Submission
No 291

INQUIRY INTO IMPLEMENTATION OF THE NATIONAL DISABILITY INSURANCE SCHEME AND THE PROVISION OF DISABILITY SERVICES IN NEW SOUTH WALES

Organisation: Mental Health Carers NSW Inc.
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Submission on the Implementation of the NDIS and the Provision of Disability Services in NSW

Mental Health Carers NSW Inc. Submission

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Mental Health Carers NSW

Introduction

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

MHCN consults with carers across the state to gain insight into their experiences of a range of service systems including disability and mental health. MHCN gathers information, through a number of Peak Advisory Committees consisting of carers and professionals with relevant knowledge, skills and experience via online surveys and by conducting community consultations with carers. MHCN engages with carers by hosting regular training events and carer forums and through social media and weekly e-news. MHCN also operates a state-wide telephone service provides information and referrals to family members and carers.

MHCN recently conducted three consultations with a combination of carers, consumers and professionals which focused on their experiences of the NDIS in NSW. In total, 26 people in attended. These consultations were held at three locations;

- The Hunter Region at Hunter ARAFMI on 24 May 2018;
- The Central Coast at Central Coast ARAFMI on the 24th of July; and,
- Sydney at MHCN's offices in Collective Purpose on the 26th of July.

MHCN also conducted an online survey which sought carers feedback on this topic. Of the 94 carers who completed the survey;

- 43 cared for someone who had never applied to the NDIS
- 10 cared for someone who had applied and had been determined to be ineligible
- 9 for someone who was currently awaiting the results of their application and;
- 31 cared for someone who is an NDIS participant.

The feedback received has been used to develop our submission.

Recommendations

1. The NSW Government should urgently develop and implement a provider of last resort program, where it is identified that a participant cannot access the ‘reasonable and necessary’ supports funded by the NDIS or where a person living with a disability does not have access to appropriate supports, due to the failure of the ‘market’ to provide the kind of support deemed necessary. The provider of last resort should be mandated to provide immediate support, including accommodation and continued case management until a sustainable solution can be identified and implemented. Where possible, the provider of last resort should work with other agencies and disability services to assist them develop capacity to provide supports to individuals with complex needs.

2. The handover and liaison between health and the NDIS should be resourced. A clearly defined referral pathway from health to the NDIS should be developed and built into the health system so that it becomes a part of normal practice. Mental health services should identify consumers when it becomes evident that their mental illness is likely to result in long term psycho-social disability and develop and implement a plan to engage them with appropriate community support including the NDIS. Referral pathways between health and the NDIS should be tailored to local needs through joint planning involving PHNs, LHDs and the NDIA. In particular consideration should be given to the way mental health services can discharge someone to ongoing support under an NDIS package; including how people receiving support through the Housing and Support Initiative (HASI) or Community Living Supports (CLS) can be handed on to the NDIS once they are deemed eligible for it, (although consumer preferences for continuity of supports may complicate this). However, if established this would create a pathway to the NDIS after early intervention which would also allow health services to open up new spaces in these programs to new people who require them.

3. Carer respite services should be funded to ensure that carers have access to support on the basis of their own needs. The assumption that access to an NDIS package will reduce the burden on carers and is the same as respite needs to be questioned. Funding should be allocated to specialised services for carers of people living with a mental illness. A population level analysis should be conducted to determine the level of unmet need for carer support services in NSW and funded accordingly.

4. The NSW Government should increase funding provided to individual advocacy services and establish a statewide advocacy and oversight service. This service should be mandated to;
    - Provide independent advocacy to people living with disability and their carers.
    - Provide education, information and support to people living with disability and their carers around the NDIS.
    - Provide independent oversight of plan implementation for people with complex needs.

The NDIA should automatically refer all participants who are established to have complex needs to this service.

5. The NSW Government should provide funding in the form of ongoing grants to registered providers that support participants with a psychosocial disability so that providers can develop and sustain a workforce with relevant qualifications and skills in mental health. The NSW government should consider gradually introducing regulations which require a portion of staff of registered providers that support participants with a psychosocial disability to have relevant qualifications and skills in mental health. To support providers to comply, the NSW government should fund scholarships and traineeships for employees of registered providers to gain relevant qualifications in mental health with preference given to carer and consumer peer workers.

MHCN notes that there are a number of reforms which are outside of the sole jurisdiction of the NSW Government, that are relevant to the terms of reference of the inquiry and would be of significant benefit to carers of people living with a mental illness in NSW. These include;

- The following programs should be continued on a permanent basis long past 2019;
    - Partners in Recovery
    - Personal Helpers and Mentors Program
    - Mental Health Carer Respite

- The NDIA should develop a formalized protocol which requires that all carers are identified and consulted during assessment, planning and review processes and receive a separate assessment of their needs.

- The NDIA should automatically include support coordination in plans for all participants who have a psychosocial disability, unless it is clear that they do not require it. Carers should always be consulted before it is decided that support coordination will not be funded. Support coordination should not be removed as a result of review processes.

- The NDIA should not remove funding as a result of the review process, unless it is clearly demonstrated that there is no need for the support. When it becomes clear during review that a participant has not spent their funding this should trigger a thorough investigation as to why supports were not accessed, including market failure to provide the relevant supports. Data should be collected on the reasons that participants did not use the funded supports and should be used for monitoring and evaluation.

- The NDIA should implement ongoing independent pricing reviews, in consultation with registered providers, including organisations that provide supports to participants with a psychosocial disability.

