet the needs of young carers, the NDIS is not.
- The transfer of this program funding into the NDIS assumes young carers will actually attend planning sessions, and their caring role will be identified by the NDIA planner or the NDIS participant if the carer is not in attendance.
- The Operational Guidelines for this program state "[d]ecisions regarding what support should be funded should be based on a formal needs assessment of each student."[34] However, there is no formal carer needs assessment in the NDIS. Therefore, the capacity of the planner to identify the support needs of the young carer will be limited.
- Young mental health carers are likely to be reluctant to talk about the impact of their caring role on their own health and wellbeing in front of the person they care for.
- Young mental health carers are unlikely to ask for supports for themselves, particularly if they believe these supports will come out of the package of the person they care for.
- There are particular sensitivities around the role of young people in supporting a parent with a mental illness. Parents may be reluctant to admit the extent to which they are supported by their child/children. This could have implications on both young carer identification and the provision of adequate young carer support.[35]
- The direct respite component of the Young Carers Activity (which is being transferred into the NDIS) is designed to provide flexible hours of respite care to free the student to spend time on their education. This support places the young carer at the centre and is designed to meet their needs. However this is inconsistent with the role of respite under the NDIS, which is designed to focus on the consumer not the carer. It is unclear how this funding would continue to focus on the needs of vulnerable young carers in the context of the NDIS where carers are not participants in their own right (for example, see case study below).

CASE STUDY

Young carer is 15 years old and cares for her mother who has mental health issues as well as physical problems. The mother became physically unwell and needed considerable care for several weeks. The young carer was under significant strain during this time because her mother also suffers from Obsessive Compulsive Disorder, manifesting itself in a cleaning obsession. The mother was incapacitated and so could not attend to cleaning, and the young carer failed to complete the cleaning chores to the mother's satisfaction. This resulted in increasing friction between the young carer and her mother who became increasingly agitated, adversely affecting her mental health. The young carer needed respite from this situation and wanted assistance with homecare tasks. The NDIA declined assistance because it was not to do with her mother's 'disability' (her mental illness).

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[34] Australian Government Department of Social Services, 2015, p.7

[35] A 2008 review of the Young Carer Respite & Information Services Activity found that how young carers and their families view the young person's caring role is a barrier to their participation in the programme. Some Commonwealth Respite and Carelink Centres reported that some parents lacked understanding of how the Programme could benefit their child and conversely, do not recognise that their children may be disadvantaged through their caring role.

With the future funding arrangements for this program still being determined, there are also concerns other components of the activity will be transitioned into the NDIS, such as the educational support component. There are also a number of other important issues requiring urgent clarification:

- Whether NDIA planners and assessors are instructed to identify any young carers that may be involved in the support of an NDIS participant.
- To what extent young carers will be encouraged, feel comfortable or be able to be involved in the NDIS assessment and planning of a family member with a mental illness who is an NDIS participant; particularly considering the main target group for the program is 12- 17 year olds, with some 12 per cent of young carers using the service actually under 12 years of age?[36]
- Whether any young carers of NDIS participants with a psychosocial disability have been, or will be able to access direct respite through the package of supports of the person they care for (considering many are caring for a parent) and particularly if the participant doesn't encourage or want this.
- If a young carer of a NDIS participant has direct respite included in the support plan of the person they care for, whether this will have any effect on their ability to access the 'indirect respite' educational support component of the Young Carers Activity outside of the NDIS.
- What impact, if any, the transfer of this program funding will have on the availability of respite for young carers of someone who is not eligible for the NDIS.

2.2 Why is it important for the NDIA to identify and refer young mental health carers?

> "The psychiatrist and GP talked to my mum even though she worked during the night and I cared for my dad every day from after school until the next morning. Their main concern is the patient, not the kid who cannot sleep through the night because their parent is threatening suicide. I was only offered help at 16 and by then it was too late, I had already had to leave school. Kids need to be included in discussions; they need to be told what is going on."
> *Young carer*[37]

The Australian Infant, Child, Adolescent and Family Mental Health Association has previously developed a set of *Principles and Actions for Services and People working with Children of Parents with a Mental Illness* for the Australian Government Department of Health and Ageing.

These Principles state 'every child has the right to participate and be heard in discussions and decisions that will affect them (when they are capable of forming their own views)'.[38] The report states services can play a key role in supporting the access of children whose parents have a mental illness to information, education and decision-making processes. This can be done by ensuring policy, practice and procedures support the involvement (where

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[36] ARTD Consultants, 2008, p. 13

[37] Mental Health Council of Australia, 2012, p. 30

[38] Australian Infant, Child, Adolescent and Family Mental Health Association, 2004, p. 9

appropriate and with parental consent) of young people in decision-making processes regarding care and support of family members.[39]

> "My life was difficult as a child, I started caring aged seven. My dad is suicidal and was not compliant with medication. Professionals do not take you seriously when you are a kid in this situation. They do not tell you what is happening and they do not offer support. They will only talk to other adults". *Young carer*[40]

The position of the Royal Australian and New Zealand College of Psychiatrists (RANZCP) on children of parents with a mental illness is that all assessment of adults with a mental illness must include identification of all dependent children.[41] The RANZCP argues young carers face barriers within the mental health system due to the fact that 'many health practitioners and allied health professionals fail to recognise or adequately acknowledge that young people are carers.'[42]

It is clear the NDIA will have a role to play in identifying and involving any young carers of participants who have a psychosocial disability associated with mental illness in the assessment and planning process, and of referring these young carers to appropriate services and support. However, identification may not be straight forward, particularly if the participant doesn't recognise the young person as a carer or if the young carer is one of several people in the family who provide support to the participant.

With vital funding for young carer respite services being transferred into the NDIS – a significant proportion of which are currently utilised by young mental health carers – it is imperative that provision is made to ensure young carers are identified and included in the assessment and planning process of the person they care for.

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[39] Australian Infant, Child, Adolescent and Family Mental Health Association 2004, p. 14
[40] Mental Health Council of Australia, 2012b, p.30
[41] The Royal Australian and New Zealand College of Psychiatrists, 2009, p. 2
[42] The Royal Australian and New Zealand College of Psychiatrists, 2012, p. 3

3. Importance of mental health carer involvement

There are a range of current guidelines, regulations and public perspectives from relevant organisations, covering mental health carer participation in mental health services, which are summarised at Appendix 3. This section however draws out the key factors, which underpin the importance of mental health carer involvement in NDIS assessment and planning.

