



**Mental
Health
Council**
OF TASMANIA

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Removing Barriers to Testing for the NDIS

Consultation with psychosocial service
providers, their clients and the Tasmanian
community

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1. Introduction

The Mental Health Council of Tasmania (MHCT) is a member based peak body. We represent and promote the interests of community managed mental health services and have a strong commitment to enabling better access and outcomes for every Tasmanian.

The Mental Health Council of Tasmania (MHCT) was contracted by Primary Health Tasmania (PHT) to identify barriers for individuals with mental ill-health in testing eligibility for the National Disability Insurance Scheme (NDIS) along with potential solutions to remove these barriers. Clients and support staff who are currently engaged in programs delivered under the National Psychosocial Support Transition, Continuity of Support and National Psychosocial Support Measure programs were invited to participate in the consultation process. Additional community perceptions of barriers to testing for the NDIS were gathered through consultation with members of Flourish and Mental Health Family and Friends (MHFF).

Key objectives of the consultation project:

- Consult with clients and staff members engaged in the National Psychosocial Support Transition (PiR, PHaMs or D2DL), MyConnections+ and MyHorizons programs using a range of appropriate methodologies.
- Identify the key reasons why clients and people with mental ill-health in Tasmania are choosing not to test for eligibility for the NDIS.
- Identify potential solutions and/or activities that will remove identified barriers to testing for the NDIS.
- Gain general community perspectives on barriers to testing for the NDIS from MHFF and Flourish.

The consultation process utilised surveys and focus group sessions with key stakeholders as the most appropriate methods to gain information on the barriers to testing for the NDIS. A core feature of consultation work with service provider clients involved the application of trauma-informed principles such as co-facilitation of focus group sessions with peer workers. A total of 77 people provided feedback during consultations in December 2019, including service providers along with their staff and clients, families, carers and people with lived experience of mental ill-health.

Feedback from the consultation identified five of the most pertinent barriers to testing eligibility for the NDIS:

- The term 'disability' is not relevant to the individual's experience
- There is a lack of clarity regarding NDIS's eligibility criteria
- The process can be triggering, overwhelming and/or anxiety inducing
- The difficulty in gaining evidence to support an application to the NDIS
- The individual's condition prevents them from applying for the NDIS

In addressing these barriers, 12 recommendations have been provided. Recommendations 1-11 have been identified by stakeholders as being helpful to removing the identified barriers to testing for the NDIS. Recommendation 12 provides a further recommendation for people currently in psychosocial support services that may be too unwell to apply for the NDIS.

1.1 Recommendations

► Recommendation 1

A communication guide is co-designed with people with lived experience of mental illness and highlights the difference between NDIS language and recovery-focused language. It is recommended that the resource is implemented across all services and organisations operating in the mental health sector in Tasmania, including NDIA staff and service providers.

▶ Recommendation 2

Implement a phone service for people living with mental ill-health and their carers to call and discuss their potential eligibility for the NDIS along with the application process. It is recommended that peer workers are trained to take the calls.

▶ Recommendation 3

An additional, optional, part of the NDIS psychosocial evidence form is developed and identifies the goals and strengths of the applicant. This information informs NDIA planners if successful and provides a strengths focus if the application is unsuccessful.

▶ Recommendation 4

Implement a service to connect NDIS applicants and their families with peer workers trained in providing step-by-step support throughout the NDIS application process.

▶ Recommendation 5

NDIA planners, senior planners and assessors undergo further training, including trauma informed practice along with implementing recovery focused language via Recommendation 1.

▶ Recommendation 6

Explore opportunities for trained peer workers to provide support to NDIA planners and the assessment team.

▶ Recommendation 7

Provide opportunities for people with lived experience of mental illness/psychosocial disability to meaningfully participate on NDIA committees and working groups.

▶ Recommendation 8

Identify positive stories, both locally and nationally, on how the NDIS has supported people with psychosocial disability. Include these stories in the suite of resources identified in Recommendation 1.

▶ Recommendation 9

Explore ways to make it easier and simpler for GPs and health professionals to provide evidence for NDIS applications. For example, extend the phone service in Recommendation 2 to support GPs along with further training opportunities and development of checklists and resources.

▶ Recommendation 10

Explore options to adjust the NDIS application process to allow support workers and non-clinical staff to provide the evidence for an NDIS application and health professionals engaged to provide a confirmation of diagnosis.

▶ Recommendation 11

In consideration of Recommendation 10, explore ways that the clinical evidence part of the NDIS application only requires one standard consultation with a GP or other health professional.

▶ Recommendation 12

Support clients in current NPS transition funded programs that are unable to test eligibility for the NDIS due to their mental health condition. It is recommended that identified clients are supported on a case-by-case basis with individual barriers identified and additional measures provided to support clients to apply for the NDIS if they wish to do so. Additionally, continue to provide measures to allow for supported handovers of clients transitioning to Continuity of Support (COS) and NPS Measure funded programs from NPS transition programs.

2 Consultation

2.1 Approach

To ensure that consultations were conducted safely and appropriately for clients of service providers, MHCT designed the consultation plan in discussion with Baptcare, Anglicare, Wellways, and Mission Australia. Subsequently, the consultation process was guided by trauma informed principles. These principles included the utilisation of peer workers to support the development of surveys and the facilitation of focus group sessions. Additionally, quiet spaces were provided for focus group participants to utilise and participants were informed of their right to participate in the focus groups to the extent that the participant felt comfortable to do so. Flourish and MHFF were additionally briefed and subcontracted to facilitate consultation with their members to gain community perspectives on barriers to testing for the NDIS along with potential solutions to removing these barriers.

2.2 Key Stakeholders

Identified key stakeholders engaged in consultation were categorised into three groups:

1. Service providers and their staff who are funded under the National Psychosocial Support Transition, Continuity of Support and National Psychosocial Support Measure.
2. Clients engaged in above funded programs who fit the following criteria:
 - Individuals who have chosen not to apply for the NDIS
 - Individuals who have not thought to apply for the NDIS
 - Individuals who have been deemed ineligible but may benefit from reapplying or resubmitting an application for the NDIS
 - Individuals currently applying for the NDIS
3. Members of Flourish and MHFF as an additional mechanism for gaining feedback from people with lived experience of mental ill-health, their families and carers.

