Breaking down Barriers:

Co-designed recommendations to reduce stakeholder identified NDIS access barriers for people with psychosocial disability

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THE UNIVERSITY OF SYDNEY

The University of Sydney Team

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Our research team are all members of The University of Sydney's Centre for Disability Research and Policy (CDRP). Our team comprises the following expertise: Deb Hamilton is a lived experience researcher, a PhD candidate studying the experience of choice and control within the NDIS, and has a psychosocial disability package with the NDIS. Dr Damian Mellifont is also a lived experience researcher and lead of the lived experience-led research work stream of the Centre for Disability Research and Policy. Associate Professors Nicola Hancock, Justin Scanlan and Professor Jennifer Smith-Merry are academics who seek opportunities to work in partnership with lived experience colleagues and have a depth mental health and NDIS-related research experience.

Acknowledgement of Expert Stakeholders:

Almost 400 expert stakeholders participated in this project. Stakeholders included 1. individuals living with mental distress, mental illness or psychosocial disability, 2. their family and friends, and 3. Individual workers and organisations who advocate for and strive to support people to have access to the opportunities needed to live the lives they want and deserve. We thank them for sharing their expertise, experiences, and perspectives to help us gather a rich and detailed understanding of the many and diverse barriers currently facing people when they contemplate or are asked to contemplate applying for the psychosocial stream of the NDIS. We also thank them for contributing to the development of recommendations to address these barriers.

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AT A GLANCE – 2 PAGE SUMMARY

Breaking down Barriers: Co-designed recommendations to reduce stakeholder identified NDIS access barriers for people with psychosocial disability

The Issue

The National Disability Insurance Scheme (NDIS) commenced in 2016 and is designed to support people with all types of disability including those living with psychosocial disability. However, many thousands of Australians living with psychosocial disability have still not applied to access the Scheme and are consequently missing out on their right to receive valuable NDIS supports to advance their social and economic inclusion.

The Project Aims

The project aims were to work with stakeholders to 1. Understand the barriers to applying to the NDIS for people living with psychosocial disability, and 2. Identify solutions to remove or reduce these barriers and to synthesise these into a practical set of stakeholder-informed recommendations.

Across all states and territories, 386 stakeholders collaborated on this project. Stakeholders included: 1. people living with psychosocial disability of mental distress; 2. their family and friends, and 3. workers and organisations engaged in supporting or advocating for them.

The Approach

The project was conducted over three phases:

1. A scoping review of literature to identify previously reported barriers to applying to the NDIS for people with psychosocial disability – used to inform phase 2 survey.
2. A national survey to identify current, stakeholder informed and prioritised barriers.
3. Co-design of practical, lived experience informed recommendations to address NDIS access barriers with stakeholders.

The Barriers

Stakeholders described ten broad and interconnected NDIS access barriers for people with psychosocial disability. These included:

1. Key information about NDIS is confusing or not accessible
2. Hard to get supports to help to apply - formal (services) and informal (family and friends)
3. Hard to obtain evidence required by the NDIA
4. Application process is too long, complicated, and inflexible
5. Application process is harmful to mental health and well-being
6. The application process does not accommodate for mental illness and psychosocial disability
7. The negative reputation of NDIA staff and culture
8. Disconnect between 'disability' and 'recovery'
9. Personal beliefs, fears and stigma, and
10. It is not worth it – NDIS won't meet my needs anyway.

Each of these is detailed within the report.

The Recommendations

Seven recommendations were identified, reviewed and refined by stakeholders. These recommendations are practical, lived-experience informed actions to address NDIS access barriers faced by people living with psychosocial disability.

1. **Build, maintain and disseminate accurate, up-to-date, easily accessible information** - Update, enhance and build upon best currently available information. Invest in and maintain the update of a single national source of information. Enhance the dissemination of this information including easy read downloadable one-pagers that can be printed and paper-based fliers to maximise accessibility.

2. **Co-develop and co-deliver systemic training and establish workforce support champions** – Co-develop and deliver continually available training for health and community service providers. GPs, public, community and private mental health, disability and social services require ongoing access to training about the psychosocial stream of the NDIS. Workforce support champions will provide expert support and guidance to complement this training so that workers can provide accurate and helpful support, advice and evidence to people who are considering or are applying for the NDIS.

3. **Establish navigator positions – independent and psychosocial specific** - Create a clear, independent NDIS Psychosocial specific Navigator role to assist individuals, family members and service providers throughout the NDIS application process.

4. **Cover out-of-pocket expenses** - Create funding streams or models of reimbursement to ensure that people have equitable access to the experts required to provide evidence of psychosocial disability without incurring out-of-pocket expenses.

5. **Commission and fund an independent evaluation of the application process specifically for people with psychosocial disability** - Independent evaluation of the impacts of: a) recent legislative changes; b) the future implementation of the Recovery Framework; and c) adoption and future implementation of the recommendations within this report, on the experiences of the NDIS application process for people living with psychosocial disability.

6. **Co-develop and co-deliver recovery and psychosocial disability training for a. NDIA staff, b) NDIA partner staff (Local Area Coordinators - LACs), and c) NDIS service provider staff (community managed/controlled organisations)** - All staff within these 3 distinct workforces need to have access to recovery-oriented, trauma-informed psychosocial disability training and education that is co-developed and co-delivered with people with psychosocial disability.

7. **Commission and fund an independent review of NDIA culture and workforce issues** - Review the impact of implementing the NDIS Psychosocial Recovery-Oriented Framework agenda on NDIA staffing practice and cultural issues.

Conclusion

Almost 400 stakeholders partnered with us to identify current barriers to applying for NDIS support. They then engaged with us to develop seven key, lived experience informed, recommendations to address those barriers. These seven practical action-oriented recommendations need urgent implementation to enable the people living with psychosocial disability who are most disadvantaged and most in need of NDIS support to be able to apply for that support. The feasibility and value of each of these recommendations is evidenced by them being raised across numerous previous national NDIS-focused reports including for example, the Tune Review and the 'Mind the Gap' report. Today, stakeholders are asking for more than policymakers' awareness of the barriers that deny much needed NDIS access – although these too are re-iterated and further detailed within this report. Stakeholders call for immediate investment in these practical actions to 'break down barriers' to accessing NDIS support and by doing so, improve the lives of many Australians living with psychosocial disability.

EXECUTIVE SUMMARY

Background:

The NDIS provides Australians living with disability, including people living with psychosocial disability, with the reasonable and necessary supports needed to live an engaged, meaningful, and productive life. However, figures from NDIA quarterly reports to COAG, as well as independent reports, evidence that many people living with psychosocial disability are still not applying for NDIS support. According to the NDIA[1], 48,460 people with psychosocial disability are currently NDIS participants. This is at least 25 percent lower than the conservatively anticipated number of 64,000. Many thousands of Australians with psychosocial disability therefore continue to miss out on the NDIS supports and services that can play significant roles in improving and saving lives.

Aims:

The overall aims of this National Mental Health Commission funded project were:
1. Understand the barriers to applying to the NDIS for people living with psychosocial disability, and
2. Identify stakeholders' proposed solutions to remove or reduce these barriers and to synthesise these into a practical set of stakeholder-informed recommendations.

Approach:

This project involved three phases:
1. Review of the literature – what barriers have been previously reported?
2. Survey stakeholders (people living with psychosocial disability or mental illness, their family and friends, and workers and organisations supporting or advocating for them) to understand current NDIS access barriers for people with psychosocial disability
3. Engage stakeholders in identifying solutions to address access barriers for people with psychosocial disabilty, and synthesise these into a set of key recommendations

Findings:

Phase 1 - what the literature tells us about barriers to applying for NDIS support

A thematic analysis of 64 publications that met our inclusion criteria identified 11 previously reported barriers to applying for NDIS support experienced by people with psychosocial disability. Note – these are detailed further within the report.

Table 1. **Themes in the literature** – barriers to applying for NDIS support:

1	The ongoing 'disability' and 'recovery' disconnect
2	Connection and access to information, advocacy, and support services
3	Experiences and symptoms of mental illness extend and exacerbate barriers
4	Clarity and complexity of the Scheme
5	Trauma and distrust resulting from previous experiences with service systems and agencies
6	Availability of expert or specialist assessments for evidence
7	Homelessness extends barriers
8	Geography – the more rural and remote the greater the barriers
9	Societal stigma relating to mental illness and psychosocial disability
10	Culture – greater barriers for Aboriginal and Torres Strait Islander people and culturally diverse communities
11	Costs of expert or specialist assessments for evidence

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[1] NDIA. (2021). NDIS quarterly report to disability ministers 30 June 2021.

Phase 2 - stakeholder identified NDIA access barriers for people with psychosocial disability

From across all states and territories, 386 stakeholders (people living with mental illness or psychosocial disability themeselves; family and friends; and mental health advocates and practitioners) actively partnered with us in this collaborative project. Stakeholders completed a national survey and then reviewed, provided feedback on, and refined our synthesis of the results. Below is a summary of stakeholder identified barriers. Further detail is contained within this report.

The quantitative findings – ranking of barriers in terms of frequency

Stakeholders were presented with a list of previously identified barriers (drawn from phase 1) to rate in terms of relevance to people with psychosocial disability (as well as identifying what barriers were missing – see qualitative findings below).

The top 5 highest-ranked barriers for people living with mental illness or psychosocial disability themselves and family and friends are listed below. Note that these items are presented in the wording presented participants responding as people living with mental illness / psychosocial disability.

- Because I think that applying for the NDIS will be too stressful or traumatic.
- Because applying for the NDIS is too hard.
- Because it is hard to know what evidence I need to be able to apply.
- Because applying for the NDIS is too confusing.
- Because my mental health is not great at the moment and this makes it hard for me to cope with applying for the NDIS.
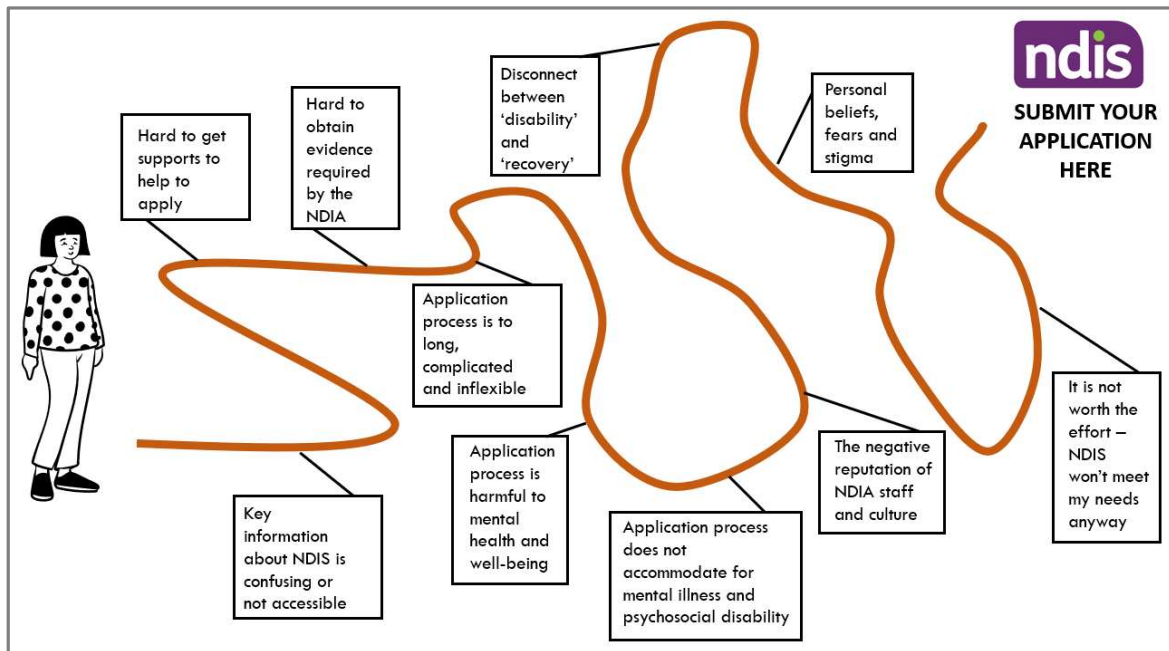
In addition to the 5 barriers listed above, the "worker" respondent group (individual workers and organisations) identified three additional key barriers that were affirmed by over 75% of respondents. These were:

- Because it is hard for them to find out how to apply for the NDIS.
- Because they do not know about support services that can help them to apply.
- Because it costs too much for people to get a specialist assessment to prove that they have a permanent psychosocial disability.

The Qualitative findings – what people said

As well as rating the list of barriers developed from the literature, stakeholders were asked to tell us what barriers were missing or not mentioned. Qualitative comments also provided more detail about the barriers developed from the literature. There were ten overarching themes identified from the analyses of these quantitative and qualitative datasets. These ten themes are shown in Figure 1 below. Each of these themes are detailed and multi-faceted. They are provided in-depth and with example quotes within this report.

