

Mental Health Carers NSW Inc.

Submission to the review of the NDIS

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About Mental Health Carers NSW (MHCN)

Mental Health Carers NSW (MHCN) is the peak body for carers of people who experience mental illness in NSW. It is a community-based, non-government organisation that provides systemic advocacy, capacity development and education for the carers, family, friends and kin of those experiencing mental illness across NSW. It has also recently been funded under the Disability Advocacy Futures program to provide systemic advocacy on behalf of those who experience psychosocial disability.

There are currently 2.7 million unpaid carers in Australia, 39% of whom provide more than 40 hours of care per week¹. Due to the demands of their full-time caring role, carers are at a high risk for developing mental health issues. Many of them care for the 175,000 people out of 240,000 with serious psychosocial disability who the NDIS made clear were never intended to enter the NDIS but who have not seen the development of adequate (or indeed any) alternative psychosocial support systems by state or federal governments. It should also be noted that the NDIS has *still* not supported the 65,000 people with primary psychosocial disability it *was* intended to support either. These failures amount to systemic human rights abuse.

We work to ensure the voices of mental health carers in NSW and the people they love and support are represented and heard in policy and service reform processes to increase the willingness of the community to ensure their rights are upheld, (which requires services to realise them to be *funded*). We endeavour to empower mental health carers and the people with experience of serious and persistent mental distress they care for to become champions for mental health reform and advocacy.

This submission provides MHCN's views on the needs of people with lived or living experience of serious and persistent mental distress (consumers) and their carers who use or need NSW psychosocial disability supports from the NDIS or from other sources.

Executive Summary

This submission will seek to address the 'Five Key Challenges' that have so far been identified by the NDIS Review and to provide both evidence of the grievous failures of many people by our disability support and mental health systems and how best to solve these five major challenges.

1. Why is the NDIS an oasis in a desert?

The NDIS is an oasis in the desert because state governments tried to 'get out of the business of disability support and the creation of the NDIS gave them cover for that.

Remedy: A Bill of Human Rights mandating people must get access to certain basic rights and supports and allowing government to be sued for failure.

2. What does reasonable and necessary mean?

Reasonable and necessary means what ever is required to help the participant overcome their experience of disability and to take the place of choice in the community. However, funding for critical supports) could be identified with expert assistance for each different class of disability (as

these will differ), and then funded on a full cost basis, while perhaps the ‘aspirational’ supports are more amenable to being (generously) set by statute or regulation.

3. Why are there many more children in the NDIS than expected?

Serious deficits in provision of both specialist education settings and support to access mainstream education settings for people with psychosocial or other disabilities are driving the blow out in NDIS participation by young people, and the costs associated.

Remedy: A Bill of Human Rights mandating people must get access to certain basic rights and supports and allowing government to be sued for failure.

4. Why aren’t NDIS markets working?

Setting the NDIS up as a market is a disaster for efficient, cost-effective service provision in many complex areas and inappropriate and inapplicable to the individuals concerned in others, depending upon the nature of the disability.

Remedy: State governments should be funded to maintain an independent, peer delivered ‘service navigation and case coordination’ support service, to assist those people who require it to manage their packages.

5. How do we ensure that the NDIS is sustainable?

There needs to be a more general NDIS market review of what can efficiently be provided by private operators or community managed organisations and what needs to be delivered as a federal government funded and state government delivered monopoly in each jurisdiction in order for it to be delivered on a cost-effective basis.

1. Why is the NDIS an oasis in a desert?

While the report states the creation of additional community supports was always intended, this utterly fails to match the rhetoric of state governments at the time or their actions subsequently. As legislated, the NDIS was never designed to support all people with disability, yet many state governments made it very clear they were ‘getting out of the business of disability support’ after contributing the manifestly inadequate disability support funding they *did* provide to the NDIS budget, closing the disability support services they did provide to do so, (e.g., in NSW; Aging Disability and Community Services, and Ability Links). Many resolutely declined to maintain, much less *increase* spending for the vast majority of people with disability who were never intended to enter the scheme.

Unfortunately, the creation of the NDIS gave excellent political cover for this act of negligent cruelty with political commentary more interested in the risk of overspending on vulnerable people in the NDIS and not the desertion of vulnerable members of our community by the states. The solution to 40 years of underfunding was never going to be merely re-shuffling the existing funds and this approach was doomed to create such a disability desert, with one clear waterhole.

The main reason that this situation has been allowed to arise is because there is no accountability for failing vulnerable people other than at the ballot box and respecting and funding the rights of people with disabilities, especially psychosocial disabilities, is not a huge vote winner, especially when this requires the expenditure of significant funds.

