



Mind Australia Limited

Response to the Productivity Commission inquiry
into NDIS costs

3 April 2017

Introduction

Mind is pleased to present its submission to the Productivity Commission's inquiry into NDIS costs. We would be happy to provide more information on any of the matters that we have raised herein, or to expand or clarify any of our comments. We would also welcome the opportunity to attend a hearing or other consultation, should this be appropriate.

Mind Australia Limited (Mind)

Mind Australia Limited (Mind) is a leading non-government community managed specialist mental health service provider. We have been supporting people who are dealing with the day-to-day impacts of mental illness, as well as their families, friends and carers for 40 years. We deliver a wide range of recovery-oriented services and supports to people challenged by mental illness and psychosocial disability, including: personalised support; group support; care co-ordination; allied psychological services; residential services; family and carer services; and, telephone helplines and online forums.

This year, Mind will provide support to around 12,000 people across five states, delivered from 64 different service locations. In addition, we provide support to 3,000 people caring for someone with a mental illness.

Mind will operate as a provider of services and supports who have NDIS funding packages in multiple locations across Australia. We are currently providing services to over 60 people in the NDIS in the North East Melbourne Area (NEMA).

In addition to our service delivery, over the last six years we have made a substantial investment in a research program that contributes to public knowledge on mental health recovery and psychosocial disability. Part of our research program focuses specifically on the NDIS and the inclusion of people with disability associated with mental illness in the scheme. We have funded the development of three literature reviews on different aspects of operation of NDIS in relation to psychosocial disability. These can be accessed via our website at the following locations:

Mental health and the NDIS: a literature review (2014)

<https://www.ndis.gov.au/html/sites/default/files/files/Mental-health-and-the-NDIS-Literature-Review.pdf>

Implications for family carers when people with psychosocial disability have individualised funding packages: literature review (2015)

https://www.mindaustralia.org.au/assets/docs/News%20&%20Media/Mind_Literature_Review.pdf

Effective evidence-based psychosocial interventions suitable for early intervention in the NDIS: promoting psychosocial functioning and recovery (2016)

https://www.mindaustralia.org.au/assets/docs/research/Mind_report_early_intervention_NDIS_full_version.pdf

Our submission draws on these pieces of work as supporting evidence for our views.

Key points

We appreciate that it is still early days in the implementation of NDIS, and commend the NDIA and departments at all levels of government across Australia for their preparedness to work hard to ensure that the scheme is working as well as possible for **all** participants. We have some preliminary comments that we consider to be of the highest importance in terms of the inclusion of people with psychosocial disability in the scheme. These comments frame our specific responses to this review:

- The vast majority of people with psychosocial disability have not had choice in their interactions with service systems – in fact, many have had choice denied or removed under the statutory powers of state/territory mental health legislation. We need to develop a shared, practical sense of how to support choice and control for this group. Becoming empowered choice-makers will, for many individuals, be a developmental and evolutionary process, during which they will require specialised support from an appropriately trained and experienced professional, such as a support co-ordinator or a peer worker, or both.
- There are many problems with the planning process as it is currently operating. We believe that these are short-term, and a result of the task of transitioning so many people so quickly into the scheme. However, beyond the short-term problems, we note the critical role that planners play in facilitating control and choice. We believe it is essential that they receive specific training and some form of certification to demonstrate competency in working with people with psychosocial disability. We are concerned that ineffective planning will lead to poorly targeted supports that will be less efficacious than they could be in supporting capacity development and independence. Put another way, without effective planning, people will become dependent on expensive supports and will not progress in their recovery of functional capacity.
- The episodic nature of mental illness and its relationship with need for support requires better understanding and practical solutions that do not encourage service dependency. The current NDIS planning cycle is 12 monthly, and the early review process appears to be inflexible and slow. This means that people ask for expensive supports in their plan **just in case** they get unwell, rather than ask for what they need, knowing that they can have a **just in time** review if things change and they need more support for a time. For instance, someone may need intensive support and co-ordination for 6 months in one year, following a period in hospital – and then return to a much lower level of support, or even no support at all. We need a **just in time** approach to planning, rather than a **just in case** approach where people emphasise their worst days, rather than what most days are like. When people are becoming unwell, they cannot wait for a review, and may not be able to attend a meeting with the planner themselves – however the current situation demands both. The result is a system that is expensive for the NDIA, the individual and for the mental health services that abuts the NDIS.
- We believe there is an urgent need to develop a standardised, validated tool to assess the level of severity and domains of functional impairment for people with psychosocial disability. Such a tool would be the basis for equitable determination of 'reasonable and necessary' supports and, over time, could be used to develop an evidence base that linked impairment to purchased supports to participant outcomes. This would be of assistance to planners, and enable participants to make informed choices about what works. A standardised, validated assessment tool would provide a practical mechanism that would enable NDIA to influence costs and ensure that value for money is being delivered.
- Packages also need to be informed by what people want. The development of a peer workforce has been demonstrated elsewhere as being an effective strategy to assist people to make choices that will build capacity and independence, rather than increase their reliance on static services funded by the state. Drawing on effective assessment of need (as outlined in the point above), peer workers are well placed to motivate people to do things for themselves and help them make and implement choices that enhance their independence and extend their aspirations – away from a reliance on the state. We note that the need for this form of support may be long term, a navigator in life to help people do things for themselves. We argue that ongoing support from a peer worker is still more likely to be cost effective than having core tasks done for you for the rest of your life, so that your house may be clean and your shopping done, but you are completely cut off from your community.

