



**NATIONAL MENTAL HEALTH  
CONSUMER ALLIANCE**

# Submission to Foundational Supports – General Supports

05/12/2024



The National Mental Health Consumer Alliance (the NMHCA) has prepared this submission in response to the consultation on [Foundational Supports – General Supports](#).

The NMHCA is the national mental health consumer peak body led by and representing the voices of people with direct lived experiences of mental health challenges. **This submission is based on a survey designed by the NMHCA and completed by forty-five (45) people with lived experience of mental health challenges around Australia.**

All references to ‘Consumer’ and ‘lived experience’ in this submission refer to mental health consumers with lived experience of mental health challenges and/or suicidality. We do not include family, carers, kin or the bereaved in our definition of lived experience as it appears in this report.

This submission should be read alongside the notes taken by The SocialDeck on behalf of the Department of Social Security at the NMHCA organised consultation with mental health consumers on Foundational Supports – General Supports, held 2 December 2024.

### **The NMHCA**

The NMHCA is the national peak body representing mental health consumers. We work together with the state and territory consumer peak bodies to represent the voice of mental health consumers on national issues. We are the people experiencing mental health issues/distress; at the table advocating with government and policy makers; and working with a robust network of grassroots communities. More information is available on the NMHCA’s website: [nmhca.org.au](https://nmhca.org.au).

### **Acknowledgement of Country**

We acknowledge Aboriginal and Torres Strait Islander Peoples as the traditional custodians of the land on which we work and pay our respects to Elders past and present. Sovereignty was never ceded.

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## Submission

### Foundational Supports – General Supports

There is general confusion – and concern – in the mental health consumer community regarding the recent, and proposed, changes to the National Disability Insurance Scheme (NDIS). There have been major changes to the legislation changing the criteria for what can/cannot be included as NDIS supports, the introduction of a new NDIS psychosocial early intervention pathway, and the introduction of Foundational Supports – General and Targeted.

These changes have come without any psychosocial disability co-design and barely any broad consultation with mental health consumers. Mental health consumers have told us that they are exhausted trying to keep up with the changes and advise that they are confused about how the proposed supports are going to work, who will be able to access them, what supports fit under what category, whether they will continue to have access to their current supports, how disability will be defined and whether they will be able to maintain the supports and services they currently receive.

The following diagram, based on Figure 1 from the Independent Review into the National Disability Insurance Scheme (NDIS) Final Report<sup>1</sup> (NDIS Review), identifies different types of funding options for psychosocial supports currently being discussed. We have included in the diagram where the NMHCA sees psychosocial services/supports fitting within the funding options. Consumers have very little information regarding the Early Transition pathway for people with psychosocial disability (included by the NMHCA in the diagram below) or on Foundational Supports – Targeted Supports (Psychosocial Supports) proposed in the NDIS Review<sup>2</sup>.

Without understanding what is proposed for these two support options, making comment on Foundational Supports - General Supports (General Supports) is difficult and consumers fear that if they fail to mention a specific type of psychosocial support during the current General Supports consultation process then it may not be considered at all.

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<sup>1</sup> Commonwealth of Australia, Department of the Prime Minister and Cabinet *Working together to deliver the NDIS - Independent Review into the National Disability Insurance Scheme: Final Report*