Figure 1. **Barriers preventing people from applying to the NDIS**

Figure showing barriers: Hard to get supports to help to apply; Hard to obtain evidence required by the NDIA; Disconnect between 'disability' and 'recovery'; Personal beliefs, fears and stigma; SUBMIT YOUR APPLICATION HERE; Application process is to long, complicated and inflexible; Key information about NDIS is confusing or not accessible; Application process is harmful to mental health and well-being; Application process does not accommodate for mental illness and psychosocial disability; The negative reputation of NDIA staff and culture; It is not worth the effort – NDIS won't meet my needs anyway

Phase 3 - stakeholder identified recommendations to redressing NDIS access barriers for people with psychosocial disability

In phase 3, we returned to stakeholders and invited them to identify possible solutions to address the barriers they reported in phase 2. Again, the stakeholder recommended solutions were synthesised with conceptually similar solutions drawn together into a final set of seven recommendations. These recommendations were sent back out to stakeholders for final review and refinement.

The seven key recommendations developed from stakeholder suggested solutions are summarised in Figure 2, and Table 3 below. Figure 2 depicts the stakeholder proposed barriers and the aligned recommendations that each address.

Figure 2. **NDIS access barriers and aligned recommendations to address these**
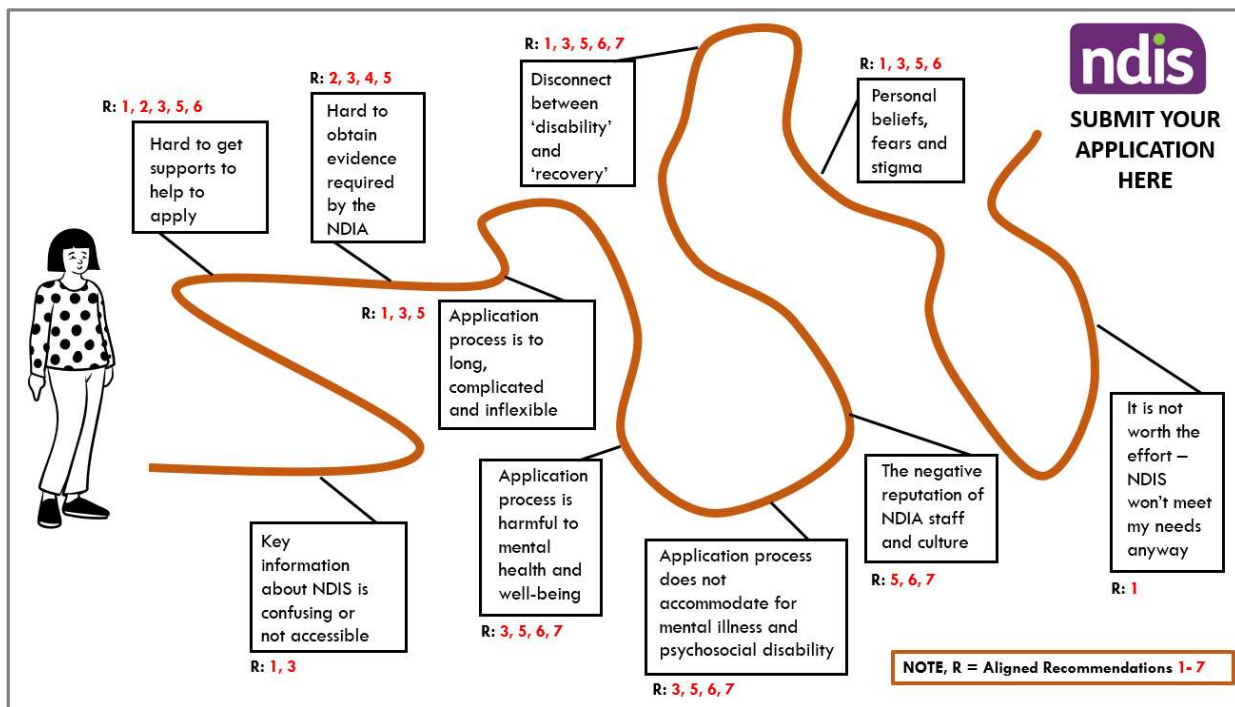

Table 3. **Brief summary of Recommendations** (see alignment to barriers in figure above and further detail in the body of this report)

SUMMARY of RECOMMENDATIONS
1. **Build, maintain and disseminate accurate, up-to-date, easily accessible information** - Update, enhance and build upon best currently available information (possibly the reimagine website - https://reimagine.today/). Invest in and maintain the update of a single national source of information. Enhance the dissemination of this information including easy read downloadable one-pagers that can be printed and paper-based fliers to maximise accessibility.
2. **Co-design and co-deliver systemic training and establish workforce support champions** - Co-develop and deliver continually available training for health and community service providers. GPs, public, community and private mental health, disability and social services require ongoing access to training about the psychosocial stream of the NDIS. Workforce support champions will provide expert support and guidance to complement this training so that workers can provide accurate and helpful support, advice and evidence to people who are considering or are applying for the NDIS
3. **Establish navigator positions – independent and psychosocial specific** – Create a clear, independent NDIS Psychosocial specific Navigator role to assist individuals, family members and service providers throughout the NDIS application process.
4. **Cover out-of-pocket expenses** - Create funding streams or models of reimbursement to ensure that people have equitable access to the experts required to provide evidence of psychosocial disability without incurring out-of-pocket expenses
5. **Commission and fund an independent evaluation of the application process specifically for people with psychosocial disability** - Independent evaluation of the impacts of a) recent legislative changes, b) the future implementation of the Recovery Framework and c) adoption and future implementation of the recommendations within this report, on the experiences of the NDIS application process for people living with psychosocial disability.
6. **Co-develop or identify and co-deliver recovery and psychosocial disability training for a. NDIA staff, b) NDIA partner staff (Local Area Coordinators - LACs), and c) NDIS service provider staff (community managed/controlled organisations)** - All staff within these 3 distinct

	workforces have access to recovery-oriented, trauma-informed psychosocial disability training and education that is co-developed and co-delivered by people with psychosocial disability
7.	**Commission and fund an independent review of NDIA culture and workforce issues** - Review the impact of implementing the NDIS Psychosocial Recovery-Oriented Framework agenda on NDIA staffing practice and cultural issues

Concluding Comments:

Almost 400 stakeholders partnered with us to identify current barriers to applying for NDIS support. They then engaged with us to develop seven key, lived experience informed, recommendations to address those barriers. These seven practical action-oriented recommendations need urgent implementation to enable the people living with psychosocial disability who are most disadvantaged and most in need of NDIS support to be able to apply for that support. The feasibility and value of each of these recommendations is evidenced by them being raised across numerous previous national NDIS-focused reports including for example, the Tune Review and the 'Mind the Gap' report. Today, stakeholders are asking for more than policymakers' awareness of the barriers that deny much needed NDIS access – although these too are re-iterated and further detailed within this report. Stakeholders call for immediate investment in these practical actions to 'break down barriers' to accessing NDIS support and by doing so, improve the lives of many Australians living with psychosocial disability.

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Abbreviations

Ps	People living with psychosocial disability, mental illness or mental distress who completed a survey
Fs	Family member who participated in a survey
MHC	Mental Health Commission
NDIA	National Disability Insurance Agency
NDIS	National Disability Insurance Scheme
PSD	Psychosocial disability
s	Survey
USyd	The University of Sydney
Ws	Advocacy or mental health service worker/organisation who completed a survey

Project Background

BACKGROUND to the NDIS

In 2011, the Productivity Commission described the disability care and support system as underfunded, unfair and fragmented and a system that provided limited choice and restricted access to appropriate supports for people with disability (Productivity Commission 2011). They called for the development of a National Disability Insurance Scheme (Bonyhady 2014). Legislation for the National Disability Insurance Scheme (NDIS) was passed in 2013 with broad political and community support (Backhouse 2017; Bonyhady 2014). The NDIS represented a dramatic shift in the way social services were delivered, shifting from a 'service-focused funding model' towards an 'individualised funding model' focused on maximising individuals' choice and control over their own planning, goal setting and service delivery (Cortese et al. 2021; p.884, Langmead 2018; Wilson et al. 2018). Within the NDIS, 'disability' is defined as a permanent impairment which necessitates supports to manage everyday activities (Quinlan, 2014b) and the primary objective of the NDIS is to provide reasonable and necessary supports to enable individuals experiencing disability to live 'an ordinary life' (Buckmaster & Clark 2018; Churchill, Sotiri and Rowe 2017). The NDIS is administered by the National Disability Insurance Agency (NDIA) and has an estimated operating cost of approximately $22 billion per annum. Initial projections estimated that, at full implementation, the Scheme would provide services to 460,000 Australians living with disability, including 64,000 people with psychosocial disability (Smith-Merry et al. 2018).

The NDIS and people with psychosocial disability

"Psychosocial disability" is described as the consequences of mental ill-health that can result in long term impacts on wellbeing and functioning. These impacts can include barriers to full, satisfying participation in work, study, community engagement or looking after themselves (Devine et al. 2019, Anthony 2020; Brophy et al. 2014). While not all individuals who experience mental ill-health will experience a psychosocial disability, those individuals who do experience a psychosocial disability are now eligible for NDIS.

In the initial phases of development of the NDIS, psychosocial disability was not going to be included. Therefore the NDIS was initially focused on people living with physical, sensory and intellectual disabilities. Advocacy from the mental health sector meant that psychosocial disability was eventually included in the Scheme (Williams & Smith 2021). However, the late inclusion of psychosocial disability resulted in a poor fit between the NDIS approach and the needs of people with psychosocial disability (Furst, Salinas-Perez, and Salvador-Carulla, 2018). Psychosocial disability was "…'made to fit' a Scheme that was designed predominantly for a population of people with physical, sensory or intellectual disability" (Taylor and McLeod, 2018, p. 14).

Issues of the "poor fit" between NDIS and the needs of individuals with psychosocial disability have continued to be raised as the Scheme has continued its roll out. Specific issues raised have been related to NDIS processes and the types of supports that are funded in NDIS packages. Given these issues, a range of previous reports and research have called for review and revision of the NDIS to make it more aligned to the needs of individuals with psychosocial disability (Hamilton, et al., 2020).

Access to NDIS for people living with Psychosocial Disability

One of the primary concerns about the misfit between the NDIS and the needs of people with psychosocial disability is related to barriers to accessing the Scheme in the first place (e.g., Cortese et al. 2021). This seems to be borne out in the numbers. Initially, NDIA estimated that at full scheme

rollout, approximately 64,000 individuals with primary psychosocial disability would be included (Smith-Merry et al. 2018). Despite this figure being considered an underestimate (e.g., Productivity Commission 2020), recent data showed that only 48,460 NDIS participants had a primary psychosocial disability (NDIA, 2021). This is only three-quarters of the original estimate. Additionally, it was initially estimated that 13.9% of NDIS participants would have a primary psychosocial disability (Smith-Merry et al. 2018), but recent figures suggest this is only 10% (NDIA, 2021). These figures show that even now, at full scheme implementation, there are many people with psychosocial disability who may be missing out on critical supports available from the NDIS. Why is this the case? Why are individuals who should be eligible not applying for NDIS?

This project

Recognising that many Australians living with psychosocial disability are still not applying for NDIS support, the National Mental Health Commission engaged our University of Sydney research team to actively involve stakeholders in co-developing an in-depth understanding of the NDIS access barriers still facing people with psychosocial disability and to explore strategies to resolve or reduce these barriers.

Approach

PHASE ONE
A scoping review of literature to identify previously reported barriers to applying to the NDIS for people with psychosocial disability – used to inform Phase Two survey

PHASE TWO
A national survey to identify current, stakeholder informed and prioritised barriers

PHASE THREE
Co-design of practical, lived experience informed recommendations to address NDIS access barriers with stakeholders

Phase 1 – Literature review of NDIS access barriers for people with psychosocial disability. A scoping review of the literature was conducted over the following five steps: 1) Identifying a research question - the overarching question was defined as: 'what are the barriers to applying for the NDIS for people living with psychosocial disability?'; 2) Identifying relevant publications - search terms were collaboratively developed among team members before being applied to several academic databases and a supplementary internet enquiry; 3) Selecting studies – inclusion criteria were also collaboratively developed and revised following a screening of the first 25 publications before a final collection of included documents were imported into NVivo; 4) Charting data - data from each relevant publication was extracted including publication details, methods used by scholarly articles, as well as details about NDIS access barriers for people with psychosocial disability; and 5) Reviewing and reporting of findings – thematic analysis was iteratively applied to all relevant publications and collaborative discussions were held among team members to reach agreement on each of the derived themes.

Phase 2 – Stakeholder informed NDIS access barriers for people with psychosocial disability. Following ethics approval from The University of Sydney, a national survey was open to stakeholders (service providers, advocates, families, friends, and people living with psychosocial disability). Respondents rated an extensive list of barriers to applying to the NDIS for people with psychosocial disability that were informed by the findings from Phase 1. Next, responses (i.e., stakeholders' informed barriers) were analysed quantitatively using descriptive statistics and qualitatively using constant comparison analysis. The qualitative themes that were derived were grounded in the data (i.e., they originated from stakeholders' replies rather than from any pre-existing ideas as held by coders). To promote research reliability, the first 10 surveys were coded independently between two team members and consensus reached before coding continued. Further advancing research rigour, reflexive discussions were also held among team members during the remaining coding to ensure agreement was reached regarding the interpretation of responses.