- The final opportunity to influence costs in the NDIS for people with psychosocial disability relates to early intervention. Connected to the lack of a standardised, validated tool to assess functional impairment, it appears that there is a lot of well-intentioned service provision that is not related back to the evidence on what works for people with mental health issues. There is good quality evidence of effective interventions that improve functional capacity for people with psychosocial disability (Hayes 2016). This includes interventions that can be applied after a period of illness when someone's functional capacity has deteriorated. However, planning, purchase and provision decisions are not being based on this evidence. The failure to deal with early intervention in relation to psychosocial disability has long-term cost implications for the NDIA.

The remainder of this submission addresses specific sections from the issues paper.

Specific issues

Scheme costs (section two in PC issues paper)

In relation to scheme costs and psychosocial disability, there are three main issues:

- Identifying practical arrangements that will deliver good outcomes for the most cost-effective price
- The challenge of early intervention, and the long-term cost implications of failing to deal with this

The pivot point for each issue is the lack of a comprehensive mechanism for operationalising 'reasonable and necessary' in ways that are equitable for participants and offer Australian tax payers value for money. Australians need the surety that the scheme is being operated in the most cost effective way **to achieve the intention of the Convention on the Rights of Persons with Disabilities (CRPD)**, the foundation for the NDIS Act 2013.

The question of how to **understand and predict scheme costs for people with psychosocial disability** is made complex because of the lack of clear evidence on the trajectory of psychiatric illnesses. The evidence shows variability in the extent to which individuals regain good levels of functionality following an episode of illness or between episodes (Nicholas et al 2014, p. 27-28). Moreover, individuals with the same diagnosis can be affected functionally very different ways by the symptoms of their illness (Meagher and Naughtin 2014, p.14). Finally, illness effects intersect with other experiences that impact on functionality, and unaddressed, tend to accumulate over a person's life course. People in their fifties and early sixties who have not received timely early intervention focused on rehabilitation following a period of illness, or who have never had psychosocial support, may end up being severely disabled, with limited functional capability and requiring a great deal of support.

On the other hand, there is significant evidence that 'people with psychosocial disability make significant gains in their capacity to engage in social and economic participation if they are offered early intervention' (Hayes 2016, p.19). **Early intervention** has been demonstrated to be efficacious in reducing people's experience of impairment and maximizing their opportunities to work, stabilize their housing, improve their relationships with people around them, gain new skills, and learn to manage their health and wellbeing. On the basis of the evidence presented in her literature review, Hayes argues that early intervention in the NDIS context may enable people to reduce their reliance on the scheme in the future, with the effect of reducing scheme costs in the long run. She notes that early intervention may also reduce pressure on other health and welfare services.