<sup>2</sup> *ibid*

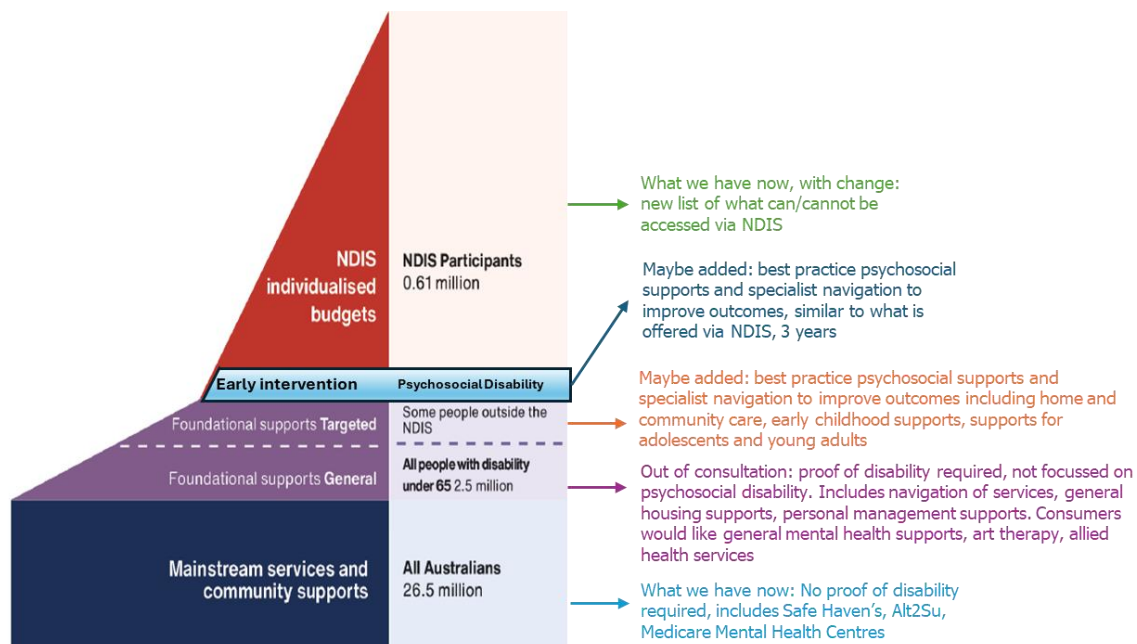


Figure 1: Proposed national supports, including early intervention, and NMHCA identification where mental health services/supports fit

There is also general confusion about what General Supports will include. Will any of the supports that are not on the NDIS approved list be available through General Supports? What proof of disability will be required to access these support services? Will access to General Supports be permanent or will ongoing proof of need be required? Despite the government's statement that "general supports are available to help ALL people with disability"<sup>3</sup> mental health consumers are rightfully concerned that not all psychosocial supports will be available through general supports. The fundamental work on Targeted Supports – Psychosocial Supports recommended in the NDIS review<sup>4</sup> has not yet begun.

There are also concerns that the unmet needs identified in the recent final report of the Analysis of Unmet Need for Psychosocial Supports Outside of the National Disability Insurance Scheme<sup>5</sup> will not be met by the proposed changes. Of issue is the continued reference to the need for a person to provide proof of their psychosocial disability to obtain services and support. This is something people with psychosocial disability find very expensive and difficult, if not impossible, to do, which will leave them unable to access the services and supports they require.

In addition, the National Mental Health Services Planning Framework (NMHSPF)<sup>6</sup> dataset used to calculate unmet need is based on diagnosis and does not consider whether a person is able to prove

<sup>3</sup> <https://engage.dss.gov.au/foundational-supports/general-supports>

<sup>4</sup> <https://www.ndisreview.gov.au/>

<sup>5</sup> <https://www.health.gov.au/resources/publications/analysis-of-unmet-need-for-psychosocial-supports-outside-of-the-national-disability-insurance-scheme-final-report?language=en>

whether they have a disability. A mental health consumers inability to prove that they have a disability is the barrier they are facing to access supports and services. As it is proposed that a proof of disability is required to access General Supports, the hours of unmet need may not be reduced, leaving people with mental health challenges in the same position that they are currently in – unable to access the supports and services they require.

There has been limited discussion on General Supports providing much needed general health support such as physical health. The Unequally Well report<sup>6</sup> identified that the majority of premature deaths of people who accessed Australian Government funded mental health funded supports in Australia were preventable. The reasons for the ongoing increased risk of premature death and significantly reduced life-expectancy of people living with mental health challenges in Australia is difficult to identify, but physical health is one of the key variables to consider. While there should be services that address the physical health of ALL people with mental health challenges, General Supports could be somewhere that ensures that the physical health needs of mental health consumers are being addressed.