2.3 Consultation Process

2.3.1 Analysis of current literature

MHCT initially undertook a thematic analysis of the current identified barriers to testing for the NDIS. The recently released CMHA report, '[Tracking transitions from PIR, PHaMs and D2DL into the NDIS](#)' has gained service provider perspectives on these barriers. Mental Health Australia's report '[National Disability Insurance Scheme: Psychosocial Pathway](#)' provides additional information on issues relating to the NDIS from health professionals, service providers and consumer perspectives. Identified barriers were collated into three themes:

1. Client perceptions and experiences of the NDIS
2. Barriers to embarking on the application process
3. Barriers to gaining adequate evidence to support the application

Table 2.3.1 provides further detail on these themes and identified barriers discussed in the literature.

Client perceptions and experiences of the NDIS

- Some individuals may have had previous negative experiences with other government agencies.
- NDIA and partner staff often do not have specific skills, knowledge and experience in supporting people with psychosocial disability, which can exacerbate a person's condition.
- Clients don't trust the system – due to either previous negative experiences and/or fear of personal information being shared with other agencies.
- Clients are fearful of the process – and may risk re-traumatisation by revisiting prior traumatic experiences in order to gain evidence.
- Clients did not accept/identify as having a 'disability' – clients either did not have insight into their mental illness or did not equate their diagnosis as a disability or illness.

Barriers to embarking on the application process

- Clients may be experiencing more pressing issues (e.g housing or physical health.)
- Clients may have fluctuating mental health making their ability to manage the application process more difficult.
- Clients were distressed and traumatised by the process.
- Clients with a recent diagnosis may choose not to apply as they are still coming to terms with their situation and the potential limitations.
- Client may be too unwell to apply - providers have identified that clients were not applying due to being acutely unwell or that their mental illness was too severe for them to be able to engage in the application process.
- NDIA provided poor feedback as to why a person was assessed as ineligible coupled with confusion regarding processes to appeal/resubmit.
- Client was too overwhelmed to reapply/resubmit an application

Barriers to gaining adequate evidence to support the application

- Financial costs involved in gaining expert advice and evidence.
- Health professionals understanding of NDIS/psychosocial disability – service providers identified that a lack of understanding of 'psychosocial' disability by health professionals led to reduced evidence required for testing to the NDIS.
- Reluctance from health professionals to diagnose someone with a disability especially in regards to young people as initial diagnosis and support needs will often change.
- Participants in rural and remote areas have reduced access to health professionals to support providing evidence
- Limited/lack of evidence available due to limited engagement with mental health services can result in applications being incomplete or submitted without the full reflection of the individual's circumstances.
- Clients are overwhelmed by the process of collecting evidence
- Resource limits of service providers to support clients in collecting evidence.

Table 2.3.1 – Literature review of current barriers to testing for the NDIS

2.3.2 Identifying barriers through consultation with psychosocial service providers, their clients and the Tasmanian community

After analysis of literature pertaining to the barriers to testing for the NDIS at a national level, MHCT consulted with each stakeholder group to gain further feedback and understanding of the barriers to testing for the NDIS.

Table 2.3.2 below provides details on the consultation process:

| | |
|---------------------|--|
| Stakeholder group | Service providers |
| Consultation method | Roundtable discussion |
| Aim | <ul style="list-style-type: none"> Gain service provider perspectives on identified barriers to testing for the NDIS (Table 2.3.1) Identify consultation methods most suitable for their clients |
| Stakeholder group | Clients of service providers |
| Consultation method | Paper survey and focus group sessions in Burnie, Launceston and Hobart – survey and invitation to join focus group sessions distributed via service providers |
| Aim | <ul style="list-style-type: none"> Identify barriers to testing for the NDIS Identify solutions to remove these barriers |
| Stakeholder group | Community perspectives via MHFF and Flourish |
| Consultation method | Online survey and focus group sessions in Penguin, Launceston and Hobart (members of Flourish) |
| Aim | <ul style="list-style-type: none"> Identify barriers to testing for the NDIS |

Table 2.3.2 – Consultation Plan: Removing Barriers to Testing for the NDIS

2.3.3 Testing solutions

After the initial consultation to identify the barriers to testing for the NDIS, MHCT developed several solutions to remove these barriers. These solutions were distributed back to participants who attended focus group sessions along with service providers and via MHFF and Flourish networks. The feedback gained assisted in refining the final key recommendations of the report.

2.4 Outcomes of consultation

In total 77 people participated in the initial consultation process, either via survey, 1-1 feedback or through focus group sessions. A content analysis of the data identified themes emerging around NDIS language, eligibility criteria, the process itself being highly triggering and overwhelming with many individuals choosing not to apply based on their own personal experience or the lived experience of others, along with difficulties in gaining the evidence required to apply for the NDIS. One barrier that was not identified via community consultations but highlighted in service provider feedback were those individuals who are unable to apply for the NDIS due to their condition. Further details on the initial round of consultation is attached in **Appendix 1**.

Case example - Falling through the gaps

A focus group participant explained that they had applied for the NDIS after a health professional at Adult Mental Health Services suggested they should apply. The participant went through the process of applying for the NDIS, stating that it was a highly confusing and difficult process. After submitting the application, they received a letter from NDIA stating they were ineligible. The participant was unsure of what to do next and did not know how to reapply or find alternate adequate support.

An aspect of the consultations that was not a barrier specific to people with mental ill-health but does deserve a degree of acknowledgement is the socio-economic factors that contribute to a person's capacity to apply for the NDIS. Broadly, participants of the consultations highlighted that individuals at the lower end of the socio-economic scale may face further barriers to applying for the NDIS including lack of access to bulk billing, lower levels of literacy and homelessness. It is suggested that further work is required to explore discrepancies in how socio-economic background may impact on an individual's capacity to apply for the NDIS.