3.1 Contributing to the wellbeing of the person with a psychosocial disability

It is increasingly recognised that the identification and engagement of mental health carers plays a key part in the wellbeing of people with a mental illness, and their involvement can be crucial to recovery based approaches to care.[43]

There is also now a substantial body of evidence to illustrate that when families and carers are involved as partners in mental health care, it has a positive impact on the wellbeing of the person with a mental illness.[44] The research evidence reveals family and carer involvement leads to:

- reduction in relapse rates through the earlier detection of symptoms and earlier treatment intervention
- a decrease in hospital admissions
- better consumer adherence to medication, including more compliant use and greater likelihood of staying on medication
- reduction in the consumer's psychiatric symptoms.[45]

Carers also play a key role in the management of psychosocial disability.[46] It is logical to conclude the role of carers of NDIS participants will have a similar dynamic. It will be important to maintain this role to ensure the ongoing support of people with psychosocial disability.

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[43] Private Mental Health Consumer Carer Network, 2010, p. 10

[44] Meta-analyses of a number of randomised controlled trials undertaken by Pharoah et al, 2006, Pitschel-Walz et al, 2011 and Cuijpers, 1999 cited in Leggat, 2011, p. 15

[45] Leggat, 2011, p. 15

[46] National Mental Health Consumer and Carer Forum, 2011b

3.2 Improving the sustainability of the caring relationship

The way in which mental health carers are involved in the assessment and planning process of the person they care for can also affect the sustainability of the caring relationship. Through the assessment and planning processes of the NDIS, the Agency has a role to play in referring carers to programs and services that can meet their needs and, where appropriate, of providing carers with a break from the caring role.

If carers of people with a mental illness are not adequately supported in their role this can have an effect on their ongoing capacity to provide care and on their own health and wellbeing.[47] They may also be forced to cease or reduce their caring role which could jeopardise the sustainability of the NDIS support plan put in place for the person with the psychosocial disability.

Alternatively, if mental health carers are educated, trained and feel supported in their caring role, they are better positioned to provide more effective support themselves. This contributes to the long-term mental wellbeing of the person with the psychosocial disability and promotes their recovery.[48]

3.3 Improving the accuracy of the needs assessment

> The person we're looking after can appear quite well for an hour long assessment, because like everyone they want to put their best face forward, so they say they're managing." *Mental health carer*[49]

The involvement of family and friend carers in the assessment of the person with a mental illness can be integral to the capacity of the assessor to gain an accurate understanding of the impact of the resulting psychosocial disability on their everyday functioning. Psychosocial disabilities include cognitive impairments which can manifest in many ways affecting memory, communication, organising skills, social interactions and visual interpretation deficits.[50] Some people with psychosocial disability are not aware of the supports already provided by their carers and unless they are appropriately conducted, "assessments of people with a disability can often fail to identify the most disabling aspects of psychosocial disability and thus lack relevance and accuracy for identifying support levels and needs".[51]

> "The viewpoint of the person who is having to pick up all the bits and pieces is absolutely essential. Somebody who is so disabled by their mental illness is not going to remember all that stuff, nor are they going to want to think about all that stuff because it's really stressful, stigmatising and exceptionally disheartening". *Mental health carer*[52]

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[47] Commonwealth of Australia, 2006, p. 294

[48] Courage Partners, 2011, p. 10

[49] 2013 NDIS Alliance Engagement Project 'Consultations with Mental Health Carers and Carers of People with Decision-making Difficulties' Conducted by Carers Australia

[50] National Mental Health Consumer and Carer Forum 2011b, p. 19

[51] National Mental Health Consumer and Carer Forum 2011b, p. 10

[52] 2013 NDIS Alliance Engagement Project 'Consultations with Mental Health Carers and Carers of People with Decision-making Difficulties' Conducted by Carers Australia

3.4 Improving the appropriateness of the support plan

The extent to which the NDIS plan of the person with a psychosocial disability is appropriate to their needs and sustainable in the longer term will often depend on the involvement and input of family and friend carers in the planning process.

It is important NDIA planners are aware of, and understand the nature and context of any informal care arrangements including whether the care being provided is reasonable and sustainable and whether the carer is willing and able to continue in the caring role. This information should have a direct influence on the types of supports funded by the Agency and their required intensity and frequency in the support plan.

The capacity of a person with a psychosocial disability to carry out an NDIS plan by accessing listed supports, engaging with providers and undertaking activities may also be dependent (to varying degrees) on the participation of a carer. This involvement may be in the form of negotiating with providers, providing transport to and from appointments or prompting, encouraging and providing emotional support to engage in certain funded activities. Indeed previous surveys of mental health carers have shown some 87 per cent organised the majority of the non-medical care for the person with a mental illness.[53] Involving carers in the planning process can therefore be crucial to ensuring the successful implementation of NDIS funded packages of support.

3.5 Informing the NDIA about informal care

Through consultations undertaken by Carers Australia with mental health carers on the NDIS, participants discussed the importance of having the option for a separate discussion with the assessor.

> "I have a real concern around how it would be for the dignity of the person with the psychosocial disability, how it would be for their morale and their dignity sitting in a room and listening to a carer saying I do x, y and z. For some that might be OK, but for some it could be really quite devastating". *Mental health carer*[54]

Carers stressed, in some circumstances, detailing the ways they help the person with a psychosocial disability in front of them could be quite distressing and may have serious consequences on their state of mind and behaviour.