Choice and Control

“I don’t think that anyone would have a meaningful package without a serious advocate, it takes a lot of work to gather the supporting evidence.” - Consumer Peer Worker

The considerable potential for the NDIS to promote choice and control for people with a psychosocial disability can only be realised for all if support is made available to help participants to identify and articulate their hopes and goals and to make decisions which will bring them closer to achieving these. The vast majority of participants with a psychosocial disability have complex needs and may struggle to exercise the level of self-direction and participant choice required to engage with NDIS processes and to coordinate their supports effectively. Feedback from stakeholders indicates that it takes considerable time, energy, resources, knowledge and skill to successfully apply for, develop and enact an NDIS plan. For some people who are very unwell this sets the barrier of entry so high as to be impossible without dedicated supports, including supported decision making. The result is that, people with a psychosocial disability are often reliant on support workers or carers to maintain contact with the scheme and to assist them with decisions.

Where people do not have access to an appropriate level of support, the result is that their goals and care needs are not well understood or catered for. Ultimately, this translates to less choice and less control. Mechanisms that will support people with a psychosocial disability to effectively engage with the scheme include: the tailored psychosocial disability pathway which is currently in development; advocacy and oversight services for people with complex needs; staff adequately trained in supporting people with psycho-social disability and a locally developed and well-resourced interface between the scheme and the health sector with clearly defined referral pathways.

Carers often provide significant levels of support to assist participants to apply for the NDIS, to engage with application, planning and review processes and to enact their plan and coordinate supports. Although in some cases this is the choice of carers and participants, it is essential that the NDIS allows for carers to choose to step back from their caring responsibilities. This requires that participants not only receive an adequate level of support in their plans, but also that they are supported to successfully engage with the scheme and to coordinate their supports independent of their carers. A number of attendees at the community consultations conducted by MHCN reported a reluctance on the part of NDIS planners to grant supports which were already provided by informal carers. In the online survey, carers of people who applied for the NDIS were also asked to indicate their involvement in application and planning processes. Over 90% of respondents had provided support in some form. Carers of NDIS participants were asked to describe how their caring role had changed since receiving an NDIS package. A number of respondents commented that they now provide significant assistance with coordination of supports. As one carer described;

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

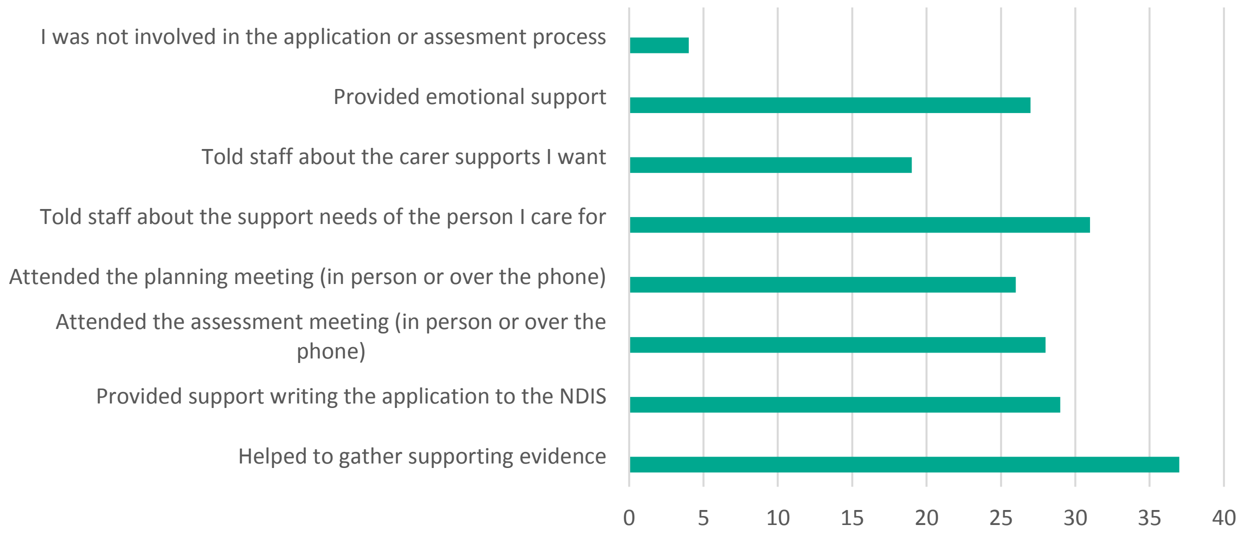
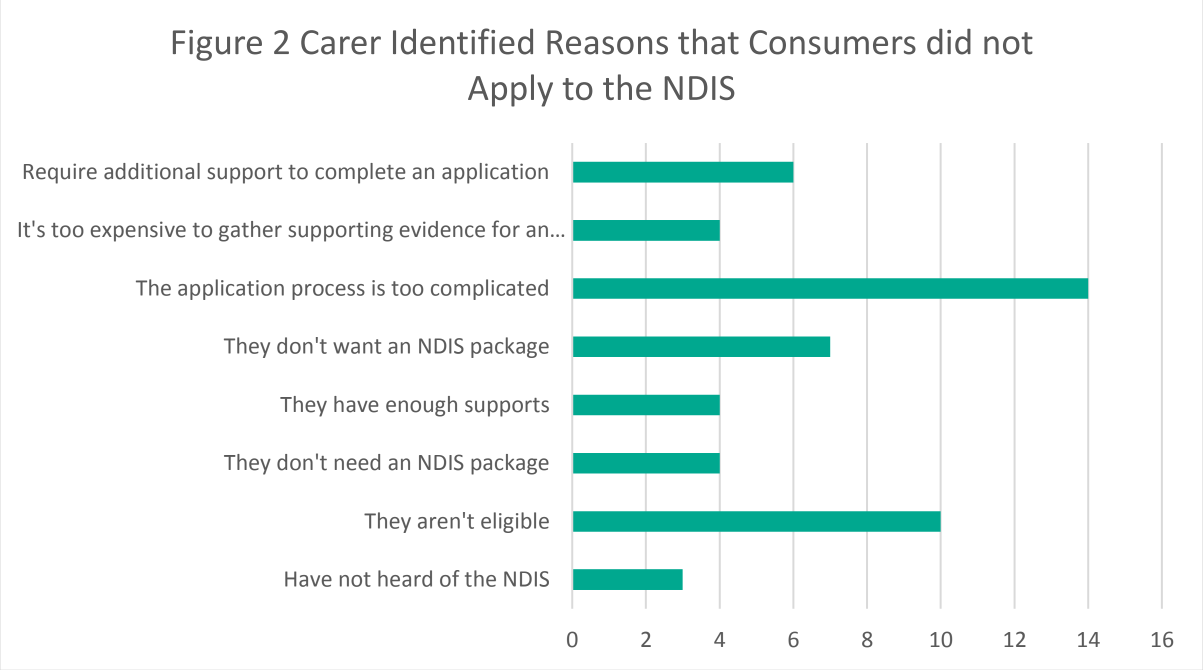