We strongly support this position, and suggest that early intervention can be efficacious at a number of significant points:

- When someone with existing psychosocial disability becomes unwell, it is not unusual for them to lose functional capacity that they had prior to their period of illness. Early intervention at this point can help further deterioration, and in some cases, assist people regain functional capacity.
- When someone is 'new' to psychosocial disability, it is likely that early intervention will be efficacious in retaining or building on existing capacity.

We note that the evidence that Hayes presents distinguishes between early intervention that is primarily aimed at ameliorating symptoms of illness (and therefore out of scope for NDIS), and interventions that are primarily aimed at psychosocial functioning and are therefore potentially in scope for the NDIS. We believe that the NDIS has the potential to prevent or delay further functional deterioration for people with psychosocial disability **if** people are able to access the right supports at the right time in their lives and in their illness journeys. The incorporation of a suite of price items on early intervention in psychosocial disability offer a cost lever that is amenable to influence by government.

To return to the issue of assessment of **'reasonable and necessary' support** need, we note that the current practice of determining the composition of packages is quite rudimentary. It is reliant on diagnostic, clinical and other allied health reports that participants are able to provide to support their claims in relation to their specific functional impairments and needs for support. Unlike some other disability types (for instance, spinal cord injuries, autism or Acquired Brain Injury), there is no validated, standardised instrument to quantify the degree of functional impairment that someone with psychosocial disability experiences, nor the specific nature of that impairment and the life domains that it impacts. This means it is very difficult to help people make choices and design packages of support that draw on targeted evidence of what works, for whom (or for what aspirations/ends) and in what circumstances. The risk of this is that people will choose what is obvious – the cleaner, the support worker to go shopping, to the swimming pool or bank – and not what is less obvious, for instance social skills training and supported employment to assist someone who wants to return to work after languishing in a psychiatric hostel for 17 years.

Understanding cost drivers, and thus being able to influence them, would be greatly improved by the **development of standardised and validated assessment tool for psychosocial disability**. This would provide a transparent and equitable mechanism for making individual resource decisions. Importantly, it would also generate data that could be used for sophisticated monitoring of expenditure, package composition and outcomes over time – a key component of the actuarial approach that underpins the NDIS. Specific monitoring needs to be designed that would provide data on supports purchased and changes in functional capability, against different demographic characteristics, including diagnostic categories. Such data would need to be set against an understanding of what supports are available in the marketplace for people with psychosocial disability, and whether these are supported by high quality evidence. The development and ongoing refinement of reference packages based on NDIS use data would also assist in influencing costs **and** improving people's life outcomes.

We understand that the development of a standardised and validated assessment tool would require specific investment by the NDIA, and we understand that this development would take around 24 months to complete. We consider that it is vitally important that this work is undertaken prior to full scheme design in 2020.

Mind is currently leading a research study in the Barwon, Hunter and Perth trial sites exploring the lived experiences of 'choice' and 'choice-making' in the context of NDIS of participants with psychosocial disability. We draw on emerging findings from this study in our responses to the questions on p12:

- Plan utilisation: people with psychosocial disability need assistance to implement their plans. Their stated preference is for independent, professional assistance (Brophy et al 2014), provided by skilled personnel with a knowledge of mental illness and psychosocial disability, trained in supported decision-making and who are also empathic, trustworthy and reliable. Most people with psychosocial disability experience cognitive impairment – either ongoing or periodically – and this makes the complex processes of the NDIS quite daunting. The closer to an episode of illness, the more likely they are to need assistance to implement their plan.
- Systemic market issues: we believe that there are gaps in the market in relation to the provision of quality psychosocial supports – in both core and capacity building. Whilst services may be available, support workers are not always trained and experienced in working with this cohort, and do not understand the support needs of people with psychosocial disability. Social anxiety, low motivation and long experiences of stigma and discrimination impact this group in ways that can make simple tasks like personal care and hygiene, shopping or house-cleaning very difficult. In turn, this can make it difficult for a participant to find a provider and a worker with whom they feel safe enough to embark on a more independent life.
- Higher than anticipated entry from trial sites: one of the factors affecting the number of entrants with psychosocial disability in trial sites is the previous inconsistent reach of disability services to this cohort. People living in the supported accommodation sector – called by different names across the eight state/territory jurisdictions – have often languished with no disability support, beyond the practical assistance with shopping, cleaning, washing and cooking provided to all residents, generally as a 'job lot'. Whilst these people may have been 'known' to mental health or housing services, they did not necessarily show up in disability services databases, since they rarely received disability supports. The regulatory settings for this sector mean that, in the context of NDIS, this is a cohort who can be identified and whose access to the scheme can be co-ordinated – thus bringing into the scheme a cohort of people who have not previously accessed disability supports.