A total of 18 people participated in the second part of the consultation process. Participants provided feedback on identified solutions to remove barriers to testing for the NDIS. The feedback was predominantly positive and has supported the development of the final recommendations in the report. A full copy of the outcomes of the survey can be found in **Appendix 2**.

3. Key Barriers to Testing for the NDIS and Recommendations

3.1 The term 'disability' is not relevant to the individual's experience

Applicable groups: *individuals who have chosen not to apply, individuals who haven't considered applying and individuals in the process of applying for the NDIS.*

The NDIA's terminology regarding the concept of 'disability' was considered to be a significant barrier in making the decision to test eligibility for the NDIS. The concept of a 'permanent disability' was identified by several participants as having deep, emotional impact on an individual along with having a traumatic impact on an individual's sense of identity. Many focus group participants expressed a view that by being diagnosed as having a permanent disability under the current NDIS psychosocial eligibility criteria would result in a negative effect on their recovery or would impair their journey towards a state of wellbeing. Several participants agreed that some individuals will not apply for these reasons. Service providers also identified that there is stigma among their clients with a reluctance to involve themselves in services that label them as 'disabled.'

"Applying for the NDIS seems to mean describing the worst day. This is not going to help recovery" - Survey respondent

"My illness is episodic. I don't believe that NDIS is set up to address my sudden need for help" - Survey respondent

The notion of being disabled or having a permanent disability made individuals believe that the NDIS was not for them. Current individuals accessing the mental health system in Tasmania are accustomed to recovery-focused language and practice, however, recovery-focused language is incongruent with notions of disability and permanence. Focus group participants cited inconsistencies in terminology between various government departments and health practitioners. This inconsistent language added to the confusion for individuals who may be considering applying for the NDIS. Service providers also identified that the language within the Access Request Form (ARF) was not 'mental health user friendly' and had not been adjusted to accommodate people with mental illness who are requiring psychosocial supports.

"The term psychosocial disability is off putting and hard to understand" - Focus group participant

"The attitude is that the NDIS is designed to help those with physical diseases, not mental (illness)" - Survey respondent's comment on their experience of the NDIS.

When focus group participants were asked how the NDIA could improve the discourse around 'disability' and make information more relevant to people with mental ill-health, consistently we heard that NDIA information and the application process needed to be recovery-focused.

The incongruity between ‘disability’ and the ‘recovery-model’ should be addressed and communicated throughout the sector. A shared language and common understanding are important factors in any communication across disciplines, sectors and departments. Furthermore, the language should reflect a positive, recovery-focused model. It is interesting to note that the NDIS was established to support people with disability to participate in the community and reach their goals, a shared principle of a recovery model. Work is required to bring together these shared understandings along with a consistent language across sectors working with people living with mental ill-health.

► Recommendation 1

A communication guide is co-designed with people with lived experience of mental illness and highlights the difference between NDIS language and recovery-focused language. It is recommended that the resource is implemented across all services and organisations operating in the mental health sector in Tasmania, including NDIA staff and service providers.

Survey Feedback:

Would you consider applying for the NDIS if staff working with the NDIA had a better way of talking about mental health and how the NDIS could benefit you? ▶

Yes: 89%

- *“Yes, current language is stigmatising.”*
- *“Yes, it is demoralising to feel labelled as permanently disabled.”*
- *“Yes, as I am not sure exactly how I could benefit from the NDIS, and if I knew how the NDIS could improve my overall psychosocial situation effectively, then I might consider applying.”*

3.2 Individuals do not think they would be eligible

Applicable groups: *individuals who have chosen not to apply and individuals who haven’t considered applying.*

The NDIS eligibility criteria was still unclear to many participants of focus group sessions. This included a lack of clarity on the eligibility criteria for the psychosocial stream, along with reluctance to go through the application process with no guarantee of a positive outcome.

“I considered it [applying for the NDIS] but I couldn’t work out if I qualify or if it will provide me with benefits that will justify the stress of applying” - Survey respondent

“I have not considered applying because I don’t think I will be approved” - Survey respondent

Community focus group participants cited having little or no knowledge of the NDIS eligibility criteria, the application process and the possible benefits of applying. One participant mentioned that they initially assumed the NDIS was just for people with a physical disability. Participants cited examples of conflicting and wrong information given about the NDIS. One participant spoke of differing knowledge of the NDIS in various clinical settings. This was consistent across all focus group sessions with several participants explaining that information from GPs about eligibility for the NDIS was inconsistent and often lacking. Service providers have also noted feedback from their clients, identifying that some clients who had accessed their GP to discuss applying for the NDIS were told that they would not be eligible, therefore the client had declined to go through the application process.

“I talked to the GP. I said, “What do you know about the NDIS?” He said, “Not much, I don’t think you need it – you’ve been doing ok all this time by yourself.” - Focus group participant

It is important to note that the issue of identifying eligibility for the NDIS is not possible until an individual has submitted their application and it has been assessed by NDIA’s assessment team. However, as identified in the next key finding, the application process is triggering, overwhelming, time consuming and can be costly.

Feedback from family and friends along within focus group session participants identified that individuals need some degree of assurity that their application will be successful before embarking on the application process. One participant explained, 'It is a significant investment in time and money to complete the application process without knowing for certain what the outcome will be.'

"Not enough information is available on exactly what to include in an application or whether or not it is worthwhile applying" - Survey respondent

The barrier potential applicants are experiencing is; how can an individual make the decision to embark on a lengthy and costly (emotionally and financially) NDIS application process with no assurance that it will be successful? Participants of the focus group sessions identified the need for clear information on eligibility guidelines, with questions specifically relatable to mental ill-health. Several participants cited the co-design work of [Reimagine Today](#) as a helpful resource. Furthermore, participants cited that it was important to have someone to talk to and discuss eligibility for the NDIS before making the decision to apply.

- **Reimagine Today**

The Reimagine Today project provides a platform to support people living with mental health conditions to navigate the NDIS. All information and resources are co-designed in collaboration with people living with mental ill-health.