Figure 1: Carer Invovement in Assesment and Planning Processes

In our experience, there are a number of common reasons that the significance of the challenges experienced by consumers and the extent of their support needs can be missed during assessment, planning and review. The feedback we have received from stakeholders is that;

- NDIS processes are complex and often inconsistent. As a result, people don't know what is required of them.
- Participants and their carers are not made aware of the types of supports which are available through the scheme for psychosocial disability and so do not ask for them.
- Participants and their carers are not made aware of the types of supports which are available through the scheme for their carers and so do not ask for them, even when they have been identified.
- The language of disability and impairment which is used by the NDIS can be confronting and stigmatising for some consumers and may miss opportunities to identify and explore supports that can build on strengths. However, use of recovery oriented language can result in psycho-social disabilities being assessed as non-permanent and result in people being excluded from the scheme.
- Carers have valuable knowledge of both consumer's strengths and support needs as well as their own needs and their caring situation. The opportunity to tap into this valuable insight is often missed when carer's feedback is not actively sought.
- The cost and time involved in gathering supporting evidence for NDIS eligibility has also been raised by multiple stakeholders as a significant barrier to engagement with the scheme. Specialised psychiatric assessments are expensive and often cannot be bulk billed via Medicare making the cost prohibitive for some, particularly after an initial rejection by the NDIA.

44 of the carers who answered MHCNs online survey stated that the person that they care for had not applied to the NDIS. These carers were asked to identify the reasons that the person who they care for had not applied to the NDIS. Only 23% indicated that the person they care for was not eligible and of these only 9% felt that the person they care for did not need additional supports. This points to need for outreach and support to assist people with a psychosocial disability who are eligible for the NDIS to engage with the scheme.



"He is not capable of applying without assistance and he is now considered to be able to manage his life. He has no idea what to do and where to go to apply. I am living a long way away from him. I don't know how to assist him down there." - Carer

The complexity and stress involved in plan enactment and in coordinating supports can pose significant barriers which prevent participants from effectively accessing the supports available in their plans. MHCN has found multiple examples where people with a psychosocial disability and their carers have not been provided with essential information and support required to enact their plans. For example, one consumer had support coordination included in their plan, however they had not received an explanation as to what it was and so had not accessed any supports in their plan. Stakeholders have also reported concerns about unscrupulous providers who misused participants funding, either referring exclusively to their own services or depleting the package to a point where no funding was available for the participants to choose other services. At the community consultations a number of carers reported that their family members had 'sacked' their workers and refused to access the supports in their package because they had no insight into their illness and did not think that they needed assistance.

Quality support coordination was identified by stakeholders who attended the community consultations as an essential support for participants with a psychosocial disability. In our experience, although support coordination often features in NDIS packages for people with a psychosocial disability it is not always included when needed. Of the 31 carers of NDIS participants who responded to the online survey, 7 indicated that coordination of supports was not included in their package and a further 5 did not know whether it was included or not. Half of these carers indicated that they had not been able to access at least one support included the NDIS package.

"There needs to be more information and links to services. I am ringing so many services some of which do not return calls, some it's very difficult to get an appointment and others that have been recommended [to me] do not provide the service that my daughter requires." - Carer

Funding which is not used in the first year of a package is often removed at review. This places pressure on participants to use their funding and can unintentionally punish participants who experienced problems accessing supports in their plan. Removal of funding is problematic where;

- The support is needed but has not been used because additional assistance was required for the participant to access it.
- The support was needed but the market failed to provide it in an accessible form / cost in the area in which the participants lived.
- The support was not needed in the past year because the participant was relatively well but due to the fluctuating nature of mental illness is likely to be important in the future due to the periodic nature of much mental illness.
- The support is needed but as a result of mental ill health the participant was not able to or choose not to access it. The support is likely to be useful in the future when the participants health improves.

MHCN firmly believes that funding should not be removed at review unless it is demonstrated that the support is no longer needed and that mere failure to access it in a period is not decisive evidence of this. When it becomes clear during review that a participant has not spent their funding this should trigger a thorough investigation as to why supports were not accessed. Although support coordination is listed as a capacity building support, the fluctuating nature of mental illness means that it will continue to be relevant for participants with a psychosocial disability on a permanent basis, (e.g. given the need to change providers on occasion), and should not be removed at review. Support coordination will always be essential for participants to access the additional supports when they become unwell or experience a crisis, if they move or become dissatisfied with the performance of a n existing provider.