Scheme boundaries (section three in PC issues paper)

In relation to the boundary between the NDIS and mental health services, there are three main issues:

- The lack of a reliable means to determine the severity of psychosocial disability, and therefore eligibility for an individual funding package
- Lack of clarity around responsibility for support provision to people with lower levels of psychosocial disability, and the risk of inequitable arrangements across state/territory jurisdictions
- Gaps in relation to psychosocial rehabilitation and uncertainty around early intervention (covered in the previous section)

We believe the eligibility requirements set out in the NDIS Act are appropriate for the psychosocial disability cohort. We note that the Productivity Commission's original estimate for primary psychosocial disability was based on the prevalence of psychotic illness in the Australian population, and gave a figure of 57,000 potential participants (Productivity Commission 2011). We also note that the National Mental Health Consumer Carer Forum (NMHCCF) provides a much higher estimation of between 149,800-206,000 people with severe or profound core activity limitations related to mental

illness (NMHCCF 2011). We understand current estimates indicate that around 70,000 people with primary psychosocial disability will access the full scheme, and a further 20,000 with dual disability.

It remains difficult to estimate accurately the numbers. There are three reasons for this. Firstly, what constitutes psychosocial disability is contested, as the NMHCCF document makes clear (NMHCCF 2011). Secondly, there is no accepted, standardised means of measurement of severity of psychosocial disability which could be used to establish a benchmark as the scheme develops (as outlined in the previous section of this submission). Finally, mental illness has a cumulative impact that intersects with other forms of exclusion and marginalisation to create impairing effects for identifiable cohorts of people with mental illness. This effect can be seen in studies on the population with severe and persistent mental illness (eg Morgan et al 2011). However, simply using illness prevalence data to estimate disability when it is understood as an interaction between an individual's pathology and social structures fails to take account of the variability in individual illness experiences and trajectories (Nicholas et al 2014).

Notwithstanding, Mind agrees that a flexible approach to the illness prevalence figures – as appears to be the NDIA's current approach – is the best mechanism available at present. A standardised, validated assessment tool, however, would enable a more reliable picture of need to be built over time.

At one level, arrangements at the intersection between mental health and the NDIS are clear. The separation between clinical and medical treatments to ameliorate the distressing symptoms of mental illness and the provision of disability supports to enable people to participate in a life of their choosing can, for the most part, be clearly understood. However, it is less clear in relation to behavioural interventions and psychological therapies. We note that people with other primary disabilities are able to access these supports, where they are deemed to play a role in maintaining or improving an individual's functional capacity. In the case of mental health, where the same services can be provided as a part of a treatment approach to illness, the boundary is less clear. Clearer guidance on the circumstances in which people can request the inclusion of behavioural and psychological interventions would be helpful in this case.

We are not aware of particular gaps or cost shifting at the interface between NDIS and mainstream services, as raised in the Issues Paper. The more problematic boundaries are at the interfaces between NDIS, clinical (state/territory-run) services and between NDIS and Primary Health Networks (PHN). Each year, around 290,000 people with severe mental illness need some kind of community support, including 180,000 adults who require individual support (Mental Health Australia 2016). In addition, there are 154,000 unpaid carers who require support without which their ability to provide essential care is jeopardised. This raises a question about what will be provided for around 200,000 individuals and up to 154,000 carers. It is unclear which level/s of government is/are responsible for ensuring that the support needs of the cohort of individuals with severe mental illness who need support in the community. The situation varies between state/territory jurisdictions, depending on specific arrangements around NDIS funding in bilateral agreements, with the potential to cause the fragmented and inequitable arrangements that led to the implementation of national scheme in the first place.