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[53] Mental Health Council of Australia, 2012b, p.24

[54] 2013 NDIS Alliance Engagement Project 'Consultations with Mental Health Carers and Carers of People with Decision-making Difficulties' Conducted by Carers Australia

4. Recommendations

This paper provides an overview of the issues facing mental health carers in relation to the NDIS and highlights the important role mental health carers play in supporting positive outcomes for mental health consumers with a psychosocial disability. To ensure the mental health carer role is acknowledged and sustained as an essential element of support for NDIS participants with psychosocial disability, the following recommendations should be implemented:

4.1 Mental health carer capacity building – recovery-focussed, mental health specific, pre-planning support

- Community mental health organisations and peak bodies (enabled by support from government programs, for example the Sector Development Fund or NDIS Information, Linkages and Capacity Building) should continue to provide successful recovery-focussed mental health specific pre-planning support for mental health carers, including but not limited to:[55]
    - outreach to hard-to-reach potential participants and their carers
    - peer-led (or peer-developed) workshops introducing mental health carers to the NDIS
    - training for peer conversation partners, i.e. mental health carers who have supported a participant through the NDIS application process, who can then support other carers to do the same
    - mental health carer led support groups where carers can support each other to engage with the NDIS
    - development and maintenance of online resources, for example: guides, webinars and information portals to help mental health carers to engage with the NDIS and provide them with information about recent NDIS related developments (e.g. extension of the NDIS to new sites as they occur).

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[55] These activities are currently being carried out by community mental health organisations and peak bodies supported by funding provided through the NDIS Sector Development Fund and state government NDIS related funding. There is scope for expansion and continuation of successful activities to ensure they reach a wider audience.

4.2 Mental health carer capacity building – information provision

- The NDIA should provide clear, accessible and timely advice to mental health carers about:
    - mental health carers' rights under the NDIS, including how the NDIS Act, Rules and Operational Guidelines apply to the role of carers
    - the option to submit a Carer Statement about their caring role (this should occur prior to the planning process)
    - the option to have a separate discussion with NDIA staff about the functional impact of mental illness on the person they care for, and of their caring role (this should also occur prior to the planning process)
    - possible supports that could be included in the package of the person they care for to help them in their caring role
    - opportunities to ask the NDIA questions about their rights and responsibilities, especially during the assessment, planning and review processes
    - the future of carer programs (i.e. whether they will be provided through or outside the NDIS, and whether the same level and type of carer supports will continue to be available).
- Mental Health Australia and Carers Australia should assist with information provision by circulating information via their NDIS related networks, on their websites and through the capacity building activities outlined in Recommendation 4.1 above.

4.3 NDIA staff capacity building

- NDIA should ensure staff receive information about:
    - the impact of psychosocial disability on an individual's everyday functioning and their associated support needs
    - the invaluable role of carers in understanding the impacts of mental illness, due to the knowledge they hold about the everyday functioning and support needs of the person they care for
    - the episodic nature of some mental health conditions and how support needs can change extremely rapidly and require contingency planning to be in place
    - the potential impact fluctuations in the severity of a person's condition will have on their willingness to have their carer involved in, and informed about their care, and that this may need to be regularly reviewed
    - some consumers' lack of understanding of the supports currently provided to them and why
    - some consumers' lack of capacity or willingness to seek help through the NDIS, and how to work with these consumers to assist them to make informed choices
    - the ways in which the mental health caring role may differ from that of carers for a participant with a physical disability, including how the importance of mental health carers' roles may not be as easily apparent
    - the ways in which the consumer's right to privacy can be balanced with their carers' need to give and receive information relevant to their caring role

    - the importance of mental health carer involvement in the NDIS. This should include information about how mental health carer involvement can contribute to the accuracy of the assessment; the sustainability of the caring relationship; the wellbeing of the person with a psychosocial disability; and the appropriateness of the NDIS support plan
    - the *Carer Recognition Act 2010*. In accordance with the obligations of all public service agencies contained within the Act, the NDIA should also "take all practicable measures to ensure that its employees and agents have an awareness and understanding of the Statement for Australia's Carers", which is contained within the Act
- The NDIA should have processes in place that ensures staff:
    - clearly understand and consistently apply the NDIS Act, Rules and Operational Guidelines as they relate to carers
    - recognise carers have their own needs which are both linked to, and separate from, the needs of the participant
    - are aware some participants with psychosocial disability may have become estranged from their family and friends, and therefore may not have any support network when they first engage with the NDIS. This may increase their vulnerability and susceptibility to become disengaged from services.

4.4 Active engagement of mental health carers in NDIS processes

- The NDIA should actively seek to identify any family and friend carers who provide support to a participant with a psychosocial disability. There should also be clear policies and protocols for NDIA staff to record the identification of any carer/s in the participant's file.
- NDIA planners may need to actively facilitate carer interaction, as they do with consumers to achieve effective NDIA outcomes. For example, this would include planners actively seeking information from carers in relation to the following issues, which are then recorded in the participant's file the nature and intensity of their caring role:
    - the ways in which they support the participant
    - how support needs may change
    - any issues that may affect the sustainability of carer support. This is related to recommendation 4.5 below.
- Where appropriate, NDIA staff should offer the opportunity to NDIS participants with a psychosocial disability to discuss and put in writing (when they are well) the level and type of carer involvement they approve. This agreement could include directions for when the participant is unwell,[56] such as an advance directive.
- Where appropriate, NDIA staff should facilitate alternative options for carer input into NDIS processes, such as through a separate conversation with the carer, or by encouraging them to submit a Carer Statement.

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[56] This is in line with the recommendations of the Royal Australian & New Zealand College of Psychiatrists' 2012 position statement on supporting carers in the mental health system.

Where the above steps are prohibited by relevant legislation and guidelines, the Government should consider options to amend legislation or guidelines to enable them to be implemented.

4.5 Assessing the sustainability of the carer role

- The sustainability of a carer's role should be addressed in a systematic way either as part of the planning process or in a separate conversation. This process and the outcomes of this assessment should be conveyed to the carer. This would include:
  - The potential impact of the participant's plan on their carer/s should be taken into account and discussed in the planning process. This includes the role the carer may need to play in supporting the delivery of a package of supports, such as identifying and engaging with providers, providing transport for the participant to and from appointments, or prompting, encouraging and providing emotional support to help the participant engage in certain funded activities.
  - The sustainability of carer support, including the health and wellbeing of the carer. Any impacts on their health and wellbeing and social and economic opportunities as a result of their caring role, should be considered by the NDIA in the assessment and support planning of the participant. There should also be consideration of the carers' ongoing willingness and capacity to continue in the caring role.
  - Where appropriate, the NDIA should refer mental health carers to services and supports which will assist them in their caring role, improve their health and wellbeing and contribute to the sustainability of the caring relationship.