Finally, without wide reaching direct involvement in the co-design process, mental health consumers fear that their voice will be drowned out and the result will adversely affect mental health consumers and specifically people with psychosocial disability.

The mental health consumer community asks for clearer advice and a timeframe on the ongoing development to meet unmet needs and the broader review process of NDIS.

## What do mental health consumers want from General Supports

Half (50%) of the mental health consumers who responded to our survey had never actively sought out formal supports for their psychosocial disability such as Disability Employment Assistance, Community Health Services and NDIS. This did not mean that they did not need nor want assistance.

Many of our participants advised that they did not seek supports as they found it far too difficult, tiring and disappointing to reach out for information only to be told there is nothing available or alternatively, to go through the unclear and expensive application process only to then be advised that their mental health challenges and individual circumstances do not warrant support.

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<sup>6</sup> Roberts, R et al (2024). *Unequally Unwell: Shorter life expectancies, reduced life opportunities. Summary Report: Mortality of people using Australian Government-funded mental health treatments. Analysis of 2016 Census, death registry, MBS and PBS data.* Charles Sturt University, Bathurst, <https://doi.org/10.17605/OSF.IO/Q5CXJ>

The General Supports identified as necessary by participants include general housing supports such as gardening, cleaning and personal management supports for paying bills, managing appointments and managing medications. Legal support was identified by some respondents as necessary to assist in applying for/appealing against rejected support applications, such as for the NDIS, and for disputes with housing. General mental health supports were also identified, such as psychology and counselling, as state run services are overwhelmed and the cost of accessing these supports privately is prohibitive despite the Better Access Initiative<sup>7</sup>. Additionally, specific supports were in demand such as art therapy and allied health services (exercise physiologists, physiotherapists, OTs, hydrotherapy, nutritionists).

A major concern consumers identified is that there are very few supports available out of business hours, which made holding down a job while also receiving required support to maintain that employment, incongruous. Consumers are faced with underemployment, or forced into leaving employment, to maintain access to their essential supports and services. Consumers advised that they would benefit from navigation services, advocacy services and supports, and services available out of usual business hours.

## How do consumers identify relevant services and supports

Mental health consumers need access to clear and comprehensive information when making decisions about what services and supports are available and of those available, which would best match their needs.

Our survey asked respondents what they needed to know about a service or support to help them decide whether to use it. Eighty five per cent (85%) of respondents advised they required detailed information about the eligibility criteria prior to contacting a service provider and 80% wanted to know where the service provider was located. Sixty percent (60%) wanted to know what funding options were available and half of respondents wanted to know that it was going to be a safe space for them based on their cultural background, gender and sexuality and would be supportive and non-discriminatory regarding their gender.

Mental health consumers need to know the length of time they are going to be able to access the service/support, how much the service/support is going to cost and whether the same service provider is going to be able to provide the service/support over the length of their access. Developing positive relationships with service and support providers takes time, and once

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<sup>7</sup> <https://www.health.gov.au/our-work/better-access-initiative>

established, changing service providers is difficult, with mental health consumers having to retell their story multiple times which can be distressing.

*“[I need] Acceptance, awareness, confidentiality and people that don't treat me like an idiot, they need to see beyond my diagnosis.”*

*Consumer*

## What do consumers need to navigate services and supports

Seventy-five percent (75%) of respondents preferred to have access to peer workers instead of clinicians or service providers to assist with navigating the various disability supports and services that might be available and suitable, regardless of the type of service: volunteer, government supports, private services, NDIS. Advocacy bodies and navigation services need to be staffed by peer workers, as mental health consumers want to talk about their needs and service options with other consumers given the higher level of trust consumers have with peer workers

Support workers should have an excellent understanding of the different support options available to the consumer based on their needs, in addition to also understanding various health supports available. The availability of easy-read documents and online navigation were second in importance with only one third of consumers identifying telephone help-lines as a useful option.