In terms of services, we believe that the emerging gaps relate to: psychosocial rehabilitation – the support that people need after an episode of illness to get their lives back on track, and to prevent or delay loss of functional and disability; and to supports for less severe psychosocial impairment and disability. The Productivity Commission's initial inquiry report into disability care and support was clear that these services sat outside of the NDIS. We agree with this position, but note that the current lack of clarity and inequity in emerging arrangements mean that there is a risk that if people cannot get the rehabilitation support they need after a period of illness, their functional capability may deteriorate,

resulting in higher levels of psychosocial disability than are currently prevalent. The same applies to early intervention. In addition to our comments in the previous section, we note that the Commission's original report placed early intervention outside of the scheme, on the basis that its focus was clinical in nature. We believe that the evidence presented by Hayes demonstrated that this is a narrow frame, and there are some early interventions that are psychosocial in nature and do fit within the scope of the scheme (Hayes 2016). Whilst we do not believe that these gaps should be solely addressed by or incorporated into the NDIS, they do need policy and funding attention as a matter of urgency.

In relation to the ILC program, using the estimate of 70,000 participants with primary psychosocial disability and the current non-eligibility rate of 22% for this cohort, we estimate that there will be around 15,000 people who will apply for individual funding who are deemed ineligible by the time the scheme is at full capacity. This group is likely to need targeted support to access mainstream services – part of the intention of the ILC program. We are unclear about the amount of funding available to support non-eligible applicants with psychosocial disability, nor the policy approach the ILC will take towards this group. We believe that the best results will be achieved by a targeted, centrally designed approach rather than the grant based approach currently being used for ILC implementation.

Planning process (section four in PC issues paper)

In relation to the planning process, there are three main issues:

- Lack of a validated, standardised assessment tool to determine functional capability and support need (outlined in the section of this submission on scheme costs)
- Support for participants, and the need to reconsider the design of the support co-ordination function
- Planner capabilities

Our major concern about planning relates to the lack of a standardised, validated tool to assess psychosocial functioning and impairment. This is compounded by the lack of publically available evidence-based reference packages. The former would ensure better targeting of supports against need, and enable the NDIA to build an evidence base on the efficacy of packages of support for particular diagnoses and circumstances. The latter would enable planners to confidently provide advice and information on effective options available to people with particular constellations of impairment and particular goals. At present, a lack of evidence on what works for whom and in what circumstances is lacking and needs to be developed as part of ensuring that planners can assist people to make purchasing decisions that are in their best interests, and which deliver sustainable outcomes desired by the scheme. Without the development and use of a standardised assessment tool, it will not be possible to construct an evidence base on what works in what circumstances. The outcome data required by NDIA on its own is insufficient for this purpose.

The emergent findings from our research study on psychosocial disability and choice in the NDIS indicate that participants experience significant problems with the planning process as it currently stands. Concerns include: lack of capability in working with people with psychosocial disability; a reliance on burdensome paper-based administrative process; and, inflexibility in changing arrangements in response to fluctuations in support need because of escalating illness. It also appears that bringing the principles of choice and control for participants with psychosocial disability is a developmental and evolutionary process, strongly linked to their experiences of planning. It appears that competency as a participant in relation to NDIS processes takes at least three years to develop, and for people with psychosocial disability, requires ongoing support co-ordination. Fluctuating mental health, impairments in cognition and in processing and organising information, the need for

specialised knowledge on interventions and support to navigate community systems are all indicators of the need for ongoing support co-ordination.

The planning process is critical to NDIS success. In relation to planning for participants with psychosocial disability, we believe there is an urgent need for a training program focused on planning with people with psychosocial disability. Effective planning with this cohort requires both technical knowledge and skills in some aspects of mental illness and impacts on psychosocial functioning and appropriate attitudes for working with people who often have significant experiences of trauma and coercion, resulting in low trust of professionals and service systems. We note that NGOs working in community mental health would be well placed to deliver such training were it to be developed.