► **Recommendation 2**

Implement a phone service for people living with mental ill-health and their carers to call and discuss their potential eligibility for the NDIS along with the application process. It is recommended that peer workers are trained to take the calls.

Survey feedback:

Would it help to have a number to call to discuss eligibility to the NDIS and the application process?

Yes: 100%

- *"Yes, a contact number to discuss the application process would be great."*
- *"Yes, this would be most helpful to ensure the person remains hopeful about the time invested. If there is no clarity in the chances of measuring possible eligibility a person may not have the energy to try."*
- *"Yes, especially if the number is local."*

Would you feel more comfortable if you could speak to a peer worker about your eligibility?

Yes: 94%

- *"Yes, if the peer worker was trained and could sufficiently understand my needs/eligibility"*
- *"Especially if the peer worker was sufficiently trained and knowledgeable"*
- *"Yes, as they are more likely to understand"*

3.3 The process can be triggering, overwhelming and/or anxiety inducing for individuals

Applicable groups: Individuals who have chosen not to apply, individuals who have been deemed ineligible and individuals in the process of applying for the NDIS.

Across all consultations, the most significant barrier to applying for the NDIS was the potential emotional impact of the application process on the individual. All barriers identified in the report are cited as having the potential to emotionally impact the individual. The following barrier describes general areas where anxiety, overwhelm and negative impacts may be exacerbated by the NDIS application process.

“The process is intimidating, people felt they were unheard, and the current process is putting people at risk” - Flourish Action in Our Hands, Tasmania

“I don’t have family support and the last time I applied it almost pushed me over the edge” - Survey respondent

3.3.1 The process is deficit-based

The application process itself has been described as highly deficit based. Several focus group participants explained that they must describe their ‘worst day’ to increase the likelihood of their application being successful. Many participants found the application confronting and the concepts of psychosocial disability difficult to understand. GPs and other health professionals have also been noted as disagreeing with the deficit focus of the application process. A support worker explained how her client’s GP was reluctant to provide evidence for an application because of its deficit-focused nature.

Understandably, the NDIS is focused on disability and the initial application process requires an applicant to describe how their mental illness impacts their daily life to the extent that their condition can be identified as a disability. However, this requires an applicant to identify all their deficits with no acknowledgement of their strengths and abilities and no guarantee that their application will be successful. If the application is deemed unsuccessful, the applicant is left with full knowledge of their deficits and little to no follow up from the NDIA.

“I have trouble telling people about my daughter because it makes me sound like I’m putting her down” - Survey respondent

“Too hard and too traumatic. Having to list all a person’s deficits and struggles with no mention of the positives, what they do well or what they are great at. This is very upsetting for someone with a Psychosocial disability and often causes them to go back into a severe low” - Survey respondent

► Recommendation 3

An additional, optional, part of the NDIS psychosocial evidence form is developed and identifies the goals and strengths of the applicant. This information informs NDIA planners if successful and provides a strengths focus if the application is unsuccessful.

Survey feedback:

Would the opportunity to provide information on your goals and strengths assist in making the application process less triggering?

Yes: 72%

- “Yes, this would be very helpful, and help the NDIS workers get to know you better.”
- “Being quizzed about my goals is triggering, I’m just trying to survive.”

3.3.2 The process is complicated

The NDIS application process is lengthy and subject to delays. Focus group participants cited experiences of being bounced around from one service to another. One participant explained how her service provider was not funded to support her anymore. She was told by her service provider that she would now have to go to another service, however, she was unsure what that would mean and what to do about this. Furthermore, participants discussed how communication during the NDIS application process between support workers, the NDIA and the applicant was confusing. Several focus group participants stated that they were unsure what to do with the information that was given to them from the NDIA suggesting that support workers and others involved in the application process should also be included in all communications.

“Families are not applying as the hassle of applying and length of time it takes is too much for many of them to take on” - Survey respondent

“Constantly jumping through hoops and having the goal posts changed mean a lot of people cannot be bothered with the stress” - Survey respondent

Case example - Service provider observations

A client has had their NDIS application refused on three occasions. The client was informed the first time that the Access Request Form (ARF) did not state their impairment is permanent/lifelong. The client was informed by the NDIA worker that they would be better off reapplying as the review process will take a long time. The client, who was highly anxious about the decision at the time agreed to reapply and completed an ARF over the phone. When the support worker spoke with the client subsequently, they stated that they did not realise they were completing another application over the phone.

The client was confused, angry, upset and highly anxious – the support worker and client rang the NDIA to discuss the clients’ application and spent almost two hours on the phone talking to two different NDIA workers who provided completely different information and advice. The outcome was still negative, and Advocacy Tasmania were engaged but the negative outcome still stood. The client was physically and emotionally exhausted and decided not to reapply for NDIS even though they have a chronic mental health condition that impacts on their ability to participate in employment, education, social and community activities.

When focus group participants and survey respondents were asked what would support them to complete an NDIS application, overwhelmingly the response was for one-to-one support, for someone, preferably a peer experienced in NDIS applications to assist side-by-side in the application process.

► Recommendation 4

Implement a service to connect NDIS applicants and their families with peer workers trained in providing step-by-step support throughout the NDIS application process.

Survey feedback:

Would having 1-1 support from a peer worker help you to make an application for the NDIS?

Yes: 89%

- *“Yes, someone who understands the framework and NDIS application process but also understands the lived experience, triggers and the need for support and anxiety reducing strategies.”*
- *“Yes, if I decided to apply, support from a trained peer worker would be beneficial.”*

3.3.3 The process is impersonal, lacks empathy and understanding of mental illness

Overall, the NDIS was perceived as an impersonal process. One focus group participant described that they felt like a 'commodity', another explained that they were just a name, stating that 'people don't know you.' Furthermore, participants cited that there were situations of repeated interactions with NDIA. One participant cited that they had called the NDIA several times only to repeat their story at each call.

Additionally, an overall response from the participants of focus group sessions centred on NDIA staff's lack of empathy along with minimal knowledge about mental ill-health and psychosocial disability. Many participants suggested that NDIA staff and providers should undertake training in working with people with mental illness along with undertaking vulnerable people checks. One participant also suggested that people with lived experience of mental ill-health should be included on NDIA committees and working groups.