4.6 Provisions for young mental health carers

- The NDIA should seek to identify any young people who may be involved in the support and care of a participant with a mental illness, even if they aren't the primary carer of the participant.
- NDIA staff should be sensitive to the fact young carers may not want to discuss their caring role in front of the person they care for, and may be reluctant or unable to identify supports for themselves.
- The NDIA should actively facilitate the involvement of any young carers in NDIS processes, especially in the assessment and planning of the person they care for and encourage their perspective on:
  - the support needs of the person they care for and its impact on the consumer's everyday functioning
  - their role as a young carer both in supporting the participant and any other flow-on responsibilities such as caring for other siblings
  - the impact of their caring role on their own health and wellbeing, and that of other family members
  - the impact of their caring role on their own educational, social and economic opportunities.
- The NDIA should provide young carers of people with mental illness with information which could assist them in their caring role, and refer them to appropriate services and supports.

4.7 Funding for carer programs

Funding for carer programs such as the Young Carers Respite and Information Services Activity and Mental Health Respite should not be transferred into the NDIS until and unless there is a guarantee that services of a similar nature and scale will continue to be available to carers, either through NDIS (i.e. via ILC) or through another arrangement. Without such a service guarantee, the transfer of this funding also risks reducing the support available to carers of those who aren’t eligible for the NDIS.

5. Conclusion

This paper has outlined the impact of the current NDIS legislation, operational guidelines and funding arrangements on carers of people with a psychosocial disability associated with a mental illness.

While the NDIS Guidelines mention carer involvement in assessment and planning, the extent to which these are understood and implemented by both NDIA staff and carers themselves appears to vary significantly. The Rules and Guidelines which cover carer supports also lack clarity, which may go some way to explaining why carers' access to support through the NDIS has also varied.

The involvement and participation of mental health carers in the assessment, planning and treatment of people with a mental illness has many benefits. This includes increasing the accuracy of the needs assessment by helping assessors to gain a fuller picture of the nature of the illness, the resulting psychosocial disability and its impact on every day functioning.

Involving mental health carers in the planning process can improve the appropriateness of the support plan and the capacity of the person with a psychosocial disability to access and undertake funded activities. The participation of carers in support planning is also associated with the increased wellbeing of the person with a mental illness, including a reduction in relapse rates, better consumer adherence to medication and a reduction in psychiatric symptoms.

However, there remain several areas of uncertainty and concern regarding carers of NDIS participants with a psychosocial disability associated with a mental illness.

In the context of funding for carer respite being transitioned into the NDIS, it remains unclear whether accessing respite within the NDIS will impact on entitlements to respite through other programs outside the NDIS. With current high demand for respite programs there is also a risk the transfer of carer respite funding into the NDIS will reduce the level of support available to carers of people who aren't eligible for NDIS-funded support.

Uncertainties around carer involvement in planning and assessment and access to respite and support are of particular concern to young carers of people with a mental illness, who currently represent a third of total service users within the Young Carer program. The partial transfer of funding for this program into the NDIS must be carefully planned in order to ensure the NDIA is able to identify and involve young carers of participants with a psychosocial disability in the assessment and planning process, and refer them to appropriate services and support.

As funding for a range of community mental health services is transferred into the NDIS, including those funded by the Commonwealth and the states and territories, there is a risk it may become harder for people with mental illness to access supports outside of the NDIS, and in turn the demands on mental health carers will increase.

As "the most significant social reform package in Australia since the introduction of Medicare in 1975",[57] implementation of the NDIS is undoubtedly a highly complex undertaking which will require much trial and error. The NDIA has been testing the rules and processes of the NDIS through the trial sites and is changing and developing its practices in response. At the same time, participants and their families and carers are also learning how to navigate a new system which comes with new rules, a new language, and a new way of supporting people with disability.

As a consequence, the experiences of those who have engaged with the NDIS to date have been varied. The degree to which carers have been involved in the planning process has often been a reflection of the planner's knowledge of the rules and guidelines applying to carers, and of the carers own knowledge of their entitlements.

The Sector Development Fund has provided funding to Mental Health Australia and Carers Australia to support carers to engage with the NDIS. These projects operate in a manner that is mindful of the issues outlined in this paper and actively work with carers to ensure they can make the most of the opportunities offered by the NDIS. However there is more that can be done to support carers to engage with and get the best results from the NDIS, as outlined in the above recommendations.

Generally, there is a need for more clarity about how carers fit within the NDIS, including the degree to which they are involved and supported, and for greater consistency across NDIA staff in implementing the NDIS operational guidelines and rules. This will help to ensure the sustainability of the caring relationship, as well as the health and wellbeing of both the carer and the person they care for.

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[57] KPMG, 2014, p. 2

6. Glossary of terms

Individually Funded Package: A package of reasonable and necessary supports for a person with a disability funded through the National Disability Insurance Scheme.

ILC: Information, Linkages and Capacity Building. Formally referred to as Tier 2 services under the National Disability Insurance Scheme.

Mental health carer: Someone who provides unpaid care and support to a family member or friend with a mental illness or mental health condition. A carer may or may not live with the person they support, and may not be identified by the individual with a mental illness to be their carer.

Mental health condition: Describes the broad range of features that characterise a mental illness whether it is diagnosed or not.[58]

Mental health consumer: A person with a lived experience of mental illness or mental health condition.[59]

Mental illness: Diagnosable illness that significantly interferes with an individual's cognitive, emotional, and/or social ability.

NDIA: National Disability Insurance Agency. Also referred to as the NDIA.

NDIS: National Disability Insurance Scheme.

Participant: A participant refers to an individual who is an eligible participant in the National Disability Insurance Scheme.

Psychosocial disability: An internationally recognised term used to describe the experience of people with impairments and participation restrictions related to mental health conditions. These impairments can include a loss of ability to function, think clearly, experience full physical health, and manage the social and emotional aspects of their lives.[60]

Primary carer: A primary carer is someone who provides the majority of unpaid care for another individual with a disability, chronic condition, mental illness or disorder, drug or alcohol problem, terminal illness or someone who is frail aged.

Systemic carer engagement: The process by which the aspirations, concerns, needs and values of carers and family members influence policy and practice of service systems that provide supports to them. For example, this process could include government or community

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[58] National Mental Health Consumer Carer Forum, 2011b, p.6

[59] Ibid.

[60] National Mental Health Consumer and Carer Forum, 2011c

service providers seeking the input of carers on decision making, planning, service delivery and evaluation.