Many people with psychosocial disability are likely to need ongoing assistance with co-ordinating their supports and navigating formal service systems and community resources. The support co-ordination function as it is currently understood is a narrow, technical support that is envisaged as a temporary component of someone's package that will diminish over time. We contest this, and argue for a reconceptualised support, priced at the same level as the current intensive support co-ordination, that combines some technical knowledge on interventions and co-ordination with the ability to 'walk alongside' someone and help them navigate complex social systems. We believe that the opportunity to purchase this kind of navigational support is an essential part of assisting people build their own capacity and become more independent – and an antidote to forms of support that encourage dependency on formal support systems and on the state.

We stress that this is a different conceptualisation of support co-ordination (a 'navigator' and 'guide' rather than a technical service co-ordinating or plan management role). Insufficient support co-ordination, or early removal, is likely to impact on the effectiveness of other support choices, in particular capacity building supports. Poorly targeted supports will increase long term scheme costs and/or diminish efficacy.

In relation to the Commission's questions on reasonable and necessary supports, we believe that the selection of core supports is relatively straightforward and generally does not require specialised knowledge of psychosocial disability. However, there are some highly marginalised participants - those living in forms of supported accommodation (e.g. boarding houses, rooming houses, hostels) where many activities of daily living are performed for them and who, as a consequence, have become very limited in capability and deeply disempowered. This group is likely to require professional input in the selection of core supports. The selection of supports for capacity building is less straightforward, and as mentioned earlier, participants are likely to require specialised advice and assistance (e.g. from a support co-ordinator) to make informed choices. Such support would assist participants interpret support criteria in relation to their own needs and goals.

We consider that the support criteria are articulated clearly, but they are nevertheless open to interpretation. What one person regards as 'reasonable' or 'necessary' may not be the same as another. We consider the current de facto provision of considering the situation of people without significant impairment in determining 'reasonable and necessary' is a poor mechanism. It does not take into account the often long-term experience of marginalisation and poverty for most people with psychosocial disability. Thus, necessary supports – such as a higher spend on activities or on transport – are refused on the basis that 'anyone in the community' might access and pay for those things themselves. As a consequence, and generally at little cost to the scheme, the individual is unable to pursue a goal-related activity, and thus fails to build their capacity:

Trevor has a severe anxiety disorder and extreme social phobia. Using his NDIS package to purchase a support worker to help him with day to day tasks in the community, he has

gradually been able to go out and do his shopping, banking, Centrelink and other important functions. His support worker also takes him to a local community organisation where he has grown a productive vegetable garden, appreciated by everyone who uses the centre. He mixes with the staff and people who use the centre. This is his only social contact outside of his support worker. He is keen to expand the garden, but needs new boots, gloves and gardening clothes. He is unable to use his NDIS package to purchase these, and cannot afford them on his DSP. Without them, he will not be able to continue gardening.

In the early conversations with participants in the choice research study, we heard other stories like this: where people wanted to pursue a goal and were able to use their package to purchase a support worker that they did not need, but were not able to use their package to make a minimal purchase that would enable them to continue a valued activity. The criteria, as they are currently articulated, do not take sufficient account of the impact of long-term poverty on people's capacity. We are concerned that, without some amendment to this, the scheme risks delivering inequitable outcomes for those groups whose achievement of goals is hampered by their own poverty. It makes little sense for a scheme to make it possible to purchase an expensive support worker, but prohibit the purchase of inexpensive consumables on the basis that they are items that might be consumed by anyone in the community.

Market readiness (section five in the PC issues paper)

In relation to market readiness, we wish to focus on three issues:

- Support for unpaid mental health carers within the NDIS, as a critical mechanism to sustain scheme costs over the long term
- Consideration of development of a peer workforce as a strategy to extend the existing pool of personnel from whom an NDIS care workforce could be built
- Participant readiness and the need for ongoing navigational support

We note the Commission's concern with the relationship between formal and informal or **unpaid care**, and the equation that a reduced burden for informal carers requires an increased need for formal carers.