As has been plainly established, the human rights of people should not be a matter for partisan political debate, which could see them be denied or abused for political gain. The performance of the Australian political system both before and after the creation of the NDIS has manifestly demonstrated that the Australian parliaments, parties and voters cannot be trusted to respect the rights of vulnerable people when this may cost them money. It should therefore be taken out of their hands as far as this is feasible within a democratic framework.

The best way to address this issue would be for the government to enact comprehensive human rights legislation that guarantees people access to certain basic rights and supports, like that of South Africa's Bill of Rights. Such an instrument which allowed citizens to demand that their basic needs be met and which allowed them to sue governments for their failure to do so would seem to be the only realistic long term remedy for this problem.

2. What does reasonable and necessary mean?

The idea that the NDIS funds 'reasonable and necessary' supports for participants has been treated differently at different points in the scheme's development. Initially, the idea was that people could be assessed for what it would cost to support them and then to be given the money to spend as they see fit. The example of someone spending physical therapy money on sexual services was actually touted as an example at the time. Thus, the idea of 'reasonable and necessary' did not need to be resolved, because rational individual choices and the omnipotent market would solve all problems. This was entirely consistent with the empowering and aspirational aspects of the scheme but was always going to be difficult to maintain without the creation of a 'statute of wounds' that fixed sums depending upon levels of disability, (anathema to the initial, intensely individualistic ethos of the scheme). Controlling and wowsery responses that threw out aspirational and empowering aspects of the scheme were inevitable once costs blew out.

However, this model was very suitable for psychosocial disability, where the experience of distress can have so many diverse causes and impacts. Allowing this level of freedom to determine the supports to be provided could make a critical difference to the lives of many.

The issue is that if you don't know what support is to be provided, it is very hard to 'cost' it to establish the *sum* that should be provided anyway, especially as previous state government department's estimate of the costs previously expended on different classes recede into irrelevance as any kind of benchmark for comparison. Worse, the fact that many participants are vulnerable and have limited understanding and capacity to be good, rational 'customers' means their ability to choose between service providers much less between services made the NDIS 'market' always highly questionable in fact.

What needs to be determined is, 'reasonable and necessary to do *what?*' It seems there are really at least two classes of service provided by the NDIS, those that need to be provided to allow people to maintain life and basic functions and those that allow them to take the place in their community that they desire. Both are critical, but some (the critical supports) could be identified with expert assistance for each different class of disability (as these will differ), and then funded on a full cost basis, while perhaps the 'aspirational' supports are more amenable to being (generously) set by statute or regulation, with a more absolute freedom being granted in their expenditure in line with the original intentions of the scheme. This would be a particularly difficult exercise for psychosocial disability, given the diversity of the experience of disability and the things that help to address it, but it *could* be done with sufficient input from people with lived experience of psychosocial disability and their families and carers.

It should also be noted that the system of assessment (with the prospect of failure and ejection into the support desert outside the NDIS as a real potential outcome) let alone the need to litigate 'reasonable and necessary' with the NDIA is very highly stressful and is especially inappropriate for people with primary or co-occurring psychosocial disability; just as seeking and managing packages of support is often beyond them and instead relies on unpaid, untrained families and carers to volunteer thousands of hours of their time to try to assist them in this.

3. Why are there many more children in the NDIS than expected?

In the area of psychosocial disability, there appears to be serious deficits in both specialist education settings and support to access mainstream education, for people with psychosocial or other disabilities driving a blow out in NDIS participation by young people, and the costs associated. One special school which works mainly with children with serious mental health issues which MHCN has had a long association with through a Board member has up to 70 applications for each available place in the school. A very large proportion of such students have Indigenous heritage. Those who do not get accepted are then returned to mainstream with very little extra support. No routine assessment or planning for those refused access takes place on the not-so-special schools they must then attend or return to, even though they have been assessed for such a placement.

Many people with mental health issues in mainstream settings do not have their needs recognised but are instead blamed for them and far from extra consideration being given to them they instead receive heavy handed supervision and disciplinary measures, often resulting in leaving school early and a life blighted by disadvantage and exclusion. As the NDIS does not provide support for carers and families as a matter of course, parents are given very little support, (as most family and carer support funding, especially from the Commonwealth, was 'in scope' for the NDIS, even though it was never intended to produce anything like equivalent support for families as the defunded respite schemes for example).

Education could be used as an excellent example of why the NDIS has become this oasis in the desert. The state Education Department is reportedly reluctant to engage with advocates, lived experience or any external parties in reviewing and addressing these problems which it has a long history of neglecting. Departmental and other leadership does not seem to consider support for disability or inclusion to be part of its core role as educators.

The same can be said around support for mental health driven disordered behaviour in public and social housing, with lack of support sometimes resulting in vulnerable people being evicted into homelessness or being incarcerated in correctional or forensic settings rather than discharged to the least restrictive care due to unresolved issues around state or federal funding responsibilities and lack of capacity for the private/CMO sector to deliver these kinds of high-risk services.