Appendix 1: Background on mental health carers

What is a mental health carer and what do they do?

A mental health carer is someone who provides unpaid care and support to a family member or friend with a mental illness or mental health condition. A carer may or may not live with the person they support. In some cases and on some occasions a person with a mental illness may not be cognisant of that illness and/or may not recognise the role of a person who provides a significant level of support to them. For this reason, a carer does not necessarily need to be identified by the individual with a mental illness to be their carer.[61]

Carers provide a range of supports to people with a mental illness; from transporting the people they care for to and from appointments, to initiating and prompting their self-care and self-management in daily living skills such as washing, cleaning, buying food and clothing. Mental health carers may also monitor medication intake and the existence of psychotic symptoms and prevent self-harm. Carers also provide help, understanding, guidance and support for mental health consumers.[62] Many carers also provide a financial safety net for the person they care for, particularly when they are unwell, such as covering rent or mortgage payments, utilities bills, fines and medical expenses.

A survey of mental health carers undertaken by Carers Victoria found 58 per cent of respondents provided supervision of household tasks, 55 per cent provided supervision for safety reasons, 44 per cent supervised self-care and 43 per cent supervised eating or drinking of the person they cared for. [63] These Victorian findings are likely to apply across the country.

> *"I'm a psychologist, a personal trainer, personal hygiene monitor, medication supervisor, financial advisor, financial assistant, dietician, a cook and chauffeur. I'm willing to attend GP, psychologist and psychiatric appointments." Mental health carer*[64]

Data from the latest Australian Bureau of Statistics Survey of Disability, Ageing and Carers shows 54 per cent of primary carers of people with a mental or behavioural disorder care for

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[61] Arafmi Mental Health Carers Australia, 2014, p.1

[62] Mental Health Council of Australia, 2012b, p.vi

[63] Carers Victoria, 2013, p.8

[64] 2013 NDIS Alliance Engagement Project 'Consultations with Mental Health Carers and Carers of People with Decision-making Difficulties' Conducted by Carers Australia

40 hours or more per week.[65] Of this group, nearly a quarter have been caring for 15 years or more.[66]

How many mental health carers are there?

It is difficult to gain an accurate picture of how many mental health carers there are in Australia as most figures rely on either the carer or the person with the mental illness accessing formal services. This excludes those who aren't linked to support. Another factor in the under-estimation of the number of mental health carers is that many people who take on this role do not identify with the term 'carer', (and nor does the person they care for) which can limit the accuracy of some surveys. Some carers are also 'hidden' because the person they care for has not yet been diagnosed with a mental illness.[67] In other cases mental health carers may be reluctant to acknowledge their caring role because of the stigma attached to mental illness.

Some carers who support a person with a mental illness are eligible for income support through the Carer Payment and/or the Carer Allowance. According to point-in-time Centrelink data from September 2011, over 51,000 Australians aged 16-64 whose carer qualified for Carer Allowance had a mental illness and there were 26,484 Australians of the same age who had a mental illness whose carer qualified for Carer Payment.[68]

The *People living with psychotic illness study* (conducted by the Commonwealth of Australia) surveys people with a psychotic illness who receive public mental health services. In 2011 this study found of the 63,533 people who accessed these services, 65.4 per cent had daily or almost daily face-to-face contact with family and almost one in five participants lived in a family residence.[69] The 2012 Australian Bureau of Statistics Survey of Disability, Ageing and Carers (SDAC) showed 3.4 per cent of Australians (770,500 people) reported having a psychological disability[70]. Approximately six out of every ten (63.1 per cent) people with psychological disability received informal care from an unpaid carer.

What is the impact of the mental health caring role?

The impact of the caring role on a carers' own physical and mental health and wellbeing can be considerable. A 2007 study into the wellbeing of carers undertaken for the Australian Unity Wellbeing Index revealed carers had the lowest level of wellbeing ever measured for any group they had studied, including people who were unemployed, or people earning low wages and living alone.[71]

In a 2012 survey of mental health carers, 71 per cent of respondents reported a deterioration of their health in the previous 12 months as a direct result of caring for someone with a mental illness.[72] A further 78 per cent reported their own physical and mental health had

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[65] Australian Bureau of Statistics, 2012

[66] Australian Bureau of Statistics, 2012

[67] Mental Health Council of Australia, 2012b, p.vii

[68] Centrelink/FaHCSIA, 2011. Point in time data cited in Carers Victoria, 2013, p. 11

[69] Carers Victoria, 2013, p. 165

[70] In the 2012 SDAC, the definition of psychological disability refers to people who reported a mental illness, brain injury, including stroke, which results in a mental illness, or nervous or emotional condition which causes restrictions in everyday activities which has lasted or expected to last, for six months or more.

[71] Cummins et al, 2007

[72] Mental Health Council of Australia, 2012b, p. 18

deteriorated more substantially when the person they cared for had been unwell in the past 12 months.[73]

Caring for someone with a mental illness is also shown to have an impact on carers' relationships with others. Almost three quarters (74 per cent) of surveyed mental health carers indicate they have experienced problems with their family and other relationships as a result of caring responsibilities,[74] and around two thirds had experienced family breakdown.[75] The financial impact of caring can also be significant. A 2013 survey of mental health carers found 64 per cent had been unable to pay utility bills on time, 58 per cent had asked for financial help from friends and 26 per cent had gone without meals.[76]

There are several factors which distinguish the impact of caring for a person with a mental illness from other caring roles. Of particular importance is the stigma around mental illness in the community which can have an effect on the likelihood of carers accessing support. Indeed previous research has shown around a third of surveyed mental health carers reported they had been afraid to ask for help, particularly those who had been caring for longer periods.[77] Mental health carers may also have few people in their support network they can confide in about their role, due to the need to protect the privacy of the individual they care for, which can also lead to social isolation of the carer.