Phase 3 – Stakeholder informed solutions to improving NDIS access for people with psychosocial disability. Phase 3 involved a co-designed and deliberative process whereby stakeholders were invited to propose practical solutions to each of the previously identified NDIS access barriers for people with psychosocial disability. Stakeholders were first emailed a table with a list of barriers in the first column and were invited to suggest corresponding solutions in a second column. The study team then synthesized the suggested solutions and emailed these back to stakeholders, therefore providing the opportunity to make any final comments or suggestions. Stakeholders' final comments were then collaboratively discussed and solutions were updated to reflect this feedback. Finally, in addition to the solutions that were deliberatively developed (i.e., proposed and revised by stakeholders), we conducted extensive internet searches in order to identify existing support for these recommendations as well as related activities that are currently underway and their shortcomings. Finally, findings from these searches together with stakeholder informed solutions were reported upon.

PHASE 1. Barriers identified previously – learning from the literature

This chapter presents a brief overview of Phase 1 Methods and Results. A full article has been developed and submitted for publication. **Please contact the authors for more information and for access to the full manuscript / publication.**

INTRODUCTION and METHODS

In this phase, a scoping review was undertaken to examine the existing published and "grey" (internet-based reports and government publications) literature for descriptions of barriers to accessing the NDIS experienced by individuals with psychosocial disability. This scoping review was undertaken following the methodology described by Arksey and O'Malley (2005). The review question guiding this study was: "'What are the barriers and enablers to applying for the NDIS for people living with psychosocial disability?'"

Five academic databases, a news article database and Google Scholar and Google search engines were used to guide the search. The search terms are listed in Table 1.

Table 1. Database Searches

Search term	Database(s)
a. 'psychosocial disability' AND 'NDIS' AND ('access' OR appl* OR 'entry')	ProQuest NewsStream
b. ('psychosocial disability' OR mental* OR psychi* OR neurodiv*) AND 'NDIS' AND ('access' OR appl* OR 'entry')	PsychInfo, ProQuest Central, Scopus, Medline, and Web of Science
c) "psychosocial disability" AND "NDIS" AND ("access" OR appl* OR "entry") AND PDF	Google Scholar
d) "psychosocial disability" AND "NDIS" AND ("access" OR appl* OR "entry")	Google (grey literature)

RESULTS

A total of 64 publications were identified from the search. The overall search process is summarised in the flowchart presented in Figure 1.
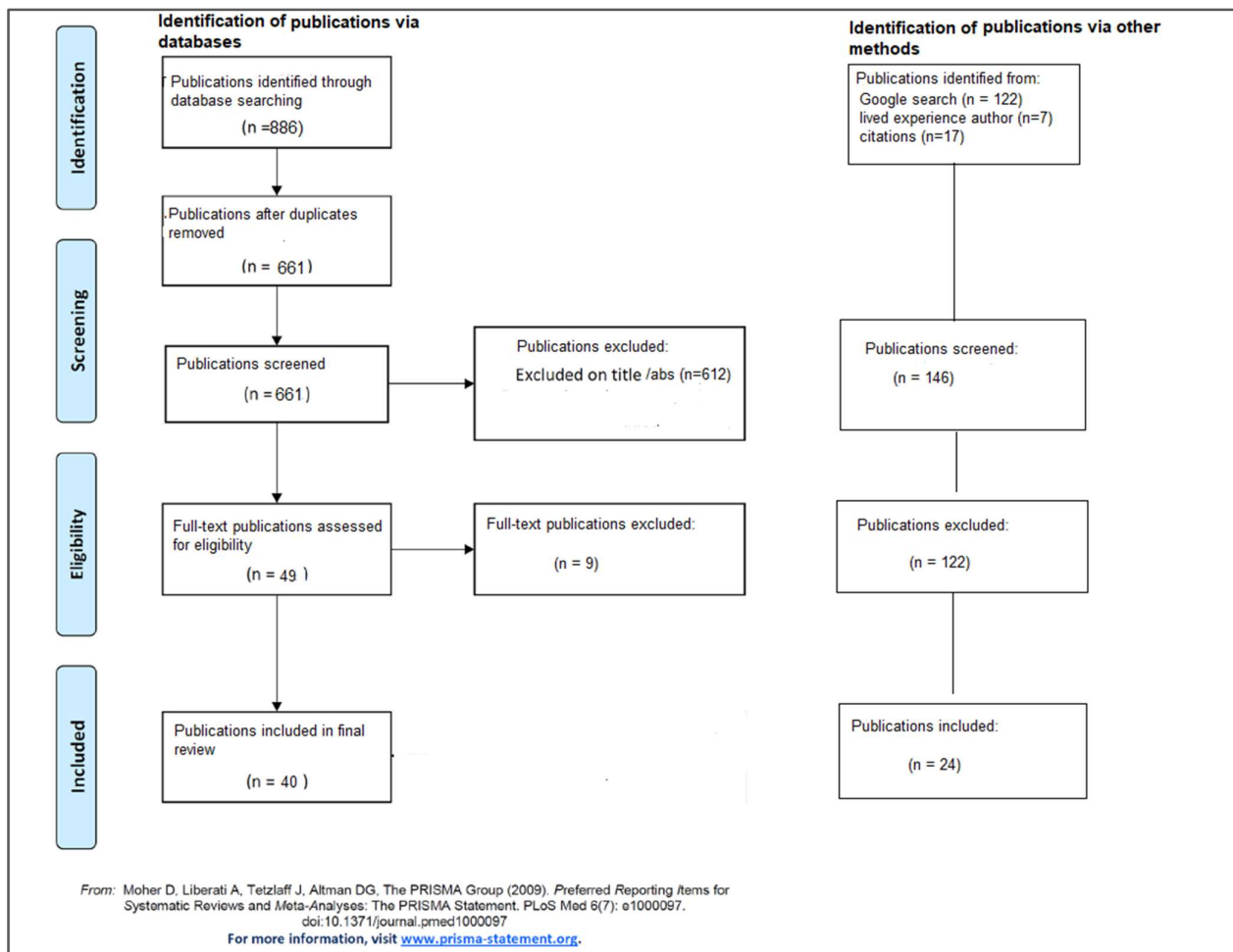
Figure 1. Publication Selection Process (using Prisma Flow Chart)

The narrative synthesis of information from the publications resulted in a total of 11 themes related to access barriers to the NDIS for individuals with psychosocial disability. These 11 themes are listed below:

1. The ongoing 'disability' and 'recovery' disconnect
2. Connection and access to information, advocacy, and support services
3. Experiences and symptoms of mental illness extend and exacerbate barriers
4. Clarity and complexity of the Scheme
5. Trauma and distrust resulting from previous experiences with service systems and agencies
6. Availability of expert or specialist assessments for evidence
7. Homelessness extends barriers
8. Geography – the more rural and remote the greater the barriers
9. Societal stigma relating to mental illness and psychosocial disability
10. Culture – greater barriers for Aboriginal and Torres Strait Islander People and culturally diverse communities
11. Costs of expert or specialist assessments for evidence

The frequency of each theme (number of publications mentioning the theme) is listed in Figure 2. Table 2 lists the individual publications identifying each of the themes.
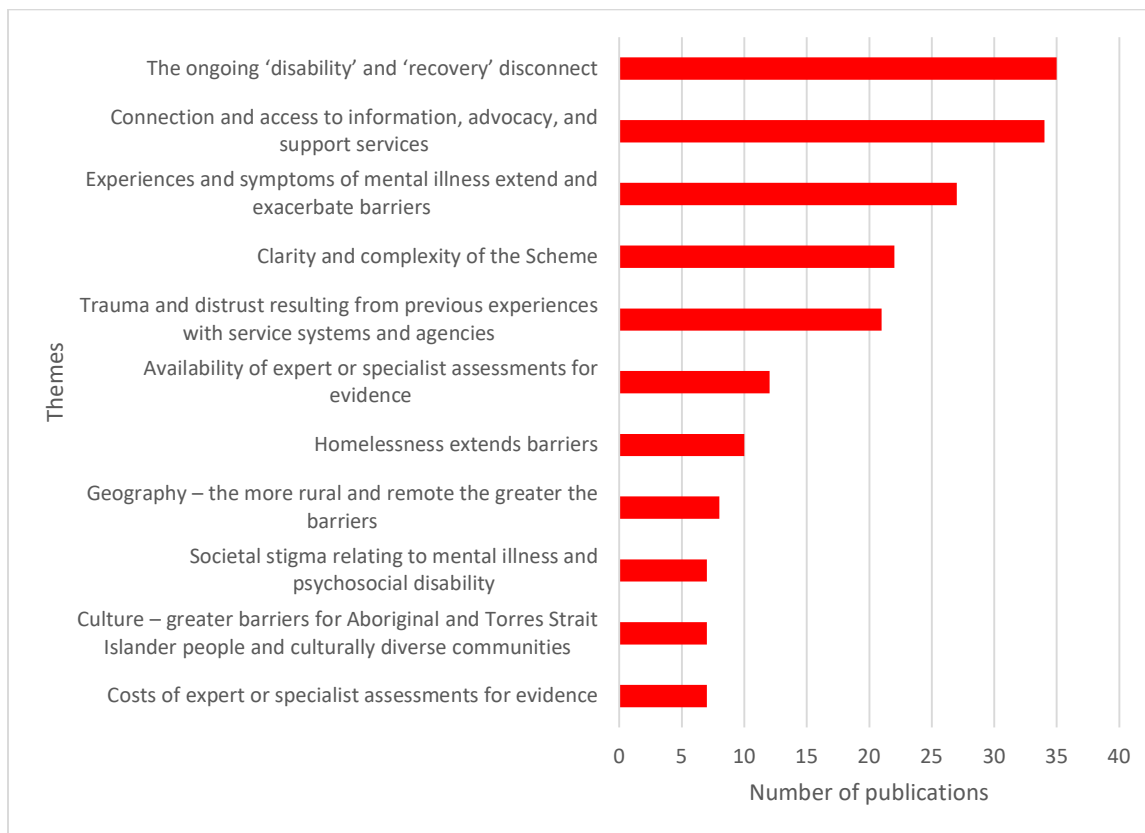
Figure 2. Themes - frequency of reporting

Table 2. Themes - barriers to NDIS access for people living with psychosocial disability.

Theme #1: The ongoing 'disability' and 'recovery' disconnect Publications: Hudson (2020), Cortese et al. (2021), Bonyhady (2014), Tune (2019), Orygen (2017), Sanders (2015), Williams and Smith (2021), Smith-Merry et al. (2018), Daya (2015), Devine et al. (2019), Hamilton et al. (2020), Hancock et al. (2018), Mental Health Australia (2019), Baistow et al. (2019), Queensland Mental Health Commission (2017), Masters and Shelby-James (2017), Australian Red Cross (2017), Brophy et al. (2014), Dickinson and Carey (2017), Hui et al. (2018), Smith (2014), Stewart, Visser, and Slattery (2020), Easton (2019), Hamilton and Sutcliffe (n.d.), Knaus (2017, September 18), Mental Health Australia (2017), Productivity Commission (2017), Quinlan (2014a), (Brophy et al. 2015), Collins (2014), Furst, Salinas-Perez, and Salvador-Carulla (2018), Langmead (2018), National Mental Health Commission (2017), Office of the Public Advocate Victoria (2017), Watson (2018)
Theme #2: Connection and access to information, advocacy, and support services Publications: Ennals et al. (2017), Smith-Merry et al. (2018), Taylor and McLeod (2018), Devine et al. (2019), Brophy et al. (2015), Langmead (2018), Hancock et al. (2018), Tune (2019), Visser, Slattery, and Stewart (2020), Hope independent NDIS assessors herald step in the right direction (2020 September 09), Stewart et al. (2018), Stewart, Visser, and Slattery (2020), Easton (2019), Hamilton and Sutcliffe (n.d.), Mental Health Australia (2019), Knaus (2017, September 18), Office of the Public Advocate Victoria (2017), Hui et al. (2018), Helping to bring the NDIS within reach (2017 December 17), Special NDIS roadshow comes to Parkes (2017 June 13), Stopher and Hughes (2017), Mental Health Australia (2019, 2016), Gendera et al. (2020), Time to apply for the NDIS (2017), Wilson et al. (2018), Baistow et al. (2019), Mental Health Australia (2017), Churchill, Sotiri, and

Rowe (2017), Kenyon (2018), Mental Health Australia (n.d.), Public Advocate Queensland (2017), Bonyhady (2014), Australian Government (2018)

Theme #3: Experiences and symptoms of mental illness extend and exacerbate barriers

Publications:
Maloney (2019 October 07), Smith-Merry et al. (2018), Kenyon (2018), Hancock et al. (2018), Hancock et al. (2019), Baistow et al. (2019), Mental Health Australia (2018), Tune (2019), Queensland Mental Health Commission (2017), Churchill, Sotiri, and Rowe (2017), Brophy et al. (2015), Dickinson and Carey (2017), Furst, Salinas-Perez, and Salvador-Carulla (2018), Brophy et al. (2014), VCOSS (2020), National Mental Health Commission (2017), Quinlan (2014a), Hui et al. (2018), Masters and Shelby-James (2017), Stewart et al. (2018), Commonwealth Ombudsman (2017), Mental Health Australia (2016), Cortese et al. (2021), Williams and Smith (2021), Community Mental Health Australia (2020), Knaus (2017), Mental Health Australia (n.d.)

Theme #4: Clarity and complexity of the Scheme.