"My carer asked why they changed their decision and was advised that the original person making the decision didn't understand the impact of Bipolar Disorder." - Survey respondent

"Very insensitive, very little understanding or knowledge of the effect of mental illness and the unpredictable and fluctuating nature of mental illness, I was dismissed instantly the first application and with my appeal because I am working due to currently being stable in my illness". - Survey respondent

► Recommendation 5

NDIA planners, senior planners and assessors undergo further training, including trauma informed practice along with implementing recovery focused language via Recommendation 1.

Survey feedback:

Would you feel more comfortable applying for the NDIS if you knew that NDIA staff were appropriately trained in mental illness, particularly understanding trauma and using recovery focused language?

Yes: 100%

- *"This has to be from the top down, not just the applicant liaison and assessment officers who actually deal with consumers."*
- *"Yes, and it would help to reduce the stigma around mental illness, and hopefully give workers more understanding."*
- *"Yes, because they would be more compassionate in the way they approach the application."*

► Recommendation 6

Explore opportunities for trained peer workers to provide support to NDIA planners and the assessment team.

Survey feedback:

Would you feel more comfortable applying for the NDIS if you knew that peer workers were engaging and supporting NDIA staff?

Yes: 94%

- *"Yes – collaboration is the only way this system will work effectively and efficiently."*

► Recommendation 7

Provide opportunities for people with lived experience of mental illness/psychosocial disability to meaningfully participate on NDIA committees and working groups.

Survey feedback:

Would you feel more motivated to apply/reapply for the NDIS if you knew that people with lived experience are part of the decision-making process?

Yes: 83%

- *“Yes, as it would help with general understanding around persons with mental ill-health.”*

3.3.4 Vicarious experience of the process

Across all focus group sessions, participants cited an apprehension in applying for the NDIS based on what they had heard from other participants. Several participants spoke of the process being dauntingly long and other participants noted that the process was ‘scary’. Community focus group sessions identified a resounding fear of applying due to perceived concerns that the process would be too stressful or traumatic for an uncertain outcome.

Case example - Focus session observations

During one focus session, a participant who had been successful in applying for the NDIS took a call from his Local Area Coordinator about his NDIS plan review. Upon returning to the focus session, the participant was clearly frustrated and shared his frustrations about the NDIS with the group. Two other participants in the focus session who were considering applying for the NDIS, promptly became anxious about NDIA’s processes and stated that they did not want to undertake the application process as it seemed too overwhelming and anxiety inducing.

► **Recommendation 8**

Identify positive stories, both locally and nationally, on how the NDIS has supported people with psychosocial disability. Include these stories in the suite of resources identified in Recommendation 1.

3.4 Individuals are finding it difficult to gain the necessary evidence from clinicians to support an NDIS application

Applicable groups: *Individuals who have chosen not to apply, individuals who have been deemed ineligible, and individuals in the process of applying for the NDIS.*

Gaining evidence to support an NDIS application was identified as a significant barrier across focus group session participants, families, carers and service providers. Several reasons were identified, including the financial costs involved in accessing health professionals, long wait-lists and the health professionals’ knowledge of the NDIS.

One focus group participant explained that to access a health professional to apply for the NDIS required travelling into Launceston from her home 40 minutes from the CBD. She explained that there were no health professionals in her area that would assist in the NDIS application process, however the travel costs involved in getting to the CBD was expensive and was a barrier to her applying for the NDIS. Other participants explained that many GPs refused to bulk bill for general appointments, let alone NDIS applications. It is important to note that many participants discussed GPs as the primary health professional in gaining evidence. This is potentially due to GPs being the most accessible health professional and located throughout the state. Additionally, it was cited that some health professionals require several consultations before they can assess how the individuals’ condition impacts their daily life and that this process can be time consuming and costly.

Case example - Gaining evidence from health professionals

A focus group participant explained that they had moved interstate and had no evidence to apply for the NDIS from within the last 2 years. The participant visited a Psychologist in their new area six times before they could gain enough evidence to apply for the NDIS. This required a significant amount of time and financial costs; many individuals would be unable to afford to undertake this process.

Focus group participants identified several ways that could potentially make it easier to gain the evidence required for an NDIS application. One suggestion involved allowing a support worker to complete the evidence aspect of the application with a health professional utilised to provide confirmation of diagnosis. It was highlighted that a support worker would know the applicant well enough and would be the most suitable person to identify the support needs of the individual. Other suggestions explored further training for GPs and other health professionals, extended bulk billing opportunities and prioritised waitlists for individuals requiring evidence for an NDIS application.

► Recommendation 9

Explore ways to make it easier and simpler for GPs and health professionals to provide evidence for NDIS applications. For example, extend the phone service in Recommendation 2 to support GPs along with further training opportunities and development of checklists and resources.

Survey feedback:

Would it be helpful to have a simple resource that you can take to your GP to assist with your NDIS application?

Yes: 94%

- *“A checklist would be useful or prompts to link medical history and pathway to NDIS criteria/assessment.”*
- *“Yes, processes need to be streamlined for GPs and other clinicians to easily present supporting information.”*

► Recommendation 10

Explore options to adjust the NDIS application process to allow support workers and non-clinical staff to provide the evidence for an NDIS application and health professionals engaged to provide a confirmation of diagnosis.

Survey feedback:

Would it help you to complete an application if a support worker or peer worker who knew you well was able to fill in the bulk of the evidence needed in your application?

Yes: 89%

- *“It would be less stressful. I dislike having to retell my story over and over.”*

► Recommendation 11

In consideration of Recommendation 10, explore ways that the clinical evidence part of the NDIS application only requires one standard consultation with a GP or other health professional.

Survey feedback:

Would it help you to complete an application for the NDIS if you knew that you only needed to attend one GP appointment in order to gain the evidence required?