The issue of protecting the privacy of someone with a mental illness can also be a key factor in the degree to which carers are informed about and involved in the treatment of the person they care for. Many carers of people with mental illness report feeling excluded by mental health professionals, with a 2012 survey finding some 28 per cent stated psychiatrists rarely or never listened to their concerns.[78] Experiences like this can discourage carers from expressing their opinions and needs in other settings which could impact negatively on their NDIS involvement. However research illustrates the involvement of families and carers as partners in mental health care can have a significant positive impact on the wellbeing of the person with a mental illness,[79] and their involvement can be crucial to recovery based approaches to care.[80]

Conversely, if carers are not adequately supported in their role and informed about how best to support the person they care for, the sustainability of the caring relationship may be jeopardised. In their 2013 National Report Card on Mental Health and Suicide Prevention, the National Mental Health Commission recommended carers need to be included and supported to continue to carry out their caring role effectively.[81]

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[73] Mental Health Council of Australia, 2012b, p.18
[74] Wesley Mission, 2012, p. 28
[75] Wesley Mission, 2012, p. 28
[76] Carers Victoria, 2013, pp. 15-16
[77] Wesley Mission, 2012, p. 6
[78] Mental Health Council of Australia, 2012b, p. 5
[79] Leggatt, 2011, p. 15
[80] Private Mental Health Consumer Carer Network, 2010, p. 10
[81] National Mental Health Commission, 2013, p. 26

Appendix 2: Carer programs and the NDIS

The first bilateral agreements between the Commonwealth and state and territory governments detailed the operational and funding arrangements for the NDIS in each trial site. New South Wales and Victoria have recently signed bilateral agreements relating to the roll out of the full scheme in those states.

Some of the programs identified in the bilateral agreements for transition into the NDIS (either in part or in full) offer support for carers. These include the following:

Respite Support for Carers of Young People with Severe or Profound Disability (RSCYP): This provides immediate and short-term respite to carers of young people with severe or profound disability (under 30 years of age) and carers who experience significant stress in caring for a person with a disability where both are under 65 years of age whose needs are not being met through existing State, Territory or Commonwealth Government initiatives. The activity facilitates access to information, respite care and other support or assistance appropriate to the individual needs and circumstances of both carers and the person they care for. The activity also aims to focus on the needs of carers by providing increased opportunities for carers to exercise choice and control over their respite care arrangements.

According to the Operational Guidelines updated in March 2015, this activity will transition in full to the NDIS by July 2019. Funding for the activity in 2015-16 is $8.4 million.

Young Carer Respite and Information Services: Highlighted in the Section 2 of this paper, this program assists young carers who need support to complete their secondary education (or the vocational equivalent) due to the demands of their caring role. It includes both an Information, Advice and Referral Component and a Respite and Education Component. Direct respite is provided to free students to spend time on their education, while Educational Support provides short term or immediate activities to provide a ‘respite effect’ in relation to young carers’ educational needs. This may include transport to and from school, material support (e.g. school books or uniforms) and tutoring.

The direct respite services provided in this program are transitioning into the NDIS.

Mental Health Respite: Carer Support: Provides a range of flexible respite and family support options for carers and families of people with mental illness whose health and wellbeing or other impediments are negatively impacting their ability to provide care.

Services provided by MHR:CS include:

- relief from the caring role to help maintain or improve the carer’s health and wellbeing
- carer support that helps the carer provide better care

- education, information and access to build the capacity of carers and their communities to respond appropriately to mental health issues.

In 2012-13, 197 existing services under this program supported 34,321 carers.[82]

The MHR:CS is of particular importance to mental health carers, going some way to providing them with the respite supports that are often unavailable from mainstream respite services.[83] The latest Operational Guidelines for this activity updated in July 2015 states that funding for MHR:CS is transitioning into the NDIS and all providers under this activity (including those who do not provide direct respite) must report whether their clients care for NDIS participants. Specifically, providers are being asked to report on:

- The number of carers who received direct respite through the care recipient's individually funded plan.
- The number of carers who received indirect respite through the care recipient's individually funded plan.

Why the transfer of these programs is concerning

The Productivity Commission anticipated that better disability support through the NDIS should alleviate some of the caring role, increasing carers' wellbeing and enabling a large number of carers to re-enter the workforce or increase their working hours.[84] At a national level this could increase gross domestic product substantially over time.

If, as an unintended consequence of the NDIS, respite services for carers were to decrease, this could undermine the original policy intent of the NDIS outlined by the Productivity Commission.

The fear that respite services may decrease is due to a number of factors, including that the aim of programs for carers is to specifically meet the support needs of carers, while the aim of the NDIS is to meet the support needs of eligible people with disability. While these two aims are not necessarily incompatible, they are also not necessarily the same. What follows are some examples of operational issues, which may arise due to this difference in program aims. However, these are observations of current operational arrangements, so it is important to point out that further details may emerge through NDIS transition and operational planning, which could alleviate the current concern and uncertainty around whether carers will have adequate access to respite services:

- The Operational Guidelines for MHR:CS require providers to complete a carer needs assessment. This is not available in the NDIS which means the ability of the planner to accurately assess the support needs of the carer will be limited.
- Providers of MHR:CS are required to develop carer support plans which are driven by the carer and reflect their preferences. In comparison, carers are not participants of the NDIS in their own right and there are no carer support plans in the NDIS. Support plans in the NDIS are designed to meet the needs and preferences of participants with a disability.
- The MHR:CS program provides a "broad range of supports to assist carers and families to maintain their caring roles and their own wellbeing". In comparison, the supports available to carers through the NDIS are likely to be limited.

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[82] Australian Government Department of Families, Housing, Community Services and Indigenous Affairs, 2013, p.68

[83] Mental Health Council of Australia, 2012a

[84] Australian Government Productivity Commission, 2011

There are a number of key issues which remain unclear in relation to carers accessing respite and other supports through the NDIS and these also need to be clarified.

- Because carer involvement in the assessment and planning process is determined by the participant, it is unclear how the Agency would allocate respite support for the carer if the participant was reluctant for this to happen. Some 80,000 carers report they don't access respite services because the person they care for doesn't want them to.[85] This is also a potential barrier to carers accessing respite through the NDIS and is a real issue for a significant proportion of carers of people with psychosocial disability who do not wish to engage with the NDIS. It is worth noting this was a key issue impacting mental health carers accessing respite prior to the NDIS[86] and will remain so under the NDIS.
- It is unclear whether carers who access respite through the NDIS will also be able to access it through carer respite programs outside the NDIS if they need more than the allocated number of days available through the NDIS.
- It is unclear whether carers of NDIS participants who have a psychosocial disability associated with a mental illness will have access to the same level and type of respite and other support within the NDIS as they are currently entitled to through other programs.
- At the time of writing it was also still unclear what the relationship would be between funding for existing carer programs being transferred into the NDIS, what supports might be available for carers through ILC, and how this would interact with the future model of Integrated Carer Supports.