Publications:
Ennals et al. (2017), Maloney (2019 October 07), Carney et al. (2019), Furst, Salinas-Perez, and Salvador-Carulla (2018), Hamilton et al. (2020), Hancock et al. (2018), Community Mental Health Australia (2020), Mental Health Australia (2018), Tune (2019), Australian Red Cross (2017), Wilson et al. (2018), Anderson (2018), Visser, Slattery, and Stewart (2020), Hamilton and Sutcliffe (n.d.), Mental Health Coalition of South Australia (2020), National Mental Health Commission (2017), VCOSS (2020), Cortese et al. (2021), Daya (2015), Devine et al. (2019), Stewart, Visser, and Slattery (2020), Australian Government (2018)

Theme #5: Trauma and distrust resulting from previous experiences with service systems and agencies.

Publications:
Ennals et al. (2017), Hancock et al. (2019), Baistow et al. (2019), Community Mental Health Australia (2020), Commonwealth Ombudsman (2017), Anderson (2018), Maloney (2019 October 07), Smith-Merry et al. (2018), Hancock et al. (2018), Mental Health Australia (2018), Gendera et al. (2020), Hamilton et al. (2020), Hui et al. (2018), Kenyon (2018), Visser, Slattery, and Stewart (2020), Commonwealth Ombudsman (2017), Hamilton and Sutcliffe (n.d.), Mental Health Coalition of South Australia (2020), Churchill, Sotiri, and Rowe (2017), Stewart, Visser, and Slattery (2020), Australian Red Cross (2017)

Theme #6: Availability of expert or specialist assessments for evidence.

Publications:
Hudson (2020), Smith-Merry et al. (2018), Stewart et al. (2018), Daya (2015), Hancock et al. (2019), Knaus (2017, September 18), Mental Health Australia (2016), Collins (2014), Sanders (2015), Taylor and McLeod (2018), Public Advocate Queensland (2017), Orygen (2017)

Theme #7: Homelessness extends barriers.

Publications:
Ennals et al. (2017), Smith-Merry et al. (2018), Baistow et al. (2019), Gendera et al. (2020), Hancock et al. (2019), Kenyon (2018), Masters and Shelby-James (2017), Watson (2018), Commonwealth Ombudsman (2017), Cortese et al. (2021)

Theme #8: Geography - the more rural and remote the greater the barriers.

Publications:

Hope independent NDIS assessors herald step in the right direction (2020 September 09), Smith-Merry et al. (2018), Hancock et al. (2019), Mental Health Australia (2018), Australian Government (2018), Easton (2019), Tune (2019), Wilson et al. (2018)

Theme #9: Societal stigma relating to mental illness and psychosocial disability.

Publications:
Hudson (2020), Langmead (2018), Baistow et al. (2019), VCOSS (2020), Brophy et al. (2014), Public Advocate Queensland (2017), Australian Government (2018)

Theme #10: Culture - greater barriers for Aboriginal and Torres Strait Islander people and culturally diverse communities

Publications:
Ennals et al. (2017), Smith-Merry et al. (2018), Hancock et al. (2018), Baistow et al. (2019), Queensland Mental Health Commission (2017), Masters and Shelby-James (2017), Tune (2019)

Theme #11: Costs of expert or specialist assessments for evidence.

Publications:
Hudson (2020), Smith-Merry et al. (2018), Hancock et al. (2018), Mental Health Australia (2019), Tune (2019), Commonwealth Ombudsman (2017), Kenyon (2018)

NEXT STEPS

The themes and subthemes identified from this scoping review were then used to develop the survey used in Phase 2 of this project.

PHASE 2. BARRIERS to NDIS access for people living with psychosocial disability – Findings from a national survey

This section details the aim, methods, results and concluding comments for Phase 2 of this research project.

AIM

The aim of Phase 2 was to understand key stakeholder perspectives on the <u>barriers</u> to accessing the NDIS for people living with psychosocial disability.

METHODS

Data collection:

The survey was open to all stakeholders (service providers, advocates, families, friends, and people living with psychosocial disability). Survey development was based on the scoping review completed in the first phase of this project as well as through consultation with key informants in industry. The survey was hosted on REDCap – a highly secure web-based application supported by The University of Sydney – and promoted widely with the support of willing industry partners.

When completing the survey, respondents indicated the single or multiple perspectives that they held (i.e., person with lived experience, friend or family member, or worker). Questions were presented to each respondent group in language that was contextualised (e.g., 'I statements' for people with lived experience respondents). Where respondents selected more than one perspective the following processes were applied: when one of the perspectives was as a worker, they were presented with the worker set of items (so they could report on their overall perspective, including their own experience and the experience of others they have worked with); where participants responded that they were both a person with lived experience and a friend or family member, they had the opportunity to select whether they wished to respond as a person with lived experience, a family member / friend or as both. Out of nine people who indicated they were both a person with lived experience and a family member / friend, four selected to complete both sets of items.

In the person and family member / friend versions of the survey, respondents indicated whether each item was a reason why they or their family member / friend had not applied for NDIS which response options of "Yes", "No" and "Not sure." In the worker version of the survey, respondents rated each item on a 5-point scale in terms of how frequently this was an issue for the people they worked with: ("Never / Almost never"; "Occasionally"; "Sometimes"; "Often" and "Very often / Always").

Data analysis:

Quantitative data from surveys: These data *were* primarily analysed using descriptive statistics. To allow for easier comparison between the worker and person and family member / friend respondent groups, worker responses were dichotomised – collapsing "Often" and "Very often / Always" into one category which was considered equivalent to agreement that the item was a barrier (and thus was comparable to a "Yes" response from the person and family member / friend versions of the survey).

For each barrier, a proportion of respondents affirming this barrier (selecting a "Yes" response for Person and Family / Friend respondents or selecting "Often" or "Very often / Always" for worker respondents) was calculated. For this calculation responses of "Not sure" were treated as missing. The higher the proportion of respondents in each group affirming the barrier, the more problematic the barrier would appear to be.

To explore whether there were differences in barriers faced in regional, rural and remote areas as opposed to metropolitan areas, Chi-Square tests were used to compare frequencies of Yes / No responses ("Not sure" responses were treated as missing) for the Person and Family / Friend respondent groups and "Often" or "Very often / Always" and other responses for the Worker group.

Qualitative data from surveys: These data were analysed using constant comparative analysis, a systematic and well-regarded qualitative analysis method (Charmaz, 2014; Glaser, 1978). First, survey data were inductively coded line-by-line. In this step, a name is giving to each small part of data that represent a particular idea (Charmaz, 2014). Each new chunk of data is compared to previous data and existing codes to determine whether the underlying concepts are the same or different. If different, a new code is created. In the second step, codes are then compared to each other to group similar codes together into higher level codes. Finally, the relationships between codes were explored and conceptually similar codes grouped together under over-arching categories or broader themes. This type of analysis ensured concepts that emerged were grounded in the data rather than influenced by pre-existing ideas, increasing credibility of the findings by ensuring they represent respondents' replies.

To facilitate interpretive rigour, the first 10 survey responses were coded independently by 2 team members. Codes were then compared, and consensus reached. The remaining survey data were coded by one researcher (DM) with ongoing reflexive discussions with the whole team to ensure consensus on the interpretation of data. NVivo qualitative data analysis software was used to facilitate data management and coding.

RESULTS

Respondents

There were 386 people who participated in the online survey. Self-reported demographic details are provided in Figures 3 to 6 below. **Further details about respondent demographics are available in Appendix 1.**

Figure 3. Respondents by type, %

Figure 4. Person respondents by state, %

Figure 5. Family member respondents by state, %

Figure 6. Worker respondents by state, %
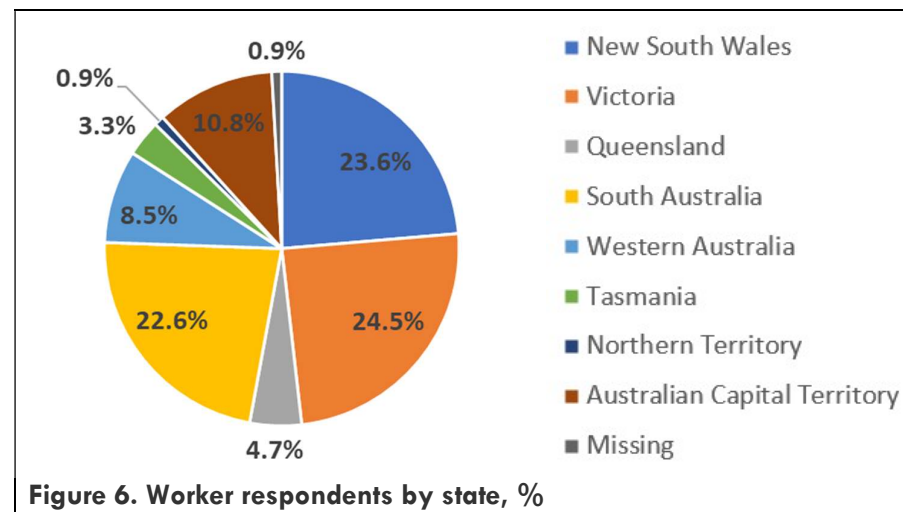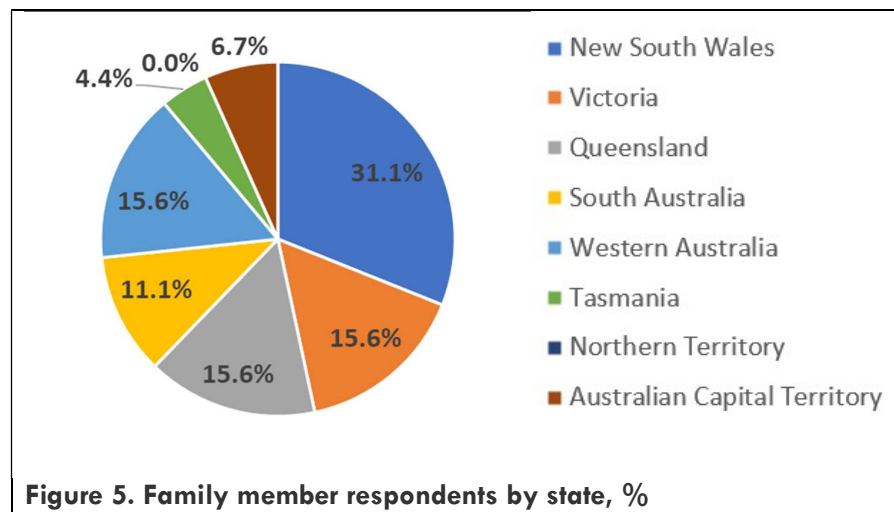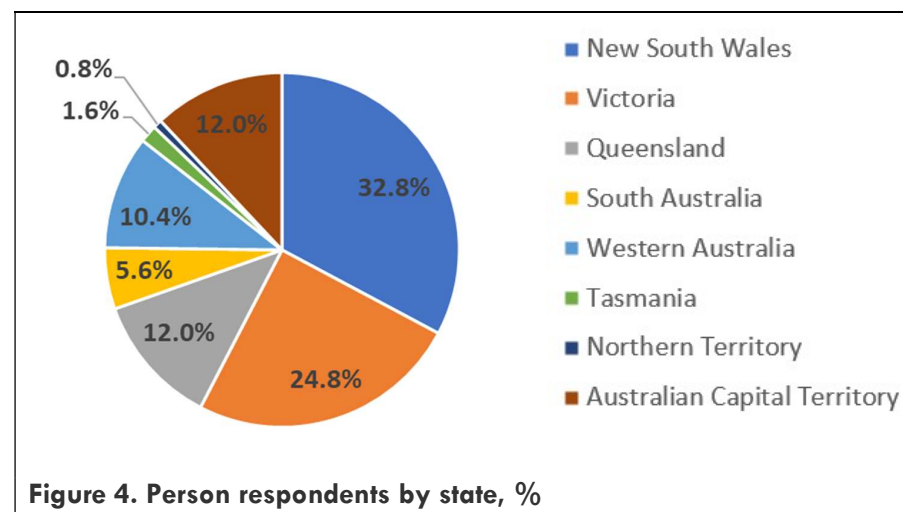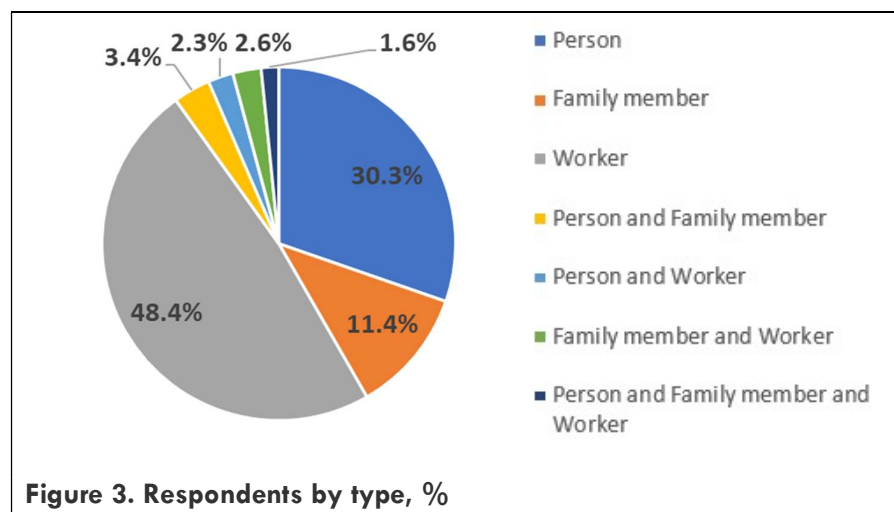
Quantitative Findings

First, we reported the ratings of importance and frequency of barrier scores for people with psychosocial disability themselves, their family and friends, and workers. In addition, we linked the relevant aspects of the quantitative data presented here with the presentation of qualitative data below.