Instead of having navigation services and individual advocacy services separate, mental health consumers advised that they would benefit from a one-stop-shop where peer workers could provide ongoing, in person support. Peer workers could support the consumer throughout the process of finding, applying and hopefully accessing the right service. This would ensure any emerging access or administrative issues that came up during this process could be addressed by the consumer with support from someone who understands the individual's pathway to date. Mental health consumers reported that they were passed from place to place, told to apply for a service, being unsuccessful as they were not “entitled” to it, only to end up not finding any appropriate services and giving up.

*“Peer workers know what's what – they know the ways of finding the help you need that no one else knows.”*

*Consumer*



## Characteristics of a good service

Mental health consumers were asked what they thought the characteristics of a good service are. In summary, services need to be appropriately monitored for safety and quality, ethical, non-judgmental, supportive and respectful. These five things are the bare minimum we would expect of any service, and more so when services provide supports to the most marginalised people in our population. The three top characteristics of a good service were inclusivity, accessibility and welcoming and we will expand on these characteristics in this section.

Further, consumers need access to consumer centric data that can be easily understood and used to look at what works and what doesn't in a service. It was recently announced that for government funded Aged Care Homes, consumer ratings of services, including the experience of residents, would be published as Star Ratings<sup>8</sup>. Given this is acceptable in aged care to encourage continuous improvements, consumers wonder why the same cannot be done for our government funded supports and services.

### Inclusivity

Unsurprisingly, a majority (75%) of mental health consumers responded that inclusive policies, being treated with respect by well trained staff, and being able to access both a person and/or online resources made them feel included by a service. The provision of information in a way that was easy to understand for them was also crucial, as was being able to participate in any decisions that impacted them. While seeing and speaking with people 'like me' was important, consumers identified that a good workplace culture was also supportive of inclusion.

*"Staff are reflective of the diverse groups they support. Not because you've hired them specifically, but because the workplace is so safe and inclusive that they want to work there."*

*Consumer*

### Accessibility

#### *Employment*

Mental health consumers advised that seamless supports, less restrictive acceptance criteria and out of hours services are required to maintain, and increase, accessibility. This is especially the case when mental health consumers are looking for employment and volunteering opportunities.

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<sup>8</sup> <https://www.health.gov.au/starratings/about>

Disability supports need to be accessed seamlessly between employment, unemployment and volunteering by being available after business hours and by having less restrictive acceptance criteria. Mental health challenges can fluctuate, and mental health consumers often have to make decisions about whether to take on paid employment based on their ongoing accessibility to services. Additionally, mental health consumers develop an ongoing relationship with their service providers and this is more often than not disrupted when a consumer is successful in obtaining employment. This results in a Catch 22, where the very supports a mental health consumer was receiving that assisted them to feel capable of finding work are no longer available to support them in that very role due to access criteria.

Mental health consumers must decide on whether to take on employment and lose access to their services either due to the accessibility requirements of the service or the times the service is open. As a result, mental health consumers often face underemployment by choosing to work part time or to volunteer so they can continue to access the support services they need and to maintain the relationship they have developed with a particular service provider.

Additionally, a majority of individual advocacy services and navigation services are unavailable outside of business hours. This makes it difficult for someone in employment to identify what services may be available and to get access to them.

### *No “disability definition” criteria*

No indication has been provided as to what criteria would be used to define disability. The NMHCA calls on general supports to be available to anyone who requires them without the onerous and costly ‘proof of disability’ process required by the NDIS. Mental health consumers advised that not meeting the criteria of a service can be embarrassing, especially when asking staff to make an exception for them. Participants are also concerned that the costs of services and supports, which are agreed to be part of the general supports category, will increase in the same way that services that were included in the NDIS when it was first introduced. This will make these services harder to afford for individuals who are not deemed appropriate to receive general supports.

## Welcoming

Nearly all our respondents advised that the key to feeling welcomed by a service was experiencing clear communication from staff, which coincides with the second most important thing being that a service be staffed by qualified and understanding staff.