MHCN notes the significant effort which has gone into developing a tailored psychosocial pathway for the NDIS. This pathway needs to be well resourced and should incorporate an array of supports ranging from outreach, education and recovery oriented pre-planning. Authentic choice and control is enabled in a safe environment where people with a psychosocial disability are given time and support to effectively communicate their goals, strengths and needs and where trusted supports are involved. This can be achieved where;

- Extensive pre-planning support is provided for participants who have complex needs, or who have not had the opportunity to exercise similar levels of choice and control in their lives previously. A similar type of support is also likely to be beneficial pre-review.
- Local Area Coordinators ('LACs') and NDIA staff routinely engage participant's existing support networks including family members, carers and support workers.
- Consumers, carers and family members are educated about the NDIS and have been provided with clear and transparent information about NDIS processes which is relevant to their circumstances.
- Support coordination is automatically included in all plans for participants with a psychosocial disability on a permanent basis unless it is clear they do not require it. Statements by them to this effect need to be carefully examined, and carers should be consulted before the decision not to include support coordination is made.
- NDIA and LAC staff have specialised training in psychosocial disability and supported decision making.

Another essential mechanism for supporting authentic choice and control is advocacy. The need for advocacy was raised by carers, consumers and professionals at all three community consultations conducted by MHCN. There was unanimous agreement that services mandated to provide this type of support should be routinely supplied to carers and consumers especially with psycho-social disability when they engage with the NDIS. Advocacy can support people to identify and articulate their goals, strengths and needs, to understand what types of supports and services are available through the NDIS and to feel confident in asking for them. Advocacy has considerable potential to enable participants to make independent choices about how they utilise supports in their plan and to ask for a review or appeal if they are unhappy with a decision and they may not be able to take these vital steps without it.

Advocacy services can provide extensive pre-planning support and also help consumers and carers prepare for a plan review. In contrast, while LACs engage in some pre-planning with participants, they do not have the capacity or specialist knowledge to provide the high level of support that may be required by people who have complex needs.[1] A number of consultation attendees reported that the NDIA often failed to inform consumers and carers that advocacy services were available.

"The Central Coast advocacy service does not cover the NDIS so if people need help with their package they need to go to Newcastle. This stretches their services." - Professional at Central Coast Arafmi.

Advocacy is a "core component" of The NDIS Quality and Safeguarding Framework which recognizes that "there is an ongoing need for independent advocacy" for people living with a disability. Data gathered by advocacy services on the nature of concerns experienced by their clients should be used for the purposes of monitoring and evaluation of the NDIS. There is significant potential for advocacy services to provide independent oversight of plan implementation for people with complex needs. People living with a disability who have complex needs are often reliant on agencies or their carers to make decisions about their care. There is the potential for these individuals to be exploited or to receive a poor quality of supports as a result of incompetent plan management. Independent oversight of plan implementation would act as a safeguard against this.

There is also a strong argument for a well-resourced supportive interface between the NDIA, health and mainstream services which includes clearly defined referral pathways tailored to local needs to ensure smooth transitions to and from the scheme and other sectors. The NDIS's requirement of permanency of disability effectively precludes access to early intervention for psychosocial disability as permanency is generally not apparent at onset of illness. Most people with a primary psychosocial disability will only be able to access support from the NDIS once they can demonstrate a lengthy history mental illness and have had significant engagement with mental health services. Mental health services are therefore ideally placed to identify where someone is suitable for the NDIS and provide support with the application and planning process, particularly NSW Health programs like HASI and CLS which provide support for people with psycho-social disability to live in the community.

The feedback that MHCN has received from mental health professionals at both Community Consultations and via our Peak Advisory Committees is that the majority had engaged in supporting clients who were eligible for the scheme through application, planning and review processes, even where the service did not receive any specific funding to perform this task. The provision of this support took considerable time and resources and often came at the expense of attending to other

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[1] Productivity Commission (2017), "National Disability Insurance Scheme: Costs", Study Report, Canberra.

core services. A number of professionals commented that there was no clarity around which services are currently responsible for providing this type of support. MHCN notes that there are some services available in the community that provide this type of support. A portion of PiR funding is allocated to provide this assistance, however it is only available to PiR clients and there is no guarantee of that this service will continue past 2019. LACs are also mandated to provide assistance with application and pre-planning supports, however as discussed above LACs do not have the capacity to provide the intensive support required by clients with very complex needs. The danger here is that without a clearly defined referral pathway from health to the NDIS some consumers will fall between the cracks and will not receive the support they need to begin to engage with the NDIS, while rare places in HASI and CLS will be 'blocked' by people with essentially permanent disabilities needing them for extended periods.

The health system should be resourced to provide liaison and handover to the NDIS. A clearly defined referral pathway from health to the NDIS should be developed and built into the health system so that it becomes a part of normal practice from either acute or community settings. Mental health services should identify consumers when it becomes evident that their mental illness is likely to be permanent, determine the services and programs in the community which will provide support appropriate to their situation (including HASI, CLS, the NDIS or any other option) and implement a plan which engages them with these supports. Indicators that an individual should receive this kind of assistance include but are not limited to; a long-term hospital stay, regular re-admission to acute mental health services and long-term contact with community mental health services or related support services such as HASI, PHaMs or the CLS.