Table 3 shows the proportions and rankings of all survey statements by respondent type (i.e., people with psychosocial disability, family/friends and advocacy/service workers). Generally, results were quite consistent across the different respondent groups, as can be seen by the colour coding of the table. There were, however, some notable differences emerging from the "worker" group in comparison to the other groups. These are explored further below. Key quantitative findings include:

- Four statements reported 80% or higher agreement across all three types of survey respondents. These statements were: 1) Because I think that applying for the NDIS will be too stressful or traumatic; 2) Because applying for the NDIS is too hard; 3) Because it is hard to know what evidence I need to be able to apply; and 4) Because applying for the NDIS is too confusing.

- Almost all (97%) of the family/friend survey respondents agreed with the two statements: 1) Because they think that applying for the NDIS will be too stressful or traumatic, and 2) Because applying for the NDIS is too hard for them.

- According to survey respondents with psychosocial disability, the statement, 'Because I think that applying for the NDIS will be too stressful or traumatic' was the top ranked barrier for them not applying to the Scheme.

- According to survey respondents who were family/friends or advocacy/service workers, the statement, 'Because applying for the NDIS is too hard for them' was the top-ranking barrier to applying to the NDIS for people with psychosocial disability.

- Workers affirmed several items at higher rates than person or family / friend respondents. These included items mainly related to knowledge of and access to supports. This may indicate that the person and family / friend respondents who participated in this study may have had more knowledge of services and supports. This is probably not surprising given that this survey was advertised through advocacy and service organisations.

- The statement, 'Because I have enough services already' received the lowest proportion of agreement (i.e., 3 % or less) across the three types of survey respondents.

Analyses of differences between respondents who lived or worked in metropolitan area (capital city) or regional, rural or remote area revealed only a few differences. For person respondents, those respondents from capital cities were more likely to agree with the statement "Because I do not think my doctor or mental health worker understands what a psychosocial disability is." For worker respondents, those from capital cities were more likely to affirm two items. These were: "Because they do not think the NDIS will improve their supports", and "Because they started applying, but stopped because they found it too stressful." There were no statistically significant differences for the family / friend respondent group between those in metropolitan and regional, rural or remote areas.

In addition to the comparisons presented in Table 3, a full set of results for each respondent group is presented in Appendices 2 to 4.

Table 3. Person/family-friend/worker - proportions and rankings

Item[a]	Person		Family / Friend		Worker	
	Percent[b]	Rank[c]	Percent[d]	Rank[e]	Percent[f]	Rank[g]
Because I think that applying for the NDIS will be too stressful or traumatic.	91.2%	1	97.6%	2	76.9%	6
Because applying for the NDIS is too hard.	86.1%	2	97.8%	1	92.9%	1
Because it is hard to know what evidence I need to be able to apply.	84.6%	3	88.4%	4	83.5%	3
Because applying for the NDIS is too confusing.	79.5%	4	93.5%	3	89.2%	2
Because my mental health is not great at the moment and this makes it hard for me to cope with applying for the NDIS.	77.4%	5	85.1%	5	74.1%	8
Because I have had previous experiences of trauma and I worry that applying will re-traumatise me.	67.5%	6	64.3%	9	47.2%	17
Because it costs too much to get someone like a doctor to do an assessment to prove that I have a permanent psychosocial disability.	66.1%	7	59.1%	10	76.9%	6
Because I do not know about any support services that can help me to apply.	63.4%	8			79.5%	5
Because services do not have the time to help me to apply for the NDIS.	52.9%	9	65.8%	8	48.3%	15
Because I do not have family or friends who can help me with an NDIS application.	50.4%	10				
Because I do not really understand what the NDIS is about and how it can help me.	48.8%	11	69.6%	7	69.8%	9
Because I do not always use mental health services, so it is hard to get someone to write a letter to prove I have a permanent psychosocial disability.	47.2%	12	58.7%	11	60.8%	10
Because I do not trust government agencies like the NDIS agency.	45.9%	13	53.7%	16	41.5%	18
Because services do not know how to help me to apply for the NDIS.	44.1%	14	52.6%	17	36.8%	22
Because I do not think the NDIS will improve my supports.	42.7%	15	47.7%	18	36.8%[M]	22
Because other people need the NDIS support more than I do.	40.7%	16	23.9%	32	21.8%	30
Because I started applying, but stopped because I found it too stressful.	40.5%	17	42.6%	21	60.8%[M]	10
Because there is no help to apply for the NDIS that respects my LGTBQI+ identity.	40.0%	18	15.0%	37	25.3%	27
Because applying for the NDIS is not a priority for me right now as I have other more urgent priorities.	34.5%	19	54.3%	15	39.3%	19
Because I cannot find out how to apply for the NDIS.	33.1%	20			79.7%	4
Because there is no one who can write a letter to prove I have a psychosocial disability.	30.5%	21	43.6%	19	60.4%	12

Item[a]	Person		Family / Friend		Worker	
	Percent[b]	Rank[c]	Percent[d]	Rank[e]	Percent[f]	Rank[g]
Because if I do talk to my doctor about the NDIS, I worry that they will treat me differently.	26.3%	22				
Because my doctor or mental health worker does not understand the NDIS.	26.1%	23	34.1%	24	48.1%	16
Because there is no help to apply for the NDIS that respects and understands my culture.	23.6%	24	28.6%	27	39.2%	20
Because I do not think my doctor or mental health worker understands what a psychosocial disability is.	19.5%[M]	25	19.0%	35	24.5%	28
Because my friends or my family do not think I should apply for the NDIS.	17.4%	26	9.5%	41	7.5%	38
Because I do not really know what a psychosocial disability is.	17.4%	27	39.5%	23	52.8%	14
Because my doctor or mental health worker does not think that I should apply for the NDIS.	12.8%	28	12.2%	40	11.4%	36
Because I do not want to be labelled as a person with a disability.	11.9%	29				
Because I did not know that the NDIS existed until recently.	11.6%	30	25.5%	30	38.9%	21
Because my doctor or mental health worker does not think I have a permanent psychosocial disability.	8.8%	31	13.6%	39	17.0%	33
Because my mental illness or psychosocial disability, is not permanent.	5.1%	32	26.1%	29	20.8%	31
Because I do not have a psychosocial disability.	5.0%	33	25.5%	30	28.4%	24
Because I do not have a mental illness	3.3%	34	18.8%	36	17.9%	32
Because I have enough services already.	3.1%	35	2.1%	46	2.4%	39

Notes:
Colour coding explanation: Red 100% to 75% of respondents agree; Orange 74.9% to 50% of respondents agree; Yellow 49.9% to 25% of respondents agree; Grey 24.9% to 0% of respondents agree

[M] Respondents who lived / worked in **metropolitan areas** were significantly more likely to affirm this as a barrier as compared to respondents who lived / worked in regional, rural or remote areas.

[a] Item wording is in the language used in surveys completed by people (i.e., individuals who experience psychosocial disability, mental illness or mental distress). Items presented to other respondent groups were worded differently, but captured the same concept. Where the column is blank for a particular item, this means that this item / concept was not relevant for that particular respondent group.

[b] This percentage is the proportion of people respondents who indicated "yes" that this item was one of the reasons they had not applied for NDIS. Responses of "not sure" were excluded.

[c] This is the rank out of the 35 items presented to the people respondent group.

[d] This percentage is the proportion of family / friend respondents who indicated "yes" that this item was one of the reasons why their family member / friend had not applied for NDIS. Responses of "not sure" were excluded.

[e] This is the rank out of the 47 items presented to the family / friend respondent group.

[f] This percentage is the proportion of workers who identified that this item was a reason for people not applying for NDIS "often" or "very often / always". (There were two items which included a "Not applicable" option. Where this was the case, these responses were excluded).

[g] This is the rank out of 39 items presented to the worker respondent group.

Qualitative findings

People with mental illness or psychosocial disability, their family/friends, and advocacy and service workers provided a wealth of written data to describe what stops some people, or makes it difficult for some people, to apply for the psychosocial disability stream of the NDIS. As well as identifying barriers not previously reported, these responses also provided more detailed descriptions of barriers drawn from the previous literature and listed within the survey.

A thematic analysis of responses to open survey questions, and consideration of the ratings of the various barriers included in the survey, resulted in ten broad and interconnected themes. These included: 1. Key information about NDIS is confusing or not accessible; 2. Hard to get supports to help to apply - formal (services) and informal (family and friends); 3. Hard to obtain evidence required by the NDIA; 4. Application process is too long, complicated and inflexible; 5. Application process is harmful to mental health and well-being; 6. The application process does not accommodate for mental illness and psychosocial disability; 7. The negative reputation of NDIA staff and culture; 8. Disconnect between 'disability' and 'recovery'; 9. Personal beliefs, fears and stigma, and 10. It is not worth it – NDIS won't meet my needs anyway.

Each of these themes are detailed below and further illuminated with sample quotes from respondents. Supplementing this qualitative information are tabulated quantitative records that are relevant to each theme.

1. KEY INFORMATION ABOUT NDIS IS CONFUSING OR NOT ACCESSIBLE

For many people, basic or fundamental preliminary information about the NDIS and the application process is not available or is too confusing and hard to follow or understand. Respondents described various fundamental points of confusion that prevent people from starting the process of applying for the NDIS. This includes a) not knowing that the NDIS exists; b) who would or would not be eligible; c) what evidence is needed; d) what supports, and services would and would not NDIS cover if eligible; e) what steps need to be navigated in the process of applying; f) how get help to apply, and g) NDIA communication and language is confusing – including the website. Each of these points are detailed below with sample quotes.

Before exploring the detailed qualitative findings, we will briefly revisit the quantitative data relevant to this theme. Table 4 shows the proportions and rankings of survey statements by respondent type (i.e., people with psychosocial disability, family/friends and service workers) that are relevant to the 'key information about NDIS is confusing or not accessible' theme. Several items had very high proportions of respondents identifying these as barriers

Table 4 Person/family-friend/worker - proportions and ranking (theme 1 related)

Item	Person Percent	Person Rank	Family / Friend Percent	Family / Friend Rank	Worker Percent	Worker Rank
Because it is hard to know what evidence I need to be able to apply.	84.6%	3	88.4%	4	83.5%	3
Because applying for the NDIS is too confusing.	79.5%	4	93.5%	3	89.2%	2
Because I do not know about any support services that can help me to apply.	63.4%	8			79.5%	5
Because I do not really understand what the NDIS is about and how it can help me.	48.8%	11	69.6%	7	69.8%	9
Because I cannot find out how to apply for the NDIS.	33.1%	20			79.7%	4
Because I do not really know what a psychosocial disability is.	17.4%	27	39.5%	23	52.8%	14
Because I did not know that the NDIS existed until recently.	11.6%	30	25.5%	30	38.9%	21

a. Not knowing that that NDIS exists

The reason for some people with psychosocial disability not applying to the NDIS is a fundamental one – **they haven't heard about it**. Many people living with psychosocial disability and their family members are still unaware of the Scheme's existence.

Sample quotes:

> *"I did not know that it existed"* [P002]
>
> *"I haven't heard about it"* [P097]
>
> *"Often they don't even know what NDIS is..."* [W061]
>
> *"I would say that most of the families that I work with, would be eligible for this streaming are not aware..."* [W079]

b. Who would or would not be eligible

Many people said that the reason they had not applied for the NDIS was because they were **confused about who would and would not be eligible** for the NDIS. Some respondents said that they thought that the NDIS was **only for people with physical disabilities** or only for **specific types of diagnoses** and not for others. Some **did not want to waste their or other peoples' time** if they were going to be found to be ineligible. The confusion was exacerbated **by hearing about other people being 'rejected'**.

Sample quotes:

"I didn't think mental illness was covered by NDIS" [P107]

"NDIS can I access it, Bipolar Type 2 alone - no doubt it" [P011]

"… gave me the impression that psychological injuries were not a "disability" and would not qualify" [P033]

"I don't know if I meet the criteria" [P034]

"I don't know if I'm eligible for NDIS" [P036]

"I have no idea if I'm eligible" [P038]

"My impression is that since I can currently work 30 hours a week for a decent salary, I would not be eligible for any support" [P042]

"Also, I didn't even think I might be eligible until a couple of months ago" [P068]

"I just assumed my application would be denied as even though I have struggled with my mental health for over 30 years" [P102]

"When I first looked at applying it was focused on physical so didn't feel like I could" [P109]

"The NDIS does not recognize the validity of psychosocial disabilities such as ADHD, which is a life-impairing and permanent disability" [W032]

"Also, autistic so this is almost definitely going to make me ineligible by stealth" [P035]

"Not sure if eligible and not sure want to put effort in and waste peoples time if not eligible" [P084]

"Heard so many stories of people being denied" [F035]

"People with Bipolar and PTSD are labelled disordered and therefore not seen as having a life-long diagnosis and are applying multiple times without success" [W092]

"Some consumers feel that they are able to manage some days so this makes them ineligible (episodic)" [W025]

c. What evidence is needed

Respondents reported that many people are **confused about what evidence needs to be included** in their NDIS applications. Some were confused about **what sort of evidence** was needed, while others were confused about **how much** evidence was needed. This confusion or lack of transparency prevents some people from applying.