The 'culture' of so many state government departments is about excluding problematic or demanding people to protect their budgets with scant regard for the human toll their negligence takes. People with psychosocial disability all too often fall into this category.

The solution would seem to be some kind of Human Rights Bill which mandates the provision of basic services, with supports provided to ensure an equivalent level of access for disabled people, that can be taken up and sued on by the individuals concerned of the Human Rights Commission. This should result in the creation of both more specialist settings and more general supports for disabilities across states and department who will not voluntarily 'step up' to their responsibilities.

4. Why aren't NDIS markets working?

Far too many people, especially in regional or remote areas are not able to find providers to spend their packages and have to subsequently fight to retain the funds they cannot spend, while their needs for support are not met. Unspent funds should be a KPI for the NDIA and if it exceeds 5 or 10% of the package it should trigger a review to see what else needs to be provided in order to help the person get the supports, they need. Because a market is not a scheme. It does not have a particular purpose to achieve. Even if a market 'fails' (as it does in the NDIS), the market isn't damaged, only the people who can't get what they need.

Setting the NDIS up as a market is a disaster for efficient, cost-effective service provision in many complex areas and inappropriate and inapplicable to the individuals concerned in others, depending upon the nature of the disability. Markets require informed customers with money able to make rational choices and with a sound understanding of the range and implications of those. Across all disabilities, but especially with psychosocial and intellectual disability, many people are not in a position to be 'informed, rational customers.

To address this, we need a recognition that giving participants meaningful choice and control over the services and supports they receive requires a lot more than giving them some faux control over their funding packages. People with psychosocial disability, or more permanent cognitive impairments require expert, disinterested supports to allow them to safely exercise choice. This would require expert staff to assist in *supporting* decision making, (with appropriate input from families and carers), rather than substituting their own decisions for the participants. (Families and carers can need education around this too sometimes).

State governments should be funded to maintain an independent, peer delivered 'service navigation and case coordination' support service, to assist those people who require it to manage their packages. This would take a huge, unfunded burden off families and carers, (who in many cases spend much more time helping to manage the package than they did doing all the supports delivered themselves before the NDIS). This service should be made generally available across the scheme for just this reason alone. It would also address conflicts of interest in getting private providers to deliver this service and even allow better coordination between sectors/state and federal funded services and better quality monitoring of services provided and service providers and better identification of unmet needs for support.

5. How do we ensure that the NDIS is sustainable?

The NDIS is an uncapped, needs-based scheme and this is right and good. But the fundamental structure of the scheme is flawed, in truth, it is as yet only half built, and this is a big driver of the unsustainable cost of the scheme. A fully privatised scheme as we currently have in place would have to be the costliest structure that could have been built.

To use a famous example, the medical system of the United States is constituted by a (number of overlapping) insurance scheme(s) supporting the fully private provision of medical services, just like the NDIS for disability services. This model has and continues to result in by far the most expensive medical system in the world, with some of the worst outcomes in the world, particularly when it comes to ensuring access to services by vulnerable people. Why such a model was chosen for the NDIS beggars' belief. *Of course*, such a model was always going to be expensive and unsustainable, just as the US system continues to demonstrate.

Part of the reason is the lack of economies of scale for many small providers delivering common services. Then for highly specialised services, we find that those that require teams to deliver them are not really suitable to be funded through individual packages, and which probably need to be able

to support 100% of the people with particular needs if this is to be done cost effectively and which will allow the specialist to have enough clients and work in the area to maintain their expertise, (natural monopolies).

There are also many services relating to disordered behaviour and 'high risk' clients that non-government organisations or services will always struggle to be able to provide due to the liability risk and difficulties in attracting and retaining sufficiently expert staff in roles long enough for them to become sufficiently expert to undertake their roles.

What needs to happen is that there needs to be a more general NDIS market review of what can efficiently be provided by private operators or community managed organisations and what needs to be delivered as a federal government funded and state government delivered monopoly in each jurisdiction in order for it to be delivered on a cost-effective basis.

Many rare and high-risk services (as are often needed for psychosocial disability), and many supporting the exercise of choice and control (free from commercial conflicts of interest) would fall into this category. On top of this, state governments should be funded to be the 'providers of last resort' for all services, so that they have some chance of efficiently delivering support to hardly reached places in their jurisdictions. There is no alternative to undertaking and implementing such an efficiency review.

Conclusion

In conclusion we can say that the NDIS is only half built. There needs to be far more thought given to what can sustainably and ethically be provided by private operators, and what needs to be delivered by government in order for it to be of sufficient quality and cost effectiveness, as well as states building the rest of the supports that the vast majority of people with experience of disability need to access their mainstream services. MHCN will be delighted to continue to advocate for people with experience of psychosocial disability and their families and carers to that end and to participate in the development of the robust solutions they need.

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