Furthermore, service integration between health and the NDIS is essential as scheme participants with a psychosocial disability will continue to require a combination of supports including clinical mental health care, primary health care and community supports from both the health and disability sector. Where people with a psychosocial disability disengage with the scheme, either because they become very unwell or because they are unhappy with the support received, health services are placed to support them to re-engage with their previous NDIS supports or to access more appropriate ones. Likewise, the NDIS is ideally placed to support participants to access mental health services as needed.

Significant inter-sectoral cooperation is required to ensure that health and disability services are delivered the integrated manner described above. The delivery of mental health and psychosocial disability services is now spread across multiple sectors including the Commonwealth government based NDIS, state government run health services and independently operated PHNs. This poses challenges for planning service integration and service delivery at a local level. Joint planning between PHNs, LHDs and the NDIA will support the development of referral pathways which are appropriately tailored to the local area. However, it is not even clear which agencies PHNs and LHDs should engage with to do this detailed service level planning, the NDIA or the many disparate services funded through NDIS packages. This points to the need for some form of mechanism or forum for collaboration between local providers of disability services and health services to be established.

Provision of Services

The NDIS is not a provider of last resort and was never intended to support everyone with a disability living in NSW. There is a real danger of significant gaps in services emerging as a result of the withdrawal of state and commonwealth funding to services which are in scope for the NDIS, which were supporting people who will not be eligible for the scheme. Of particular concern is the provision of carer services, community supports to people living with severe or moderate mental illness and specialised services for people with complex needs and behaviour issues associated with comorbid mental illness and intellectual disability.

Carers

“We are struggling at the best of times and now with no respite we have had more hospital admissions as we can't cope anymore.” - Carer

“We are no longer able to afford to access short term respite from our caring role. In the past the available respite has helped to reduce tension and resentment in the family. Now any options for respite come with financial difficulties that foster feelings of guilt and shame.” - Carer

“Knowing that the respite cottage at … has closed down this is a big loss for carers just to know it was there for a short breaks it was a very special place for carers and families... I will miss this so much as a carer it was my peaceful & quiet sanctuary by sea.” - Carer

The shift to a consumer directed funding model on the private market coupled with cuts to block funding of carer services at both a state and federal level is likely lead to a significant gap in the provision of carer support services. The future of carer respite services in NSW is particularly tenuous as the vast majority were funded through ADHC or supported by Commonwealth Respite programs which are set to be defunded later this year. The new Integrated Carer Support Services will have limited scope to provide respite support as only a small portion of funding is expected to be allocated for individualised carer packages. In particular, MHCN is concerned that the defunding of Mental Health Carer Respite will leave mental health carers without the specialised services that they require. As block funding is scaled back, carer services can be expected to be increasingly reliant on the NDIS, which has extremely limited breadth for the provision carer supports.

The participant driven nature of the NDIS means that the needs of carers are often not accurately reflected by the types of supports provided by NDIS packages or are missed entirely. MHCN has found multiple examples of NDIS packages which do not include carer supports even though family members had significant caring responsibilities. In fact, 73% of the carers of NDIS participants who responded to MHCNs online survey indicated that carer supports were not included at all in their NDIS package. Furthermore, carers of people with mental illness who are not eligible for the NDIS will continue to require supports outside of the scheme.

The NDIS lacks a formalized assessment process for family members and carers which would ensure that carer’s needs are routinely considered during assessment, planning and review. Carers who attended MHCNs consultations or training events, reported that they had not been informed that carer supports were available through the NDIS at all, that they were not aware that they could submit a carer statement to the NDIA, that no one had asked them about their needs during the assessment and planning processes or that the NDIA did not identify or involve them at all. Less than half (42%) of the respondents to MHCNs online survey who cared for someone with an NDIS package indicated that they had discussed carer supports during planning processes.

The exclusion of carers from planning processes means that the NDIA is often reliant on participants portrayal of their informal care network and the needs of their carers when planning carer supports. It is not uncommon for people with a psychosocial disability to lack insight into the impacts of their mental illness and to experience difficulties in communicating their own support needs, let alone being able to present an accurate picture of their carer's support needs.

An additional issue which hinders carer's access to supports via the NDIS is that the NDIS will only fund carer services where it can be demonstrated that supports will improve the care provided to the participant or the sustainability of the caring role. Supports which are 'reasonable and necessary' for the participant and which may have a positive 'flow on effect' for carers can also be funded. For example, carer respite is not provided by the NDIS however some supports may allow for the carer to take a break from the caring role while the participants attends activities or spends time in short term supported accommodation.

These supports are not funded on the basis of carer need but rather must be justified in terms of the benefit to the participant. However, there is much more content to effective carer respite and support than temporary relief from the hands-on caring role. There is no guarantee that supports will be available to carers in a timely manner when they need it as the participant decides when and how these supports will be accessed. Supports with positive 'flow on effects' to carers, while valuable, are not the same as carer services which incorporate carer outcomes as a primary purpose of their service delivery. Carers needs are distinct to and may occasionally conflict with the needs of the people that they care for. When this happens, carers of NDIS participants require an alternative avenue for support.

Carer services can have a diverse range of positive outcomes for carers which are not valued within the NDIS pricing framework including;

- Improving carers physical health and emotional wellbeing.
- Promoting opportunities for and supporting social and economic participation.
- Supporting and building personal relationships including the caring relationship and relationships with other family members, friends and acquaintances.
- Providing an opportunity for carers and consumers to spend time apart from each other and focus on their individual needs. This also provides careers with a break from their caring responsibilities[2].