How will this funding change affect mental health carers?

With the operation of the NDIS still in its infancy, the full impact of program funding changes is yet to be fully understood. However, there are a number of key risks and concerns.

Potential reduction in services available to mental health carers outside the NDIS

There is a risk the transfer of carer respite funding into the NDIS will reduce the level of support available to carers of people who are not eligible for NDIS-funded support.

In 2009, the Australian Bureau of Statistics estimated almost 42,000 primary carers had indicated a need for more assistance with respite alone.[87] A 2011 evaluation of Commonwealth Respite and Carelink Centres (CRCCs) also found almost all centres reported they faced difficulties meeting the demand for respite.[88] As a result, many rationed funding between carers and not all needs for respite could be met; with just over one third of carers surveyed stating they had occasionally been refused emergency respite support when their funding or hours had been used up and over half of carers unable to choose the type of respite they needed because of limited respite options available.[89]

In 2012-13, 197 existing services supported 34,321 carers under the Mental Health Respite: Carer Support program.[90] This was an increase of over 5,000 from the previous year.[91] Any

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[85] Australian Bureau of Statistics, 2012

[86] Mental Health Council of Australia, 2012a

[87] Australian Government Productivity Commission, 2011, p. 126

[88] ARTD Consultants, 2011, p.xvii

[89] ARTD Consultants, 2011, p.xvii

[90] Australian Government Department of Families, Housing, Community Services and Indigenous Affairs 2013, p. 68

[91] Australian Government Department of Families, Housing, Community Services and Indigenous Affairs, 2012, p. 90.

reduction in respite funding could therefore have a significant detrimental effect on the sustainability of caring relationships for mental health carers who aren't able to access vital respite support outside of the NDIS. (For more information on the impact of the mental health caring role, see Appendix 1).

Impact on the ability of respite providers to continue meet a range of carers' respite needs both within and outside of the NDIS

An evaluation of the Respite Support for Carers of Young People with Severe or Profound Disability (RSCYP) found both the RSCYP and the Young Carers programmes' operational costs were being cross-subsidised by funding derived from the National Respite for Carers Program. The report made clear this cross-subsidisation was more significant than savings achieved simply through economies of scale by centres which provided services across all these programs. It showed the arrangements allowed "minimally funded programs to punch over their weight."[92]

Any reduction in, or changes to, funding for some carer respite services could therefore potentially impact on the viability of other respite programs.

There are also concerns the types of support currently offered to carers under the Mental Health Respite: Carer Support program won't necessarily fit within the NDIS catalogue of support. This could potentially result in mental health carers losing access to supports that sustain them in their caring role when the person they care for becomes an NDIS participant. See case study below.

CASE STUDY: Mental Health Respite: Carer Support (MHR:CS)

A mother cares for her 16 year old daughter, who has a treatment resistant mood disorder, ongoing suicidality, and an Autism Spectrum disorder. At the time of application to the NDIS, the daughter had been an inpatient at an adolescent mental health unit for the previous five months, and was looking to be discharged from the unit gradually, requiring a lot of support.

Prior to her becoming an NDIS participant, the Mental Health Respite: Carer Support program had funded the daughter's recreational activities and interests; however most funding was used to provide respite and recreation for the wellbeing of both the mother and the daughter's sister. At the planning meeting in April 2015 (at which an MHR:CS staff member was present), the NDIS planner noted such services will not be funded by the NDIS, and expressed concern about how the mother and daughter's sister will maintain their caring role.

A reduction in mental health services could increase mental health carer responsibilities

As funding for certain mental health services is being transferred into the NDIS, there is a risk it will become harder for some people with a mental illness who aren't eligible for the NDIS to access supports outside the NDIS. Mental health programs identified for transition into the

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[92] ARTD Consultants, 2011, p. 72

NDIS (according to the intergovernmental agreements) include Personal Helpers and Mentors (PHaMs), Partners in Recovery (PIR) and Support for Day to Day Living in the Community.[93] It has been highlighted by the mental health sector that the current eligibility for the PHaMs program captures a much broader group of people with psychosocial disability than would necessarily be eligible for funded support through the NDIS. It is therefore feared this group of consumers may miss out on vital support.

There are also reports some state and territory governments are reducing funding for some mainstream services, and potentially seeking to reduce their investment in other disability services.[94]

It remains to be seen what effect these funding changes will have on the availability of mental health services outside the NDIS. However, mental health carers are often at the centre of community mental health care providing the bulk of support and assistance and often with little, if any, specialised training or expertise in the area.[95] Consequently, there are concerns about the capacity of mental health carers to take on even greater caring responsibilities in the event other mental health services are reduced, and the flow-on effects this may have to their health and wellbeing, and that of the person they care for. (For more information about the role of mental health carers in supporting people with mental illness, including estimates on the number of mental health carers in Australia, see Appendix 1).

Mental Health Australia and Carers Australia welcomed the ILC Framework's reference to the important place for activities funded beyond individually funded packages particularly to addresses illnesses that are episodic in nature. At the time of writing, the NDIA had recently completed a co-design consultation process on the NDIS ILC Commissioning Framework, which will outline the priorities for spending under the ILC in more detail.

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[93] For more detailed information about the types of support offered under each of these programmes visit www.dss.gov.au

[94] National Disability Services, 2014, p. 29

[95] Commonwealth of Australia, 2006, p. 271

Appendix 3: Guidelines, regulations and perspectives on mental health carer involvement in assessment, planning and mental health care

In examining the way forward for involving mental health carers in the assessment and planning process of NDIS participants with a psychosocial disability associated with mental illness, it is useful to look at current guidelines and regulations on mental health carer participation in mental health services, and the perspectives of other organisations and peak bodies.