Yes: 78%

- *“I find going to appointments very stressful.”*
- *“It would assist, however, I do not mind attending more than once.”*
- *“Yes, as going back over and over for the same thing can make someone feel stupid, overwhelmed and denigrated.”*

3.5 An individual's mental health and associated circumstances impact on applying for the NDIS

Applicable groups: All

A barrier not clearly identified in focus group sessions but has been identified from carer and service provider feedback is the nature of an individuals' condition. Service providers identified that those individuals with episodic conditions can experience a build-up of symptoms, hospitalisation and then a recovery phase. During this time, individuals are not thinking clearly and may feel too overwhelmed to apply for the NDIS. Those who have a chronic mental health condition can experience persistent low moods and low motivation where they are unable to engage in daily activities including activities that relate to applying for the NDIS such as seeing a GP. Other individuals may experience persistent elevated moods where completing forms and lengthy processes are not prioritised.

In addition to an individual's condition, other complicating factors may also contribute to barriers to applying for the NDIS. These include homelessness, family relationship issues, drug/alcohol conditions, lack of insight into the individual's condition in relation to psychosocial disability, low levels of literacy and impaired cognitive function.

Service providers are currently putting several practices in place to best support their clients who are too unwell to apply for the NDIS. These practices include the development of concise communication and processes when requesting evidence from health professionals, using a range of communication methods to engage clients who have been difficult to contact or reach and assisting with supported handovers to other service providers as required.

"Many people who are suicidal, and struggle with psychosocial disability just won't (apply), and don't bother as it's too hard" - Survey respondent

"My daughter's mental health issues stop her from understanding how it could improve her life" - Survey respondent

Case example

A support worker described how her client was unable to gain any evidence for the NDIS. Due to the client's condition, she was unable to leave her home. This restricted the client's ability to access health professionals to gain evidence for the NDIS application. To date the client is unable to make an application to the NDIS.

► Recommendation 12

Support clients in current NPS funded transition programs that are unable to test eligibility for the NDIS due to their mental health condition. It is recommended that identified clients are supported on a case-by-case basis with individual barriers identified and additional measures provided to support clients to apply for the NDIS if they wish to do so. Additionally, continue to provide measures to allow for supported handovers of clients transitioning to Continuity of Support (COS) and NPS Measure funded programs from NPS transition programs.

Appendix 1

Summary of findings from the ‘Removing Barriers to Testing for the NDIS consultations’:

Service Provider Feedback

Roundtable - 7 attendees

Email feedback - 1

Service Provider Staff feedback – 3

General themes:

- The barriers to testing for the NDIS identified in the Removing Barriers to testing briefing document were accurate, along with waitlists to gain evidence being a barrier.
- Concerns were raised about people falling through the gaps and not wanting to change service providers.
- Gaining evidence was cited as the most common barrier to completing an application.
- There are clients with severe and fluctuating mental illness, who are too unwell to participate in the application process. One staff member stated that they had a client who was unable to leave their home. This was a significant barrier to gaining evidence as there were no health professionals who would do house visits.
- The language used in the access request form is not recovery focused.
- Suggestions to support clients in testing for the NDIS: engagement with clients, education and consistent discussion about the NDIS with clients, easy English NDIS resources, example NDIS plans, NDIS information sessions, warm handovers, assertive follow-up, cross service relationship building.

Consultation with clients of current Service Providers

Survey - 3 respondents

Focus Sessions - Burnie, Launceston, Hobart - 15 participants in total

General themes:

- The focus sessions explored barriers to testing for the NDIS along with potential solutions to removing those barriers.
- The language of ‘disability’ was identified as a pertinent barrier. The concept caused misunderstanding regarding eligibility for the NDIS, along with a consensus that the language did not reflect a recovery model. Difficulties were also raised in language such as ‘permanence’ which was identified as having deep emotional impact on a person’s identity.
- Participants also identified that the application process was triggering, overwhelming and/or anxiety inducing. Discussion centred on the emotional impact caused by the application process with many citing uncertainties and change in service providers being a barrier, the impersonal nature of the NDIA, previous negative interactions with NDIA staff (either directly or via family and friends), and the process being confusing.
- Gaining evidence for the NDIS application was also cited as a barrier to completing an application. It was acknowledged that GPs were the most commonly used health professional to provide evidence, however accessing GPs who provide such a service and at bulk billing rates was highly limited. Additionally, participants identified that GPs and health professionals had limited knowledge of the NDIS in relation to psychosocial disability.
- Suggestions to remove barriers included:
 - Streamlining the application process, training GPs and health professionals in psychosocial disability, training NDIA staff in MHFA and trauma informed practice, changing the language of NDIS to a recovery focus, bulk billing for gaining NDIS evidence, support workers providing the bulk of evidence for an application, peer workers to offer side by side support in the application process, consistent and coordinated information from the NDIA, a better understanding of eligibility criteria.

Consultation with Flourish Members - Subcontracted to Flourish

Survey - 14 respondents

Focus Sessions - Hobart, Launceston, Penguin - 10 participants in total

General themes:

- 78% of survey respondents were aware of the NDIS and how it can help
- 28% of survey respondents had made an application to the NDIS with 85% of those respondents identifying that their application was unsuccessful.
- Focus sessions centred on identifying the barriers to testing for the NDIS.
- Barriers identified included:
 - The emotional cost of applying for the NDIS, the financial cost of gaining evidence from health professionals for the application process, health practitioners' (in general) lack of knowledge of the NDIS application process, NDIA's lack of knowledge and minimal promotion of the psychosocial disability stream, lack of support to apply for the NDIS, the time involved to make an application for the NDIS, NDIA documents were identified as confusing with the terminology difficult to understand, apprehension of being labelled as 'disabled' or having a permanent condition.

Consultation with MHFF Network - Subcontracted to MHFF

Survey - 24 respondents

Note: a mix of respondents - including carers, people with lived experience and people working in the sector.