The focus of the NDIS on participant outcomes means that services which are oriented around carer outcomes may not be as viable in the private market. MHCN has been informed of the closure of a number of respite services. A number of services, including Bradfield Park Carers Program, which previously provided carer focused supports have also informed us that they have now shifted to consumer oriented models of service delivery because the carer oriented model was no longer sustainable with the shift to a consumer directed funding model. 26% of carers who responded to MHCNs online survey indicated that they had lost access to carer services since the NDIS rolled out in their area, with 18% indicating that they had lost respite supports. This is in line with the findings of the National Disability Services (NDA) State of the Disability Sector Report which indicates that respite services are under significant strain. The NDA surveyed 516 organisations providing disability services and found that 6% plan to stop providing respite services and an additional 16% plan to reduce them (NDS, 2017).

For services which specialise in the provision of mental health respite supports, the pressures on carer services outlined above are compounded by the fact that a significant portion of people with a severe mental illness are not expected to be eligible for the scheme or able to access it in its current form.

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

Specialised services which supply mental health respite are essential because the stigma associated with mental illness and the unique nature of mental health caring compared to other types of care means that mental health carers often feel uncomfortable seeking support from mainstream services. Carers of this cohort will continue to require respite support outside of the scheme, however block funding for specialised mental health carer respite is due to be discontinued and there are no alternative plans to fund this type of support by any tier of government. Furthermore, research indicates that niche services often fail to be financially viable within a consumer directed funding model[3], so it is questionable whether specialised mental health carer supports can be sustainably provided through the scheme, especially in regional or rural areas.

The economic and social contribution of mental health carers to their communities is significant. A recent report by Mind Australia estimated the economic value of informal mental health caring at $60.3 billion nationally[4]. Mental health carers play an integral role in supporting the wellbeing of the person they care for and promoting recovery which is increasingly understood to happen in the context of an individual's familial and social networks[5]. The challenges associated with mental health caring are not inconsequential. The fluctuating nature of mental illness means that carers often experience a great deal of unpredictability within their lives. Many carers describe the need to be 'on call' to provide support with crises on an almost permanent basis, which can be very inconsistent with maintaining employment.

Access to carer services is essential to support carers health and wellbeing as well as to improve the sustainability of the caring role. The Carers Recognition Act 2010 states that carers should be able to 'enjoy optimum health and social wellbeing and to participate in family, social and community life'. It also endorses carer's rights to be to be 'acknowledged as individuals with their own needs within and beyond their caring role.'[6] MHCN firmly believes that carers should be able to access supports either outside or within the scheme in their own right and on the basis of their own needs regardless of whether the person they care for is an NDIS participant or not. This requires that alternative services which provide carer oriented supports including carer respite continue to be funded at a rate which is similar or greater than that which it was funded at the start of the scheme.

Community Mental Health

"I applied for myself and was rejected. I believe I need support but was found to be too capable. I totally disagree. I struggle within myself and that impacts my daughter. I had good support and now that has been removed because I do not qualify. Pre NDIS I was part of the PHAMs program which was very helpful. We are both struggling now." - Carer and Consumer

MHCN is concerned that the planned closure of Personal Helpers and Mentors Program (PHaMs) and Partners in Recovery (PiR) will widen gaps in the provision of community mental health supports, placing greater strain on acute mental health services. It is clear that many people with severe,

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

[4] Diminic, S., Hielscher, E., Lee, Y., Harris, M., Schess, J., Kealton, J. & Whiteford, H. (2016) "The economic value of informal mental health caring in Australia: technical report.", The University of Queensland, Brisbane.

[5] Rhys Price-Robertson, Angela Obradovic & Brad Morgan (2017) Relational recovery: beyond individualism in the recovery approach, Advances in Mental Health, 15:2, 108-120

[6] Commonwealth of Australia (2010), Carers Recognition Act, Commonwealth of Australia, Canberra.

permanent psycho-social disability and major support needs will not wish to, or be capable of accessing support under the current NDIS package model but are currently effectively supported by these schemes. Community mental health is already under resourced and is not uncommon for consumers to have to wait until they become very unwell and require acute services before they are able to access mental health care. This creates a cycle in and out of hospital for some consumers which is costly to both the health system and at a personal level. It also generates poor outcomes for carers who often, in the absence of services, take on significant caring responsibilities sometimes at the expense of their own health and wellbeing. The NDIS is expected to provide support for only a small minority of people living with severe mental illness so it is essential that a variety of supports are readily available outside of the scheme to meet the needs of the population. Furthermore, community supports provide essential outreach and assistance to people who experience barriers accessing or maintaining engagement with the NDIS due to the nature of their illness.

MHCN notes the continuation of state funding to the Housing and Accommodation Support Initiative (HASI) and Community Living Supports Program (CLS) and commends the commitment to providing these community supports. This demonstrates an acknowledgement that community mental health programs need to continue to be available outside of the NDIS. These two key programs provide services which would otherwise not be accessible outside of the NDIS including; support to maintain stable tenancies, increase independence in daily living, maintain and develop relationships and participate in community activities, education and work[7]. However, both HASI and CLS are currently operating at full capacity and have significant wait times for access in some areas. Funding to these programs needs to be expanded in order to meet the needs of the population. A pathway to NDIS supports through these programs could significantly alleviate this.