Guidelines and regulations on mental health carer participation

The *National Standards for Mental Health Services,* produced by the Australian Government Department of Health (in consultation with stakeholders) applies across the broad range of mental health services including community mental health services, clinical, non-government, private sector, primary care and general practice. Standard 7 covers carers and stipulates that:

- The mental health service (MHS) has clear policies and service delivery protocols to enable staff to effectively identify carers as soon as possible in all episodes of care, and this is recorded and prominently displayed within the consumer's health record.
- The MHS implements and maintains ongoing engagement with carers as partners in the delivery of care as soon as possible in all episodes of care.
- In circumstances where a consumer refuses to nominate their carer(s), the MHS reviews this status at regular intervals during the episode of care in accordance with Commonwealth and state/territory jurisdictional and legislative requirements.
- The MHS provides carers with a written statement, together with a verbal explanation of their rights and responsibilities in a way that is understandable to them as soon as possible after engaging with the MHS.
- The MHS provides carers with non-personal information about the consumer's mental health condition, treatment, ongoing care and if applicable, rehabilitation.

- The MHS actively seeks information from carers in relation to the consumer's condition during assessment, treatment and ongoing care and records that information in the consumer's health record.
- The MHS provides information about and facilitates access to services that maximise the wellbeing of carers.[96]

The ***Implementation Guidelines for Public Mental Health Services and Private Hospitals*** which accompany the *National Standards* outlines the carer statement of rights and responsibilities (which should be prominently displayed by mental health services) should include statements such as:

- The relationship between a carer and the person they care for is respected and honoured.
- Carers have the opportunity to work in partnership with service providers.
- Carers are respected for the critical role they play.
- Carers are supported to balance their caring role with their own needs. [97]

The ***Mental Health Statement of Rights and Responsibilities 2012*** was prepared under the auspices of the Mental Health Standing Committee of the Standing Council on Health (and endorsed by Australian Health Ministers), states that:

- Services have the responsibility to respect the skill and abilities of families and carers, consider their views and improve communication between services, families and carers.
- Carers have the right to comprehensive information, education, training and support to facilitate their care and support roles, and to receive support for their own difficulties that may be generated through the process of caring for or acting as an advocate for the mental health consumer.
- With the consent of the mental health consumer, and where it is appropriate to do so in accordance with legislation and policy, guardians, carers and support persons have the right to;
  - Participate in treatment decisions about ongoing care.
  - Seek and receive additional information about the mental health consumer's support, care, treatment, rehabilitation and recovery.
  - Arrange support services for the mental health consumer, such as respite care, counselling and community care facilities.[98]

The principles underlying the ***Fourth National Mental Health Plan 2009-2014*** also state:

"Families and carers should be informed to the greatest extent consistent with the requirements of privacy and confidentiality about the treatment and care provided to the consumer, the services available and how to access those services. They need to know how to get relevant information and necessary support. The different impacts and burdens on paid and unpaid carers need to be acknowledged."[99]

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[96] Australian Government Department of Health, 2010, pp. 16-17

[97] Commonwealth of Australia, 2010

[98] Commonwealth of Australia, 2012, pp. 12-20

[99] Commonwealth of Australia, 2009, p. 13

Perspectives on mental health carer participation

Productivity Commission

The Productivity Commission *Inquiry Report into Disability Care and Support* which informed the development of the NDIS, recommends where an informal carer provides a substantial share of the care package, they "should receive their own assessment if they wish", which should "seek to identify their views on the sustainability of arrangements and the ways in which the NDIS should support their role."[100] The Commission also states the need for respite services would be fully appraised as part of the individual's assessment in consultation with the carer.[101]

Department of Social Services

The Personal Helpers and Mentors (PHaMs) programme which is funded by the Federal Department of Social Services aims to provide increased opportunities for recovery for people whose lives are severely affected by mental illness. The PHaMs Resource Kit which is developed by the Department for providers of PHaMs services states the programme should be implemented with "family sensitive services" and the "input of families and carers can be invaluable because they know the participant better than anyone else does."[102] An evaluation of PHaMs services undertaken by the Benevolent Society also recommended the programme increase its focus on developing and building participants' existing relationships (including family relationships) and on developing and implementing strategies aimed at increasing participant's families' involvement in the service planning and delivery.[103]

ARAFMI Mental Health Carers Australia

The ARAFMI Policy Brief 'Involving carers and family members in the NDIS' states there is an "inherent tension between the traditional role of carers in supporting decisions of those living with psychosocial disability and impaired decision making capacity, and the self-directed funding model aimed at promoting choice and control by the person with a mental illness."[104] The Policy Brief states carers require assessments of their needs which should be coordinated with assessments of service users so information from both assessments can be brought together to inform support planning.[105]

Private Mental Health Consumer Carer Network

In 2010 the Private Mental Health Consumer Carer Network was contracted by the Australian Government Department of Health and Ageing to develop "Nationally consistent policies and good practice protocols to identify carers of people with a mental illness and nationally consistent information for carers on admission to a service." This report stated:

"Consumer refusal to identify carers and privacy legislation is NOT a basis for preventing clinical staff across a range of settings from having a working relationship with the family/carer. Carers still have a right to give information to clinical staff to assist in assessment, treatment and ongoing care."[106] (Original emphasis).

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[100] Australian Government Productivity Commission, 2011, p. 71
[101] Australian Government Productivity Commission, 2011, p. 331
[102] Australian Government Department of Social Services, 2014b, p. 22
[103] Benevolent Society, 2013, p. 8
[104] Arafmi Mental Health Carers Australia, 2014, p. 1
[105] Arafmi Mental Health Carers Australia, 2014, p. 3
[106] Private Mental Health consumer Carer Network, 2010, p. 11

Royal Australian and New Zealand College of Psychiatrists

The College's Position Statement on supporting carers in the mental health system states "Accurate identification of carers is important to ensure that all carers have access to support and services to assist them in their role and to maintain their own social and emotional well-being."[107]

Mental Illness Fellowship of Australia

The Position Paper of the Mental Illness Fellowship on 'Working with the Whole Family' states "families, friends and carers are key partners in recovery." MI Fellowship says it works "within a family sensitive practice framework, developing opportunities to engage, listen to and support families, friends and carers of people with a mental illness."[108]

Academic Research

Leggatt (2011) reports studies in China, Spain, Scandinavia and Britain have shown when consumers, family carers and mental health professionals are able to meet together and work on plans of action agreed to by all parties, "many of the issues around privacy and confidentiality disappear."[109]

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[107] Royal Australian and New Zealand College of Psychiatrists, 2012, p. 1

[108] Mental Illness Fellowship of Australia, 2012

[109] Leggatt, 2011, p. 2

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