General themes:

- 96% of survey respondents were aware of the NDIS.
- Of the survey respondents who had received an unsuccessful outcome from an NDIS application, approximately 50% have not reapplied or have not considered reapplying.
- Survey respondents had mixed experiences with the NDIA. Suggesting that there were inconsistencies in the level of empathy and understanding of psychosocial disability among NDIA staff.
- Survey respondents identified that having 1-1 support to complete the application process would be most helpful.
- Barriers holding respondents back from applying/supporting someone to apply included: complicated and confusing process, fear of the process, literacy issues, lack of understanding about how the NDIS can help, concerned about stigma and prejudice.
- There were mixed views in terms of the ease of gaining evidence to support an application. Many found the process difficult, on average, from the data it appears the process takes 3-6 months. Other respondents state difficulties in gaining evidence. In general, it seems there is a lot of inconsistency in an individual's capacity to gain evidence.
- Those who decided to apply for the NDIS most commonly stated that they needed extra supports to assist with their condition. Those who had reapplied did so because they still felt that they needed the extra supports available through the NDIS, one respondent had attended an NDIS information session where it was recommended that they reapply.
- Those who had chosen not to reapply stated that having 1-1 support would assist in making the decision to reapply. Information sessions and some reassurance regarding the application being successful were also factors in making a decision to reapply.

Appendix 2:

Summary of findings from the 'Solutions Survey':

Flourish network: 13 respondents

MHFF network: 4 respondents

Focus session participants: 2 respondents

(Note: comments from survey respondents are unedited)

Barrier 1: The language around 'disability' is not relevant to my experience. The language of 'permanent' and 'disability' can have a negative impact on a person's identity. Many participants identified that the NDIA should provide a more recovery focused perspective.

Solution: Co-design resources with consumers that highlight the difference between NDIA language and Recovery focused language. Use these resources to engage with NDIA staff and NDIA providers, supporting them to communicate what NDIS can offer in a recovery focused way.

Question: Would you consider applying for the NDIS if staff working with the NDIS had a better way of talking about mental health and how the NDIS could benefit you?

89% Yes

- I would still need someone to translate and explain and not take the attitude I was entitled to the minimum possible
- There's still some stereotyping that is unhelpful. For example, I was told I will probably be rejected because I am educated to a university level and most people who qualify are grade 7 level. I think this is a misunderstanding. I do not think that disability infers anything about education level.
- Yes, especially if it was made clearer how the NDIS could benefit.
- I would be more comfortable talking with my peer.
- Current language is stigmatising
- Yes, current language is stigmatising
- An emphasis on recovery and not having to use the worst day in order to apply would be great
- Yes definitely
- Yes, it is very demoralising to feel labelled as permanently disabled.
- Yes, as I am not sure exactly how I could benefit from the NDIS, and if I knew how the NDIS could improve my overall psychosocial situation effectively, then I might consider applying.

Barrier 2: I don't think I would be eligible. There is not enough information about whether a person should apply for the NDIS and where to start in the application process. Additionally, concerns were raised about the process being a significant investment in time and money with no guarantee of a positive outcome.

Solution: You are able to contact a peer worker (someone with a lived experience of mental illness that is trained in identifying potential eligibility for the NDIS) in your area to discuss the NDIS, if you may be eligible and the application process.

Question: Would it help to have a number to call to discuss eligibility to the NDIS and the application process?

100% Yes

- Yes, very useful. I am currently very confused about process and how to take first steps
- Yes, a contact no to discuss the application process would be great
- Yes, a face to face appointment would be even better
- Yes, this would be most helpful to ensure the person remains hopeful about the time invested. If there is no clarity in the chances of measuring possible eligibility a person may not have the energy to try.
- Especially if it was a local area number
- It would need to be my peer for me to be comfortable.
- I am very confused about the process and how to take first steps
- If the staff responding could assure that information discussed would not result in the removal of existing service provision.
- Yes, especially if the number is local, rather than Canberra

Question: Would you feel more comfortable if you could speak to a peer worker about your eligibility?

94% Yes

- Exactly right! Provided the peer worker did not have a conflict of interest and was very knowledgeable about cases like mine
- Especially if the peer worker was sufficiently trained and knowledgeable
- talking to my peer means I would not have to explain myself all the time.
- This would be a valuable resource
- Yes - someone who better understood the process and language, and evidence sources.
- Yes, could be helpful to have a peer available for both the support person and if possible also for the person applying
- Yes, as they are more likely to understand.
- Yes, if the peer worker was trained and could sufficiently understand my needs/eligibility

Barrier 3: The process for applying for the NDIS is triggering, overwhelming and/or anxiety inducing. Participants identified that the application process can be impersonal, complicated and confusing. In addition, concerns were raised about the emotional impact of the application process as the application form is focused on deficits rather than strengths.

Solution 1: An additional part of the NDIS application form identifies the applicants' goals and strengths. This information informs NDIA planners in developing a plan that assists in reaching goals.

Question: Would the opportunity to provide information on your goals and strengths assist in making the application process less triggering?

72% Yes

- It is the overwhelming importance of the process that is the trigger.
- It would make the whole process a lot more positive and constructive for people.
- I would only be more comfortable talking and sharing with my peer.
- My goals are wellness focused - I want support and hope
- being quizzed about my goals is triggering I'm just trying to survive
- Yes, this would be very helpful, and help the NDIA workers get to know you better.

Solution 2: Peer workers are trained in assisting consumers/family and friends with NDIS applications. A peer worker provides step-by-step support throughout the application process.

Question: Would having 1-1 support from a Peer Worker help you to make an application for the NDIS?

89% Yes

- Very much so, provided the peer worker did not have a conflict of interest and was very knowledgeable about cases like mine
- Yes, if I decided to apply support from a trained peer worker would be beneficial
- I would only trust my peer to understand me and my goals.
- At the moment I feel overwhelmed and anxious
- Maybe - have the peer's received training in evidenced based practices such as trauma informed care or recovery focused practices. Do they hold qualifications that will ensure they put the consumer's health, goals and well-being before the need for the system to determine eligibility.
- Yes - someone who understands the framework and NDIS application process but also understands the lived experience, triggers and the need for support and anxiety reducing strategies.
- It does sound helpful
- Yes definitely
- Yes. A peer worker has more patience and understanding to support a person applying for NDIS.
- Yes, if the peer worker was able to support me sufficiently well.