Sample quotes:

"There are no clear instructions I could find about what support material / evidence to include. I still don't really know, even after talking to an NDIS provider" [P002]

"I don't know what I need to get or how to get it" [P026]

"Want to get it right and not miss out on anything" [P068]

"I am not sure what is necessary to qualify for NDIS" [P090]

"The person is forced to play a guessing game as to what will amount to enough "proof" for the NDIS..." [W042]

"Confusion about the... evidence required" [W120]

"The NDIS is not transparent enough about the evidence required" [W126]

"What medical support staff I needed to already be seeing to get the appropriate recommendation letters" [P002]

d. What supports and services would and wouldn't NDIS provide if eligible

Repeatedly respondents said that people are confused about **what types of services and supports the NDIS could or would provide** a person if they were eligible, and what they would not. Not understanding the potential value of the NDIS results in people not applying.

Sample quotes:

"Aboriginal and Torres Strait Islander communities have very little information about the possible support available through NDIS" [W120]

"They don't understand what help is available" [W071]

"I'm also not sure what services NDIS could provide that would help me" [P040]

"Not knowing what I can get funding for" [P058]

"I'm also not sure what supports I can access through NDIS" [P085]

"I'm also not entirely sure what the NDIS would offer me" [P088]

"I have no idea what support the NDIS could or would give me" [P107]

"Not understanding the supports they can receive" [W003]

"Understanding what the NDIS is about and how it can help" [W027]

"Understanding what NDIS will actually do in a concrete vision that makes sense to the individual who has a chaotic lifestyle" [W040]

"They don't understand what help is available" [W071]

"Lack of understanding about what the NDIS offers" [W082]

"Not understanding what NDIS is, and/or if it is right for them" [W113]

"Difficulty understanding what NDIS can offer" [W176]

e. What steps need to be navigated in the process of applying

Respondents repeatedly said that the **application system and processes involved are too confusing** and that this resulted in people being overwhelmed and not applying. People do not understand **where to start** in making an application or **what steps to follow**. Confusion is amplified by a system that is **difficult to navigate**.

Sample quotes:

"Most people find the whole application process overwhelming, confusing and daunting" [W010]

"The system is so incredibly un user friendly - we have staff across the sector with Masters degrees that find it confusing" [W022]

"Application process is not clear. Do not know where to start with my application" [P012]

"It is confusing, impossible to navigate and just as impossible to apply for" [P061]

"The entire process is ridiculously hard and it's almost laughable that they expect people with a psychosocial disability to navigate this" [P067]

"Too hard to navigate" [W029]

"Not being able to navigate very difficult system" [W034]

"Unable to navigate the complex NDIS processes" [W089]

"The NDIS pathway is confusing and difficult to access and understand" [W171]

"I don't understand the paperwork, how NDIS works, I've heard stories of how stressful it is" [P059]

"Not sure how to undertake process" [F035]

f. How to get help to apply

A lack of knowledge about **who to ask and where to go to get help or support** to apply for the NDIS is a barrier for many.

Sample quotes:

"Don't know who to ask for assistance" [W072]

"Who can help with application" [W115]

"Not knowing or understanding available supports" [W116]

"lack of understanding of current supports" [W208]

g. NDIA communication and language is confusing – including the website

The **language that is used by the NDIA about the NDIS is confusing** for many. Respondents said that there was **too much jargon that frightened** or turned people off applying. The **term psychosocial disability** itself added to this confusion. Information about the Scheme was hard to locate and retrieve. In particular, the NDIS **website was described as confusing and stressful to use**.

Sample quotes:

"Too much jargon" [W075]

"Jargon scares people" [W076]

"…I tried to read and understand the NDIS website" [P033]

"The process & language are huge barriers to people commencing / completing NDIS application" [W115]

"Too hard to get correct information" [F026]

"Too complicated to understand the language they use" [P121]

"I have no information" [P038]

"I personally find it an extremely confusing website…" [P033]

"Difficulty navigating the minefield of information on NDIS website" [W127]

2. HARD TO GET SUPPORTS TO HELP TO APPLY - formal (services) and informal (family and friends)

A second group of barriers that were described related to finding, accessing, and getting the formal and or informal help or support needed to apply for the NDIS. These support related barriers included: a) hard to find or access supports; b) formal supports are not reliable or not meeting individual needs; c) person is disconnected from supports – formal and or informal; d) person is fearful of, or doesn't want to use supports – formal and or informal; e) supports (formal or informal) say the person will not qualify/discourages them from applying; f) formal supports do not include informal or formal supports; g) family member blocking formal or informal supports from helping, and h) poor quality/capacity/NDIS knowledge of supports – formal and informal. Each of these are detailed below.

Before exploring the detailed qualitative findings, we will briefly revisit the quantitative data relevant to this theme. Table 5 shows the proportions and rankings of survey statements by participant type (i.e., people with psychosocial disability, family/friends and service workers) that are relevant to the 'hard to get supports to help to apply' theme. The most significant barriers identified in this section was related to services not having sufficient time to support individuals to apply. This adds to the qualitative comments about lack of availability and access to services that could help individuals to apply.

Table 5. Person/family/friend/worker - proportions and ranking (theme 2 related)

Item	Person		Family / Friend		Worker	
	Percent	Rank	Percent	Rank	Percent	Rank
Because services do not have the time to help me to apply for the NDIS.	52.9%	9	65.8%	8	48.3%	15
Because I do not have family or friends who can help me with an NDIS application.	50.4%	10				
Because services do not know how to help me to apply for the NDIS.	44.1%	14	52.6%	17	36.8%	22
Because there is no help to apply for the NDIS that respects my LGTBQI+ identity.	40.0%	18	15.0%	37	25.3%	27
Because my doctor or mental health worker does not understand the NDIS.	26.1%	23	34.1%	24	48.1%	16
Because there is no help to apply for the NDIS that respects and understands my culture.	23.6%	24	28.6%	27	39.2%	20
Because I do not think my doctor or mental health worker understands what a psychosocial disability is.	19.5%	25	19.0%	35	24.5%	28
Because my friends or my family do not think I should apply for the NDIS.	17.4%	26	9.5%	41	7.5%	38
Because my doctor or mental health worker does not think that I should apply for the NDIS.	12.8%	28	12.2%	40	11.4%	36
Because my doctor or mental health worker does not think I have a permanent psychosocial disability.	8.8%	31	13.6%	39	17.0%	33

a. Hard to find or access supports

Both people themselves and workers repeatedly highlighted how hard it can be for some with mental illness to access formal mental health supports or services that they need to help them to navigate the process required to apply for the NDIS. Barriers to accessing this support were greatest for **those who were not already connected with mental health services and supports**. Barriers included a **lack of mental health services available** – particularly, but not only for people living in rural, regional and remote areas. For others, while services did exist, there were again, **long waiting lists** to being accepted by the service and thus being able to access support.

Sample quotes:

"I also can't find any advocacy groups near me who are willing to assist" [P093]

"Limited resources to assist in NDIS applications… our waitlist alone is 6 months long" [W081]

"And services that could help, put you on a waiting list that can take weeks and months" [F048]

"Not supported enough with the process" [W196]

"I don't know where to look for support" [P085]

"lack of appropriate supports in remote locations" [W057]

"limited support to understand process" [F036]

"Not everyone has a Support Coordinator … who will be able to gather medical evidence and know the pathways to joining the NDIS" [W070]

"Many people with psychosocial disability do not have access to or are not eligible for services to assist with application process" [W015]

"not enough direct worker support purely for NDIS access" [W034]

"lack of support to complete applications" [W053]

"Not enough services funded to complete NDIS applications" [W061]

"nobody to support them through the process" [W119]

"Limited support network to support to complete the application" [W167]

"No organisations that will help with application process" [W196]

"No support/funding for them to go through the application..." [W206]

"Inability to access services that support an application" [W207]

"Many people with mental health issues cope by themselves because they don't qualify, or can't afford help, or can't find any help especially in regional and remote areas and so can't get the evidence they need - catch 22" [W161]

b. Formal supports are not reliable or not meeting individual needs

Even when people were able to assess formal (mental health service) supports, many still experience barriers. Many described **inconsistent, unreliable supports**. Some said that **services terminated their support mid-way through the process of applying**. Others described **high turn-over of support staff** resulting in the process of application stalling or stopping. Others again described **supports that didn't accommodate for or meet their individual needs**. This included things like supports not having any lived experience, supports **unprepared to do home visits** if the person was not able to leave their

home, **inflexibility of hours** available to provide support, and services that are **not culturally inclusive**.

Sample quotes:

> *"His case management was stopped because he had been managed for too long and was left for his family to help him"* [F034]

> *"Should be some services that do home visits..."*[F014]

> *"...there is no help to applying outside of work hours"* [P074]

> *"Not enough culturally appropriate support and services available"* [W0150]

> *"He did contemplate applying for the NDIS, when he was case managed, but his case management was stopped before the paperwork was done..."* [F034]

> *"In my professional experience, people who have a severe psychosocial disability are often the ones who are not on the NDIS because they need to be proactively identified by formal supports as eligible and then really need the whole process of applying managed by a formal support from end to end"* [W203]

> *"Assertive follow-up is essential with psychosocial disability. People need to know the service providers really care"* [W159]

> *"The mental health worker said that she would get the paperwork for NDIS but she hasn't done it - that was before lockdown - I spoke to her the other day and she said she hadn't done it. When I speak to anyone from mental health when you need them, they say that they are busy"* [P060]

> *"Not everyone has a Support Coordinator with Lived Experience who will be able to gather medical evidence and know the pathways to joining the NDIS"* [W070]

> *"Why doesn't NDIS have Aboriginal / Torres Strait Liaison Officers in areas with high Aboriginal Torres Strait populations? NDIS seems to talk the talk but doesn't walk the walk!"* [W038]

> *"language and cultural barriers to accessing support"* [W045]

> *"Processes not always designed in culturally safe ways for Aboriginal and Torres Strait Islander people"* [W168]

> *"not culturally friendly"* [W194]

c. Person is disconnected from supports – formal and or informal

Repeatedly we heard that there are many people who are disconnected from any potential supports that might be able to help them to apply. Some people were **disconnected from or didn't have family and friends to support them**. Others, **particularly those who are homeless or living a transient lifestyle,** are either disconnected from, unable or unwilling to seek assistance from formal supports. Some emphasised that it was **their disability that prevented them from being able to access the supports that they needed** to apply for disability supports.

Sample quotes:

> *"I do not have a carer or advocate who can help me with the process"* [P101]

> *"I live alone, no partner, family or friends support"* [P106]

> *"Those I work with have often been very isolated, unable or unwilling to connect with services"* [W086]

"Our cohort are homeless or at risk of homelessness and have very displaced, isolated lives" [W061]

"The people I have historically worked with within the homelessness sector often have complex social and medical histories and also few/no informal support who can advocate for them in the NDIS process or assist with an application" [W203]

"People with mental ill health are sometimes not well connected" [W147]

"Many MH consumers just lead an increasingly small life circle and are often not engaged with the world around them" [W162]

"Transient" [W023]

"Not accommodating for norms in remote locations (i.e. transient nature of people and families)" [W134]

"People living transient lifestyles going between services…" [W068]

"My psychosocial disability (including severe social anxiety) prevents me from seeking help" [P026]

"She has cut herself off from all her friends and social contact generally" [F017]

"She does not have anyone to advocate for her" [F044]

"and there are difficulties with supporting consumers when there is little family engagement" [W210]

d. Person is fearful of, or doesn't want to use supports – formal and or informal

Respondents said that for various reasons, some **people feared or did not want to use formal or informal supports.** Some workers and family members said that they were unable to help their client, friend or family member to apply because they **had not provided their consent** to do so.

Sample quotes:

"Fear of external supports" [F009]

"She does not have anyone to advocate for her (actually she finds it hard to accept help at all)" [F044]

"…he would not let me apply for him" [F034]

"Those I work with have often been very isolated, unable or unwilling to connect with services, so find ways to self-manage their illness without formal documentation or help" [W086]

"People with a psychosocial disability are often reluctant to connect with services..." [W148]

"The biggest challenge I find is for people who are deemed to have decision making capacity but they are not willing to apply for the NDIS or provide consent for someone to assist them (for many complex reasons)" [W159]

"fear of services" [W011]

e. Supports (formal or informal) say the person will not qualify and discourages them from applying

Some formal and informal supports **discourage rather than encourage people from applying** to the Scheme. People described seeking assistance to apply, but being **told by doctors, service providers and/or family and friends that they were not disabled enough,** that they would not qualify and that

they should not apply. Both people themselves and workers described frustration at experts and other service providers **dismissing what they deemed to be very real disabilities and disability-related challenges.** Other people assumed that their doctors would suggest applying for the NDIS if they thought that they had a disability and took the fact that **the doctor had not raised the topic** as a message that they should not consider applying.