PiR and PHaMs provide essential services to people with significant mental ill health who cannot or choose not to be supported through the NDIS. Consultations with carers, consumers and professionals indicate that PiR and PHaMs programs are highly valued by all three groups. PHaMs and PiR both have a significant outreach and community engagement component and have demonstrated success in engaging with clients who would not otherwise access mental health services. PHaMs employs a ‘no wrong door’ policy and does not require a formal diagnosis of mental illness in order for a person to access services. PiR organisations typically seek to engage with services and families within the community to develop trust and awareness and thereby encourage consumers to access their services. MHCN routinely refers callers to our Carer Connections Helpline to both programs where relevant. In our experience, where consumers have no previous history of engagement with community mental health services, PiR is often the only affordable service which will agree to conduct a house visit. Both services provide intensive case management and service coordination as well as wrap around support to consumers. The same level of case co-ordiantion is unlikely to be available through the NDIS. PiR and PHaMs services employ a skilled workforce which risks being lost with the transition to the NDIS, as the current prices set by the NDIA are likely to be insufficient to retain highly qualified staff. MHCN strongly urges that funding to both PiR and PHaMs continue past 2019, however if funding is discontinued, alternative programs which provide the same type of supports will need to be funded or many people will simply be ‘lost to care’.

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[7] Bruce, J., McDermott, S., Ramia, I., Bullen, J. and Fisher, K.R. (2012), Evaluation of the Housing and Accommodation Support Initiative (HASI) Final Report, for NSW Health and Housing NSW, Social Policy Research Centre Report, Sydney.

Comorbid Mental Health and Intellectual Disability

"[Loss of support services] has come at a time of change of circumstances, worsening symptoms and challenging behaviour, this is having negative flow on effect on family members and significant negative financial impact, also impacting on ability to remain in affordable accommodation in our area [which is] accessible to services, school and support networks" - Carer of a person living with mental illness and intellectual disability.

MHCN is gravely concerned that there is no provider of last resort for people living with a disability in NSW, particularly for people with complex needs. Prior to full scheme implementation, ADHC was responsible for ensuring that adequate disability supports were available at a population level on the basis of need. As of July 2018, the NSW government transferred responsibility to the NDIA and it is intended that, where 'reasonable and necessary' supports are not accessible, the NDIA will intervene to ensure that alternative solutions are made available.[8] However, provision of disability services via the NDIS is entirely reliant on market capacity as the NDIA has no policy in place which guarantees that a provider of last resort will be made available in the case of market failure.

The concern is that non-government organisations are likely to be reluctant or unable to accept clients who have severe behavioural problems associated with intellectual disability including those with comorbid mental illness. The level of specialist expertise and high staffing requirements involved, means that specialised services for people with very complex needs (especially those that must be delivered by teams), are unlikely to be financially viable in the private market. These circumstances leave the people with the highest support needs without an assurance to lifelong access to the level of specialised care and supportive accommodation which they require. There is potential for a number of very vulnerable individuals to be rendered homeless.

In the absence of appropriate support from the disability sector, these individuals will be forced to seek assistance from mental health services, which can allegedly cope with disturbed behaviour. This will place significant strain on mental health services which are not designed to provide long term care to people with intellectual disabilities. To illustrate the possible extent of the issue, the Survey of Disability Ageing and Carers found that around 2.9% of people living in Australia aged have an intellectual disability.[9] The rate of mental illness among this cohort has been estimated at 40%.[10][11] Limited data is available to determine portion of people living with intellectual disability who also have complex health needs, however some figures suggest that at least 15,000 people in NSW would fall into this category.[12] By contrast the total number of publicly provided mental health beds in NSW is 2803[13]. A number of health officials have indicated to MHCN that they have observed an increase in the number of people with significant behavioural issues as a result of intellectual disability whether or not they also experience comorbid mental illness and presenting to acute mental health services at their local health district. This situation needs to be closely monitored and there is the need for data collection on the number of people with intellectual disability who present to mental health services.

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[8] NSW Government (2015) "NDIS Communications Handbook" NSW Government, Sydney.

[9] ABS (2012), Survey of Disability Ageing and Carers, 2012

[10] Einfeld S, & Tonge B. (1996)." Population prevalence of psychopathology in children and adolescents with intellectual disability: I. rationale and methods". Journal of Intellectual Disability Research, 40(2), 91-98.

[11] Einfeld S, & Tonge B. (1996b)." Population prevalence of psychopathology in children and adolescents with intellectual disability: II. epidemiological findings". Journal of Intellectual Disability Research, 40(2), 99-109.

[12] KPMG (2009), "Analysis of costs and benefits of specialized intellectual disability health services and enhanced clinical leadership", NSW Health, Sydney.

[13] NSW Health , "Annual Report 2016-17", NSW Health, Sydney.

A small number of government-run disability services have yet to transition into the private market, including the Integrated Services Program and the Community Justice Program. These programs provide support to individuals with highly complex needs and fill a gap in service provision which is unlikely to be covered by either health services or the NDIS. Both programs support individuals who are at a high-risk harm, either to themselves or others. This level of risk would make private providers hesitant to accept these individuals as clients. The Community Justice Program provides supported accommodation, case management and clinical support to individuals with an intellectual disability who are exiting a criminal justice facility. The program aims to reduce reoffending by supporting the transition of these individuals into the community. The Integrated Services Program provides cross-agency coordination and case management to individuals with complex support needs many of whom have multiple diagnoses including mental illness, intellectual disability, physical disability and issues related to substance use. The program provides support and accommodation to individuals while seeking to "develop sustainable, long term models of support for clients and to identify appropriate agencies to implement them".[14] The program has been demonstrated to reduce the need for clients to use of health services and decrease contact with the criminal justice system, which also reduced costs to both systems[15]. This model is highly effective and could be considered for people with highly complex needs who do not have access to reasonable and necessary supports via the NDIS.

MHCN urges the NSW government to block fund a provider of last resort for crucial services the market will not provide. Where it is identified that a participant cannot access the 'reasonable and necessary' supports funded by the NDIS or where a person living with a disability does not have access to appropriate supports, the provider of last resort should be mandated to provide immediate support and continued case management unless and until a sustainable solution can be identified and implemented. Where possible, the provider of last resort should work with other agencies and disability services to assist them develop capacity to provide supports to individuals with complex needs. Furthermore, remaining government run disability services, including the Community Justice Program and the Integrated Services Program, should not be transitioned into the private market.