Solution 3: NDIA planners, senior planners and assessors undergo further training. For example, training in trauma informed practice, and recovery focused language.

Question: Would you feel more comfortable applying for the NDIS if you knew that NDIA staff were appropriately trained in mental illness, particularly understanding trauma and using recovery focused language?

100% Yes

- This has to be from the top down, not just the applicant liaison and assessment officers who actually deal with consumers
- Yes, and it would help to reduce the stigma around mental illness, and hopefully give workers more understanding
- I was badly upset to discover that NDIA staff had no experience with mental illness themselves.
- I would think this is an essential competency
- I can't believe this wasn't an obvious requirement to everyone involved.
- Yes, I would presume this is a core competency for staff.
- It is appropriate they have these skills
- Yes, I don't believe NDIA assessors are sufficiently qualified.
- Yes, because they would be more compassionate in the way they approach the application.
- Yes, this would be highly beneficial, and also help to reduce the stigma around mental illness in the worker/NDIS participant relationship.

Solution 4: Trained peer workers are linked in with and provide support to NDIA planners and the NDIA National Assessment Teams.

Question: Would you feel more comfortable applying for the NDIS if you knew that peer workers were engaging and supporting NDIA staff?

94% Yes

- If this means relieving NDIA workers of stress then yes, otherwise it depends upon the level of input the peer worker can have in decision making, it is no good them just making the consumers feel better in the short term if this does not affect the assessment.
- I would rather talk to my peer in the first instance.
- This collaboration is vital for success.
- Yes, collaboration is the only way this system will work effectively and efficiently.
- Yes, I believe NDIA staff definitely need assistance around interpreting answers to some of the questions asked in the application, and also supporting documents that may be provided by applicants
- Yes, if peer workers were more engaging it would feel like they care more about a person's long-term wellbeing.
- Yes, they could make a big difference if sufficiently trained and across the issues.

Solution 5: People with lived experience of mental illness/psychosocial disability meaningfully participate on NDIA committees and working groups.

Question: Would you feel more motivated to apply/reapply for the NDIS if you knew that people with lived experience are part of the decision making process?

83% Yes

- Um, if there is a need to re-apply, then those with lived experience have been superfluous in the first place
- Yes, at it would help with general understanding around persons with mental ill-health
- I think that only people who have a lived/living experience should be involved with this process.
- I would feel that I may be understood and my needs/goals better understood
- Thank you for listening, please continue to involve us
- Yes, I currently feel overwhelmed and stigmatised. Having staff and support people that have a lived experience and who would understand wellness and living well with my illness would be wonderful.
- Yes, if they were involved in the application process in addition

Barrier 4: It is difficult to gain the necessary evidence from clinicians to support an NDIS application. The costs involved in accessing clinicians, along with finding clinicians that are willing to assist in providing evidence and the level of health professionals' understanding of the NDIS application process were all barriers to completing an application.

Solution 1: Explore ways to make it easier and simpler for GPs and health professionals to provide evidence for NDIS applications. For example, exploring a helpline number for health professionals to access, training for medical administrative staff, development of simple checklists and resources that GPs can use to provide evidence.

Question: Would it be helpful to have a simple resource that you can take to your GP to assist with your NDIS application?

94% Yes

- Sounds like a great idea, as it would help approaching the GP more confidently
- As it is at the moment, the language used in promotional material is the opposite to acceptable language needed in an application. This leads to many people needing to re-apply for the NDIS.
- A checklist would be useful, or prompts to link medical history and pathway to NDIS criteria/assessment
- Not until GPs are trained in MH, Recovery Focused and Trauma Informed care and practices.
- Yes, guides and checklists would be useful, go guide me on first steps and what kind of evidence to focus on, the what and how steps.
- "Yes. Processes need to be streamlined for GPs and other clinicians to easily present supporting information.
- I portent that when applying the story does not have to be told multiple times - very exhausting and stressful"
- Yes, these would be good, and also information given to GPs about the NDIS in general, which may help them in the initial

Solution 2: Support workers and other non-clinical staff provide the bulk of evidence for NDIS applications and health professionals then need only provide a confirmation of diagnosis. (Note: This solution is out of reach of MHCT's sphere of influence but may be passed on to federal government/NDIA for consideration).

Question: Would it help you to complete an application if a support worker or peer worker who knew you well was able to fill in the bulk of the evidence needed in your application?

89% Yes

- I would prefer to fill out the application myself
- it would be less stressful. I dislike having to retell my story over and over.
- This would work best as a collaboration with me, not for me
- Someone to work with me, not do it for me - that would be disempowering. To provide guidance on evidence needed, the what, how, from who and when (history).
- Yes, means story does not have to be rehashed
- I think this would be helpful although in my case it is not applicable
- Yes, because a big application can be so overwhelming for a person with a Mental Health Illness.
- Someone to work with me, not do it for me - that would be disempowering. To provide guidance on evidence needed, the what, how, from who and when (history).
- I would rather complete my own forms.

Solution 3: The clinical evidence aspect of the NDIS application would only require that you attend one standard consultation with your local GP or other health professional. (Note: This solution is out of reach of MHCT's sphere of influence but may be passed on to federal government/NDIA for consideration).

Question: Would it help you to complete an application for the NDIS if you knew that you only needed to attend one GP appointment in order to gain the evidence required?

78% Yes

- No, I am happy to attend more than one appointment. I understand this is a process - I would more want to ensure each appointment is valuable and I am gathering the right evidence and understand what I am doing.
- Yes, GPs need to have appropriate support - time, payments (bulk billed?), system processes
- Yes, as going back over and over for the same thing can make someone feel stupid, overwhelmed and denigrated.
- It would help but would not matter greatly to me if I had to attend several times.
- A GP may not have the experience or qualifications to diagnose or form judgments about MH matters. Additionally, the cost of reports is not refundable or claimable.
- It would assist, however, I do not mind attending more than once

- I find going to appointments very stressful.
- I am happy to attend more than one appointment but I would like a guide or checklist to ensure I am following guidelines in gathering evidence