## Community participation

Like many Australians, mental health consumers are missing out on social connection resulting in higher rates of isolation and loneliness. Engagement with, and support by, the broader community was not assisted by the NDIS, with all our respondents who currently receive services through the NDIS advising that participating in the NDIS did not help them be supported by their community. The State of the Nation Report – Social Connection in Australia 2023<sup>9</sup> identifies that loneliness is associated with increased likelihood of being diagnosed with clinical depression and anxiety and can result in increased use of mental health services including psychologists, counselors and psychiatrists<sup>10</sup>.

We know that discrimination stops people with mental health challenges from participating in community groups and activities that are not run specifically for people with mental health challenges and/or other disability, despite their desire to. While some consumers felt safe enough to join non-mental health focused groups, others reported that the stigma surrounding mental health challenges often meant that they felt even more lonely attending these groups. The tolerance threshold of the general community can be very low leading to some consumers being asked to no longer come to group meetings as they were incompatible with the other members.

Half of our survey respondents advised that community programs and volunteer organisation programs had assisted them with community support and just under a third (30%) remembered fondly the Personal Helpers and Mentor Service (PHaMs). Additionally, there is a growing movement of mental health consumers wanting to see the return of PHaMs<sup>11</sup> and PHaMs type services. When asked what services increased participants social connection, the results were mixed but generally the following were reported:

- Organised, free, social, exercise (dance, sport) and educational groups, generally of peers but some people would prefer mixed groups
- Better access to public transport so people can travel to participate in groups. Access included closer housing to transport routes as well as financial assistance to travel.

Further work needs to be put into the development and implementation of discrimination elimination programs including financed training programs for all Australians regarding psychosocial disability to allow people with psychosocial disability to join in social activities and feel connected

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<sup>9</sup> [https://ncq.org.au/wp-content/uploads/2023-Loneliness-Awareness\\_State-of-the-Nation-Report.pdf](https://ncq.org.au/wp-content/uploads/2023-Loneliness-Awareness_State-of-the-Nation-Report.pdf)

<sup>10</sup> *ibid*

<sup>11</sup> <https://bringbackphams.com/>

and safe within their communities. Including a compulsory subject on discrimination and working with people with disability in all Certificate IV qualifications could start addressing this at the activity/supports level.

## Recommendations

1. Include the NMHCA, the national independent lived experience peak body, in consultations and co-design processes in order to carry the voice of mental health consumers forward.
2. Employ well supported and trained peer workers to provide consumers with seamless assistance throughout their service navigation for appropriate and relevant services. This assistance should extend to the application, rejection, and appeals processes as well as the identification of alternative services.
3. Remove the requirement to prove disability to access services. If they are required, then it should be:
  - easy to prove,
  - seeking proof should be subsidised and inexpensive, and
  - modelled in a way that provides support to mental health consumers whether they are in paid work or not.
4. Ensure general supports, including navigation and advocacy, are available outside of business hours to ensure support is available to consumers who are working/volunteering.
5. Finance, develop and implement discrimination elimination training programs regarding psychosocial disability to allow people with psychosocial disability to join in social activities without fear of discrimination.
6. Collection, and publication, of consumer centric data that indicates how good service and supports are, such as the Aged Care Star Rating launched recently.

## Recognition of Lived Experience

As a consumer lived experience-led organisation, the National Mental Health Consumer Alliance values the skill and expertise of consumers with lived experience. We pay tribute to those we have lost for the work that they have done to advocate for our rights. We acknowledge that we stand on the shoulders of giants who have paved the way for the rights we have today, and we will continue their work today and every day until the mental health system recognises and upholds our human rights. Nothing about us without us.



Submission prepared November 2024.

National Mental Health Consumer Alliance.

See [nmhca.org.au](https://nmhca.org.au) for more information about the NMHCA.

For questions about this submission, please contact us at [policy@nmhca.org.au](mailto:policy@nmhca.org.au).