> Sample quotes:

> *"Since my doctors aren't suggesting the NDIS, I feel like they don't think I need it"* [P038]

> *"I was told by both my support network and the NDIS on the phone that because I have bipolar and that it's episodic that I wouldn't qualify when every six weeks I go through hell to keep my life together but that apparently means I don't qualify"* [P046]

> *"Our clients are being told by other service providers that they won't qualify for funding for their needs that they are requesting for, despite having the significant needs for their requests"* [W078]

> *"…I'm told I am high functioning (I hate that label, they don't see me trying to get out of bed on my own), and don't need it"* [P025]

> *"They don't think my mental health is bad enough for support"* [P048]

> *"I feel like I keep being told by everyone that my illnesses aren't 'bad enough' and that they aren't a 'disability'- but I can't function"* [P072]

> *"doctors and clinicians refused to send me for a referral"* [P126]

> *"Being advised they are not disabled enough to meet the NDIS criteria when this impacts their lives each day"* [W171]

f. Formal supports do not include informal or formal supports

Some **family members described being blocked or excluded from participating in supporting the person's application** by service providers or formal supports. Some family members said that because they had been blocked or not consulted, an inadequate and ultimately unsuccessful application had been submitted by services – missing the history and information that they could have provided. Workers said sometimes **family involvement** was **controlling and unhelpful.**

> Sample quotes:

> *"Not involving families and support networks when participant wants"* [W022]

> *"Services have applied and it was not approved without any information from the family…"* [F005]

> *"Carer involvement in the process is sometimes difficult - trying to control the process"* [W140]

> *"There is limited consultation with family and all stakeholders who could provide input into the application* [F005]

g. Family member blocking formal or informal supports from helping

Less frequently, we heard about families, or **a particular family member preventing or not consenting** for other family members or services to assist with NDIS applications.

> Sample quotes:

"My son's father actively discourages him from seeking medical attention even though he has had a diagnosed mental condition for 21 years... The times I encouraged him to apply, his father talked him out of doing so" [F049]

"Older carers/allies trying to support a child into the scheme may be blocked from assisting due to family member not consenting" [W076]

h. Poor quality/capacity/NDIS knowledge of supports – formal and informal

Respondents frequently described the **limited quality, capacity and NDIS-specific knowledge of supports** (formal and informal) as barriers to people applying for the NDIS. Skill, capacity and knowledge were all reduced **because of a high turnover of staff within mental health support services**. Family and friends often didn't have the capacity, energy or NDIS-related knowledge needed to effectively support people applying.

Sample quotes:

"Few providers have a strong understanding of application processes" [W015]

"Health professionals who do not understand the application process" [W057]

"Short term contracts from Govt for advocacy agencies leads to staff turnover and the need to retrain" [W064]

"existing professional supports don't know enough about the NDIS" [W129]

"Family and carers don't know how to access" [W062]

"Lack of knowledge amongst mainstream support providers who would be able to support applications. Limited understanding of the level of details required for the application process. Limited understanding of the NDIS as a whole" [W167]

"Also, my partner would not be able to cope with applying, so it would be up to me, and honestly I just run out of energy doing everything, particularly financial" [F024]

"Very few of our clients have carers with the capacity to negotiate the system" [W187]

3. HARD TO OBTAIN EVIDENCE REQUIRED BY THE NDIA

Respondents repeatedly described difficulties related to obtaining the evidence required by the NDIA to prove that they have a psychosocial disability. These barriers included: a) hard to access experts to obtain evidence of impairment and psychosocial disability; b) adequate historical and longitudinal evidence doesn't exist or is hard to get; c) the volume of evidence expected is huge and overwhelming; d) fearing the consequences of documenting evidence of disability; e) fear of being re-traumatised by the experience of gathering evidence of permanent disability and the loss of privacy, and f) costs associated with gathering evidence are prohibitive.

Before exploring the detailed qualitative findings, we will briefly revisit the quantitative data relevant to this theme. Table 6 shows the proportions and rankings of survey statements by respondent type (i.e., people with psychosocial disability, family/friends and service workers) that are relevant to the 'hard to obtain evidence required by the NDIA' theme. Fear of being retraumatised by gathering evidence was a prominent concern for Person and Family / Friend respondent groups and cost was identified as a barrier by all a significant proportion of respondents in all groups.

Table 6. Person/family-friend/worker - proportions and ranking (theme 3 related)

	Person		Family / Friend		Worker	
Item	Percent	Rank	Percent	Rank	Percent	Rank
Because I have had previous experiences of trauma and I worry that applying will re-traumatise me.	67.5%	6	64.3%	9	47.2%	17
Because it costs too much to get someone like a doctor to do an assessment to prove that I have a permanent psychosocial disability.	66.1%	7	59.1%	10	76.9%	6
Because I do not always use mental health services, so it is hard to get someone to write a letter to prove I have a permanent psychosocial disability.	47.2%	12	58.7%	11	60.8%	10
Because there is no one who can write a letter to prove I have a psychosocial disability.	30.5%	21	43.6%	19	60.4%	12
Because if I do talk to my doctor about the NDIS, I worry that they will treat me differently.	26.3%	22				

a. Hard to access experts to obtain evidence of impairment and psychosocial disability

The difficulty accessing an expert who was able and prepared to do an assessment and provide the expert evidence of the person's psychosocial disability was a frequently reported barrier. Experts included clinicians, GP's and psychiatrists. Some respondents describe the **lack of any available experts** – particularly for those living in rural and regional areas. Others described **long-waiting lists** and thus the extended time it took for people to get an appointment, particularly for people not currently connected with or using expert or clinical mental health services and, again, for those living in rural and regional areas. Finally, many people described potential **experts being unwilling to provide evidence** for various reasons including the lack of adequate government funding for the time required.

Why are some experts unwilling to help? One reason provided for expert or specialist lack of willingness to do the assessment and report was the **lack of adequate funding through Medicare to cover the extended appointment time**/s that would be needed. Some said that they **lacked an**

understanding of their client's needs and or the NDIA requirements. Others said that witnessing or hearing of **others being rejected even with evidence provided** deterred some experts from being prepared to assist.

In addition to these barriers to accessing expert evidence**, people who were too mentally distressed to leave their homes and people in prison services** both faced additional barriers to accessing experts to obtain evidence of their psychosocial disability**.**

Sample quotes:

"I don't currently have a psychiatrist or psychologist I trust and who understands me" [P095]

"Difficulty getting doctors etc to support the application" [F043]

"Mental health professionals can also be reluctant to help with applications when they have seen or heard of other applications being rejected" [W129]

"Person unable to leave unit, therefore can't access treatment or proof that they need NDIS help" [F014]

"The government also needs to pay additional attention to rural areas that experience limited specialist services and inconsistent GP availability" [W009]

"Psychiatrists saying that it is not their job to support the application and that it should be done by and Occupation therapist" [F043]

"limited access to medical supports/reports to provide evidence of condition/diagnosis" [W190]

"Specialists refuse to fill out forms" [P053]

"Finding specialists to complete assessments not easy" [W202]

"Most do not have access to a regular GP who can fill out the NDIS forms correctly and understand their client's needs" [W212]

"In the current Covid climate it is near impossible to see cost effective psychiatrists/ psychologists without waiting a protracted period" [W172]

"treating doctor refuses to provide evidence or does not respond to request for evidence" [W113]

"GPs that deny their responsibility to assist with the supporting evidence" [W155]

"The main things stopping them from applying is lack of support from their psychiatrist and the fact that their psychiatrist does not understand what the NDIS is or how best to support my friend" [F030]

"my Psychiatrist treats me as if they don't have the time to complete an application" [P024]

"People with psychosocial disability in prison are significantly less likely to have access to medical services/information/reports needed to meet strict eligibility criteria" [W015]

"Conflicts with Medicare requirements (some MH professionals say they can only continue to claim Medicare benefits if the client is improving, and therefore will not say the client's functional impairments are permanent)" [W132]

"getting a client a psychologist which regionally can have a waiting list of months" [W055]

"GPs that deny their responsibility to assist with the supporting evidence. They state they do not get "paid" (Medicare rebate) for the time it takes to complete paperwork" [W155]

"Also, the GP and Psych's that support be don't really understand it so how can they help when the NDIA doesn't really support them" [P046]

"There is also a large gap in finding practitioners who are willing to support with bulk billing NDIS access reports. This needs to be a Medicare funded item." [W126]

"needing medical psychological assessments. Waiting time for specialist appointment" [W199]

"The evidence needed is often hard to obtain" [W200]

b. Adequate historical and longitudinal evidence doesn't exist or is hard to get

Repeatedly respondents said that people faced difficulties meeting the requirement for evidence of disability over an extended time. For many people, **this evidence does not exist**. These are people who might well be very 'disabled' by their illness, but for various reasons **have had only sporadic, very limited or no contact with mental health services and treating doctors**. For some, this is because they do not identify as having an illness. For others, it is because they have led an itinerate or transient lifestyle or are homeless and have therefore not had a consistent single treating team. For these people, **evidence might exist, but it is not available within a single 'patient file' and thus is exceedingly challenging to find, access and collate**. People reported forgetting the various services and doctors' names that they had accessed in the past. This disconnection from services and use of different services over time results in a lack of documented medical history or dispersed historical evidence that impedes people's ability to apply the Scheme.

Finally, some people reported perceived or real 'constraints' such as not being able to access and use evidence they had previously gathered and provided to Centrelink in order to apply for the Disability Support Pension.

Sample quotes:

"Many of our clients move from GP to GP and do not have a history with their GP to provide this evidence" [W187]

"lack of evidence due to limited engagement with MH services - not reflecting the full individual circumstances" [W026]

"Homelessness and finances are a big barrier to people having records of past engagement in treatment" [W103]

"I don't remember the names of the doctors, psychologist and psychiatrist I have dealt with in the past" [P026]

"Transient" [W023]

"Lack of long-term medical evidence if people are transient" [W208]

"Don't know where to get their medical history" [W029]

"no record of previous diagnoses" [W124]

"Don't know where to get their medical history" [W029]

"with limited specialist services available some clients do not have records of their illness" [W009]

"lack of evidence due to limited engagement with MH services - not reflecting the full individual circumstances" [W026]

"Gathering the required evidence with health professionals reluctant to support and the psychosocial disability often making it hard for a person to have a history with a GP or to retain reports" [W051]

"they can't use any details from Centrelink on her condition as they are not allowed" [F027]

"Without a history of diagnosis and treatment, it is very difficult for a person to show permanency" [W042]

"memory of personal history" [W124]

"Further, there is often a history of fractured or broken-down service delivery which makes chasing collateral evidence of a person's disability extremely difficult and further hinders the application process" [W203]

"They also tend to have significant side effects, which may be unacceptable to some people and they should not be forced to try things they are not comfortable with in order to be eligible for the NDIS" [W042]

c. The volume of evidence expected is huge and overwhelming

The sheer **volume of evidence needed** to be gathered in order to apply for the NDIS is a barrier that prevents many people applying for the Scheme. The volume of evidence needed **often requires the involvement and contribution of several service providers,** and even then, the NDIS can ask for additional assessments to be carried out. Obtaining and collating this large amount of evidence can be arduous. People variously described it as **'time-consuming', 'exhausting', 'overwhelming' and 'arduous'.**

People were **worried that** the evidence they had collected **would not be enough.** They also feared that they would **have to collect even more evidence.** Establishing that people had **'exhausted' all available treatment options** was another important barrier. Having to try new treatments expected by the NDIA before applying, was too costly for some and too traumatic for others.

Sample quotes:

"Too many forms, assessments and processes involved, making it an exhaustive and stressful experience, and in some cases traumatic" [W031]

"The amount of evidence and supporting documentation required to make access to the NDIS" [W088]

"People with Psychosocial conditions may stop seeking treatment due to the trauma or other reasons which gives NDIS the option to deny access due to treatment not explored" [W052]

"The amount of evidence needed" [P082]

"the required doctors reports" [P094]

"It is difficult to get all the medical evidence etc together" [F039]

"The length & breath of details/ reports and tasks required are to overwhelming for the person with lived experience" [W023]

"were overwhelmed by the process of collecting evidence" [W026]

"amount of supporting evidence" [W053]

"The amount of evidence that is required for a person to get onto the NDIS" [W055]

"challenges in compiling relevant documentation" [W057]

"If a medical professional has signed off an application and disability, that should be suffice. i.e. not having to provide copious reports and proof" [W081]

"The amount of evidence and supporting documentation required to make access to the NDIS" [W088]

"or they feel they won't be successful even with further evidence" [W082]

"too onerous, or unable, to obtain the required evidence" [W119]

"The amount of evidence that is required" [W174]

"The evidence required is also a barrier. The NDIS requires proof of diagnosis, evidence of treatment, hospital discharge summaries, OT assessments etc" [W187]

"and the huge amount of evidence and paperwork that is need to support a successful outcome' [W200]

"People are intimidated by the amount of paperwork and associated medical reports required" [W209]

"One of the criteria for accessing the NDIS is that all treatments available (that may improve the disability) need to exhausted first. People with a psychosocial disability may find it difficult to participate in treatments like counselling etc due to previous trauma" [W141]

d. Fearing the Consequences of Documenting Evidence of Disability

Respondents said that some people avoided applying for the NDIS because they feared the potential consequences of there being documented evidence that they had not only had a mental illness, but also a disability. They feared that **documenting their disability might result in others intruding in their lives and curtailing their freedom**. Some feared, based upon previous experiences of disclosing in the past, that they might be **involuntarily admitted to a psychiatric hospital.**

Some people feared **losing their children** if there was evidence of their psychosocial disability.