Mind recently commissioned the University of Queensland to undertake a study to estimate the economic value contributed to the Australian economy by informal **unpaid mental health carers**. The study demonstrated that mental health carers contributed \$13.2 billion to the Australian economy in 2015, whilst the total government spend on the same cohort of carers was around \$1.1 billion (Diminic et al 2017). The report also provides a detailed profile of mental health carers, the people they care for and the labour of care that they undertake. Primary mental health carers provide, on average 36 hours of care per week, and many have been caring for longer than ten years. Based on these figures the report estimates that it would cost \$129,000 per year to replace each primary carer. The report makes clear that mental health carers do not currently receive sufficient support to enable them to continue in their caring role.

Given the size of the contribution made by informal mental health carers, it is imperative that they receive the support they need to carry on in their caring role. At present, the NDIS does not include an independent assessment of carers' needs, nor are carers able to access a funded support package in their own right. We recognise that current NDIS provisions allow carers to submit a carer statement as part of the planning process. However, this is not well understood amongst mental health carers nor, it appears amongst NDIS planners. Organisations who support and work with carers – such as Mind

Australia – are unaware of how this works in practice. In short, there is a great deal of confusion around what this is and how it works (Carers Australia 2016).

This concern extends to the lack of clarity around access to respite via an individual's package of funded supports. We recognise that it is possible for someone to ask for a support that will give their carer/family member respite, but in practical terms, we are concerned that this is not happening. We are also concerned that purchased supports that provide respite are not being measured as such – with the result that the NDIA is not collecting data about need in relation to carer respite.

Given the contribution made by unpaid carers (representing a twelve-fold return on government investment, and 1.7 times the total government spend on all mental health services), we argue for expanded provision for carer support within the NDIS. We believe that this is likely to generate cost savings over the lifetime of the scheme. Clearer guidelines around and greater promotion of the supports that carers can access, how the carer statement works and training for planners in family-inclusive practice in the context of psychosocial disability are all urgently required. Moreover, we would like to see consideration of the inclusion of a carer assessment and provision of some funded supports for carers, such as exists in the individual funding system in the UK. We believe that this, whilst initially pushing costs up would, in the long run, work as cost containment.

The situation would also be immediately improved if planners were trained in family-inclusive approaches, and the provisions for carer statements communicated assertively to planners, providers, potential participants and their families and advocates. Increased levels of funding for advocacy support informed by family inclusive approaches for people going through the planning process would also assist.

One strategy to increase the care workforce is to develop a **paid peer workforce**. This applied to both family/carer peer workers, and to consumer peer workers. Many people with lived experience of mental illness and psychosocial disability (including both family/carers and mental health consumers) have developed good competencies around how to support someone to lead a contributing life. Many of this cohort, for different reasons, are seeking part-time work that either can supplement their disability pension, or provide them with income alongside their caring duties. As such, this cohort represents an available but untapped source of labour for an NDIS care workforce. However, peer work is not 'free work', and peer workers would need to be trained, developed and supported as a discreet component of the paid workforce.

In relation to participant readiness, we return to our early comments on the need for ongoing support to operationalise a package of funding and navigate social systems in ways that increase independence. People with psychosocial disability are keen to be placed in the driving seat for the supports they need, but for many their experience of service systems means that they are not well-equipped to do this. The early indications from the choice study that Mind is leading suggest that three years is the minimum amount of time for people to begin to feel like competent, empowered operators in the disability support market – and the assistance from a trusted and skilled supporter/navigator is a critical part of this. Support to make the most of NDIS resources begins in the negotiations with planners where participants feel the power differential keenly. Participants are more able to negotiate with support providers – often, they have been doing this for years anyway. But they are not confident in managing the NDIS processes nor in negotiating with planners. As one participant in the choice project said, 'it feels like negotiating with Centrelink.'

The more marginalised the participant is or where they have had significant experiences of being subject to treatments and orders through mental health legislation, the less well-equipped they are to interact with the scheme. Moreover, when processes are overwhelming or negotiations are difficult,

the impact on an individual's mental health can be devastating. One participants in the choice project said that when she was accepted into the NDIS, she thought that getting good support would mean fewer stays in hospital. In fact, she was admitted to hospital eight times in her first year in the scheme, which she put down the stress of dealing with the NDIS and NDIS processes. Ongoing navigational support is one means to address this situation.

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