WORKFORCE & SECTOR DEVELOPMENT

According to the NDIA's Integrated Market, Sector and Workforce Strategy, the disability workforce will need to more than double in size to 162,000 FTE nationally between 2015-16 and 2019-2020, in order to meet the new demand for disability services. This requires considerable investment and strategic planning to support the development of a skilled workforce which has the capacity to provide quality disability services. Given the long history of underfunding of mental health and disability services, the NDIS should be viewed as an opportunity to bolster funding to the mental health and disability sector and workforce rather than as an alternative source of funding.

MHCN is concerned that at present the NDIA price guide does not match the cost of the provision of supports to people with a psychosocial disability. This has led to a loss of infrastructure and skilled workforce within the psychosocial disability sector. This will be compounded by the withdrawal of funding to PiR and PHaMs as both programs employ highly qualified staff. The uncertainty of the current funding environment has contributed to the casualisation of the workforce and the

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[14] Purcal, C., Zmudzki, F., & Fisher, K.R. (2016). Evaluation of Outcomes for People Nominated to the Integrated Services Program. (SPRC Report 18/16). Sydney: Social Policy Research Centre, UNSW Australia.

[15] Purcal, C., Zmudzki, F., & Fisher, K.R. (2016). Evaluation of Outcomes for People Nominated to the Integrated Services Program. (SPRC Report 18/16). Sydney: Social Policy Research Centre, UNSW Australia.

introduction of the 'gig' economy to the disability sector. A number of stakeholders have reported that the NDIAs pricing determinations do not reflect the costs of;

- Hiring and retaining qualified workers with specialised knowledge in mental health;
- Upskilling workers by providing training and other opportunities for professional development; and,
- Providing appropriate levels of supervision to staff.

Changes to the workforce have had a significant impact on both carers and consumers. People with a psychosocial disability rely on consistency of workers as this allows for the level of trust necessary for a supportive relationship to develop. At all three of the community consultations, carers and consumers reported significant dissatisfaction and distress around the chopping and changing of workers by services, often at short notice or without proper handover. Another common concern was that supports often are unavailable when a staff member is absent as there is no replacement, implying that services are hiring a bare minimum of staff. Carers reported having to step in at short notice to ensure that their family member received the support they required as a result. Finally, there was significant anxiety, on the part of carers and consumers, around the fact that it is not uncommon for support workers to have no specialised knowledge in mental health. This is of concern as the type of care which is supportive of people living with psychosocial disability differs significantly from other types of disability and requires considerable knowledge of recovery-oriented practices and trauma informed care.

There is the need for considerable investment into the psychosocial disability sector to ensure that services are provided by a skilled and appropriately qualified workforce. For services to be able to provide the conditions, wages, job security and training necessary to attract skilled staff, the price of service delivery set by the NDIA needs to increase considerably. Following the release of the independent pricing review earlier in 2018, the NDIA is developing a definition of complexity which takes into account the high level of skill required to meet participants needs and is developing an additional high level pricing tier which will take this into account. This needs to be completed as a matter of urgency as in the interim the sustainability of psychosocial disability services is at risk and highly skilled staff are leaving the sector. The NSW government should consider injecting additional funds into the psychosocial disability sector to support providers to train and retain skilled employees and to continue business. MHCN is also supportive of ongoing pricing reviews, conducted in consultation with providers of psychosocial disability supports, to ensure that prices appropriately reflect the cost of delivering services. A significant factor in regional service provision for example is the fact that travel time between different clients is not funded, meaning that effective rates of pay for many workers can fall well below award levels if their time in traveling between clients is considered. This makes this sector deeply unattractive to highly skilled workers. The NDIA should review its pricing model to better understand the effective rates of pay it allows employers to offer.

The combination of untrained workers operating at a low level of supervision can be a dangerous one, as is evidence by recent reports that have highlighted links between unsupervised and unskilled staff and disability and elder abuse[16][17][18]. Although the NDIA has set specific qualification requirements

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[16] Australian Law Reform Commission (2017), "Elder Abuse – A National Legal Response", ALRC Report 131, Australian Law Reform Commission, Sydney.

[17] NSW Parliament (2016), "Elder Abuse in NSW", General Purpose Standing Committee No. 2, Sydney.

[18] The Senate (2015) "Violence, abuse and neglect against people with disability in institutional and residential settings, including the gender and age related dimensions, and the particular situation of Aboriginal and Torres Strait Islander people with disability, and culturally and linguistically diverse people with disability", Commonwealth of Australia, Canberra.

around the delivery of some types of support, many supports do not have a minimum standard of worker qualification. This is in recognition of the fact that a range of qualifications, skills and experience will support the development of a diverse workforce and because a significant expansion in the workforce is necessary. However it is of concern that the standards described in the *Provider Registration Guide* do not address the level of supervision or training provided to staff once they are employed within the sector.

To support the development of a skilled psychosocial disability workforce, the NSW government should consider funding scholarships and traineeships for employees of registered providers to gain qualifications in mental health. MHCN notes the success of this approach in supporting the expansion of the peer workforce in NSW. The NSW government should also consider gradually introducing regulations which require at least a portion of staff of registered providers that provide support to participants with a psychosocial disability to have relevant qualifications and skills in mental health. This recommendation is given with the caution that providers will need to be supported to train and employ staff so that they have the capacity to meet this standard.

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