Others worried about the process of evidencing their disability **impacting upon their relationship with, or how they are viewed by, their psychiatrists or treating doctors.**

Sample quotes:

"Individuals with Psychosocial disability often don't want to disclose their difficulties to psychiatrists and medical professionals, as they have had experience with involuntary hospital admissions" [W109]

"… now I'm concerned if I do start seeing therapist all will be documented and I don't want to risk losing my kids" [P073]

"Lack of trust in being open to health professionals about their disability" [W109]

"I'm concerned that it would negatively impact my treatment/ therapeutic relationship with my Psychiatrist" [P024]

"I don't want to become dependent (playing the victim my Psychiatrist called me)" [P051]

e. Fear of Being Re-Traumatised by the Experience of Gathering Evidence of Permanent Disability

Many people feared the process of gathering evidence – being assessed and reported on by experts. Some described having **previous negative or traumatic experiences with therapists or doctors** and they **feared being retraumatised** if they re-engaged in this assessment process. Others said that they **do not trust mental health professionals** because they positioned themselves as experts over their lives and said this led to a **loss of control and agency**.

People reported being frightened by the thought of seeing a new mental health professional for an assessment with **no established therapeutic relationship and sense of trust**. Others expressed **fears about a lack of data security** and raised the risks of sharing personal and private information.

Sample quotes:

"I gather that, in order to be approved for NDIS funding, I would need to see a therapist again to be evaluated? Never again! The last therapist I went to destroyed all hopes I have for a happy life, and wilfully left me wallowing in a fate worse than death. She harmed me terribly. I'm never going back to therapy again" [P054]

"Sounds very difficult and retraumatising (PTSD)" [P092]

"I have trauma from health professionals and healthcare. The bureaucracy involved seems extremely stressful. I fear applying would result in more trauma from not being understood or believed, and from having to go through my health history and how impaired I am" [P095]

"They often feel less personal control over their experience where others are seen to be more 'expert' in things that are likely to impact their experience, eg., new people coming and going" [W076]

"Many with MH conditions find it very difficult to go over their experience with anyone, and less likely to do so where there is not an existing and strong respectful relationship" [W162]

"Further assessments can be overwhelming for clients, particularly if they have to go see a new professional" [W009]

"Also, vicarious trauma associated with having to re-tell their story over and over again" [W178]

"Some people are paranoid about the institution/govt having personal and private information and data security" [W169]

"Privacy laws are obviously very important but there is a disconnect between systems" [W159]

f. Costs associated with gathering evidence are prohibitive

The costs associated with obtaining expert assessments were also repeatedly described as a significant barrier for people considering applying for the NDIS. **Medical appointments for assessments are very expensive** and, as noted previously, not covered adequately by Medicare. Many people did not have the financial means to cover these appointments. People described feeling **trapped by poverty** – unable to provide evidence to access NDIA supports because of the poverty that has resulted from their disability. Some people already had **previous debts**. Others went into debt to see mental health specialists for assessments. Moreover, **sometimes the NDIA required applicants to engage in additional treatments or therapies** (such as CBT) to prove that their disability could not be resolved. The costs of engaging in these NDIA prescribed and required therapies or treatments were prohibitive for some and resulted in them withdrawing from the application process.

People repeatedly lamented the **lack of NDIA or other funding and resourcing to support application related costs.**

Sample quotes:

"I'm unwilling to apply given that involves significant costs to collect medical evidence" [P029]

"Cost involved in Assessments before applying" [P022]

"Also getting that evidence is very expensive, and I'm on JobSeeker, and unable to afford it" [P039]

"They don't have the funds for gap payments" [W002]

"It's always go to your GP and that's not enough to provide evidence. Then to go to specialist services for access assessment you need $800 min not paid by Medicare same as OT report" [W112]

"Access to psychologist reporting due to financial outlay to see a psychologist in first place" [W034]

"I feel trapped by poverty and mental illness and unable to obtain support due to poverty" [P040]

"A major barrier for me has been the restrictive cost of obtaining diagnosis as I cannot find a bulk bill psychiatrist. In order to be eligible, I would need extensive assessments and formal diagnoses that my clinical psychologist cannot provide" [P040]

"I can't afford the expense of obtaining all of the required documentation that is needed" [P119]

"Not being financial enough to see psychologists to help support the application" [F043]

"Financial barriers in accessing reports, appointments to gather evidence" [W022]

"Barriers to collecting appropriate evidence - unable to afford appointments with specialists, or unable to afford diagnosis in the first place" [W045]

"I'm a psychologist. Most people who want to apply can't afford the psychometric testing required for them to "prove" their disability… often costs upwards of $2000 and they simply do not have access to that kind of money. Thus, they can't get the help they desperately need from the NDIS" [W059]

"People cannot afford the assessments required e.g. Psychiatrist assessment, Cognitive assessment and O.T Functional Assessment" [W103]

"needing formal reports but they are expensive" [W133]

"Client not able to access clinical diagnosis due to expense" [W150]

"Diagnostic processes too expensive and involved for many people to use" [W155]

"Unable to access therapy - no transport, no money" [W029]

"Needing to engage with months of therapy before even being considered, some participants don't have the money to do so" [W081]

"too many expensive assessments to be done" [W178]

"additional resourcing is needed to support people to apply" [W015]

"Not enough services funded to complete NDIS applications" [W061]

4. APPLICATION PROCESS IS TOO LONG, COMPLICATED, AND INFLEXIBLE

Respondents repeatedly described the long and complicated application process as barriers that dissuade people from applying to the Scheme. Barriers included: a) process is too long or too complicated, and b) process is inflexible, unaccommodating, and impersonal. These are both described in more detail below with example quotes provided.

Before exploring the detailed qualitative findings, we will briefly revisit the quantitative data relevant to this theme. Table 7 shows the proportions and rankings of survey statement(s) by participant type (i.e., people with psychosocial disability, family/friends and service workers) that are relevant to the 'application process is too long, complicated, and inflexible' theme. A very large majority of all respondents identified that a barrier was "applying for the NDIS is too hard." It was the highest rate barrier for family / friend and worker respondent groups and second only to "I think applying for the NDIS will be too stressful or traumatic" for the person respondent group.

Table 7. Persons/family-friend/worker - proportions and ranking (theme 4 related)

	Person		Family / Friend		Worker	
Item	Percent	Rank	Percent	Rank	Percent	Rank
Because applying for the NDIS is too hard.	86.1%	2	97.8%	1	92.9%	1
Because applying for the NDIS is not a priority for me right now as I have other more urgent priorities.	34.5%	19	54.3%	15	39.3%	19

a. Process is too long or too complicated

A notable barrier standing in the way of many people applying to the Scheme is the **lengthy and complicated application process**. The rankings above show that this (the application process being too hard) was ranked highest or second highest by all 3 respondent groups. Respondents said applying was **overwhelmingly complex and exhausting** with far **too much paperwork** required. Participants were also put off applying by the **length of the application** and **hearing about long and difficult appeals process experiences** – a process that was seen by some to be all but inevitable.

Sample quotes:

"Overwhelmed by application process" [P008]

"A lot of hoops to jump" [P009]

"It's too overwhelming to do myself" [P085]

"Overwhelmed by the length of the application" [P094]

"Complex process" [P099]

"The monumental amount of effort involved in the application process is my primary reason for not persevering" [P016]

"It just seems overwhelmingly complex" [P096]

"Applying is too complicated" [F048]

"The process seems needlessly bureaucratic and exhausting" [P032]

"The application process is too arduous" [F004]

"The paperwork and process is overwhelming" [F029]

"The mere thought of the paperwork required is enough to put me off" [P102]

"Too long process" [P090]

"And the amount of paperwork they have to complete. The amount of time it takes for all of the documents" [W008]

"The volume of paperwork required" [F031]

"the appeals process is stressful enough for any participant, but for a person with psychosocial disability it can be especially traumatic" [W042]

"The application process is very complicated" [W047]

"The complication of the forms" [W196]

"not having capacity to manage the inevitable appeals process" [P037]

"Clients have also said they get lost in the sea of paperwork that is involved and often get frustrated and give up on applying due to this" [W211]

b. Process is inflexible and impersonal

Respondents reported that the impersonal and unaccommodating NDIS application process was stopping people from applying. People said the process was inflexible and not able to accommodate their individual needs. They also reported that the process was an unfriendly, overly bureaucratic, 'tick-a-box' approach.

Sample quotes:

"I don't want to expose myself to a process that I don't feel is particularly interested in accommodating me" [P003]

"General inaccessibility of NDIS Access process" [W132]

"There seems to be a lack of understanding or empathy regarding individual needs and wants. The system seems to be that of a 'tick box' approach" [W006]

"It can be exhausting for clinicians and psychiatrists to have to learn the lingo that will be acceptable and to try and push people into boxes. A less bureaucratic process would be amazing!" [W179]

"Consumers and families are both disadvantaged by the way it's not consumer family friendly. But rather very similar the way of a frustrating Centrelink" [W112]

5. APPLICATION PROCESS IS HARMFUL TO MENTAL HEALTH AND WELL-BEING

Respondents repeatedly reported that the application process was **experienced as, or anticipated to be,** based upon what they had heard from others, **harmful to people's mental health and well-being.** Barriers relating to these negative impacts on well-being included: a) Process is degrading, disrespectful, humiliating, and dehumanising; b) Process exacerbates mental ill-health due to stress and anxiety, and c) Process triggers fear of rejection. Each of these are detailed with sample quotes below.

Before exploring the detailed qualitative findings, we will briefly revisit the quantitative data relevant to this theme. Table 8 shows the proportions and rankings of survey statements as by participant type (i.e., people with psychosocial disability, family/friends and service workers) that are relevant to the 'application process is harmful to mental health and well-being' theme. Concerns about the perceived stress of the application process were ranked very high by all respondent groups, especially individuals themselves (i.e., the Person respondent group) who rated this as the most common barrier to applying.

Table 8. Person/family-friend/worker - proportions and ranking (theme 5 related)

Item	Person Percent	Person Rank	Family / Friend Percent	Family / Friend Rank	Worker Percent	Worker Rank
Because I think that applying for the NDIS will be too stressful or traumatic.	91.2%	1	97.6%	2	76.9%	6
Because I started applying, but stopped because I found it too stressful.	40.5%	17	42.6%	21	60.8%	10

a. Process is degrading, disrespectful, humiliating, and dehumanising

For many people with psychosocial disability, applying to the NDIS is either anticipated or experienced as a **humiliating and demoralising process**. People expressed with passion, the feelings of **powerlessness, disrespect and intrusion**. For some this was a direct experience and led them to withdraw from the application process. Others had heard this from peers and workers recalling negative experiences of people applying. For some, the benefits of a successful application were outweighed by **risk to their own mental health and well-being**. Not applying was seen as **self-protection**. The NDIA **requirement for people to exhaust all treatment options before applying** was part of what made the application experience degrading and humiliating for some.

Sample quotes:

"I am also apprehensive about how abusive and punitive is the application process..." [P104]

"I cannot apply for NDIS, I cannot put myself through that type of process again. It terrifies me" [P011]

"The process of the application terrifies me" [P020]

"My only expectation on a gut level, regardless of knowing the intent of the NDIS, is the same gaslighting about my disabilities, denial of any assistance, re-traumatisation, further impoverishment, and denial of any opportunity to actually improve my life" [P029]

"My sense is that these people are being discriminated against to save money" [W127]

"Systemic ableism that decides I am not 'disabled enough' [P087]

"Be dismissed and made to feel lesser" [P011]

"systemic ableism that decides I am not 'disabled enough'" [P087]

"It is a humiliating and demoralising process" [W118]

"The process is really depressing, dehumanising and just awful" [W169]

"The application procedure was a 'cross between " the Trueman show and being treated like a Tamagotchi"!" [P001]

"It is placing a vulnerable person in an awful position with a huge power imbalance. It should be a cooperative, supportive process, not an adversarial one" [W042]

"The access and 'planning'/ 'review' process is just 'not worth it'" [P024]

"It doesn't seem worth the hassle of jumping through hoops" [F008]

"We don't know how many treatments they need to try before it's seen as all options being exhausted [F041]

"Process of application and reviews viewed as invasive, distressing or triggering" [W208]

b. Process exacerbates mental ill-health due to stress and anxiety

Beyond the barrier related to feelings of humiliation and disrespect described above, respondents also said that the **stress and anxiety associated with the application process** was a barrier that prevented many people with psychosocial disability from applying. Participants described the process of applying to the NDIS as being **distressing, anxiety-producing, destabilising and traumatising.** Again, for some this stemmed from direct experience and lead people to withdraw from the process. Others had heard this from peers and workers recalling negative experiences of people applying.

Sample quotes:

"The application process - especially having to provide third party consent for further information, this can cause distress, escalate anxiety around people talking about them" [W090]

"there is significant anxiety involved in applying..." [W120]

"I do know the process will be stressful, exhausting and drawn out, and my various conditions respond poorly to stress" [P034]

"Don't know if I can cope with another trauma from the process…" [P053]

"I figure there's no point. I am barely hanging on. Having to deal with NDIS would tip me over the edge" [P018]

"I strongly suspect it would be extremely destabilising for me" [P024]

"From experience supporting others, the entire process is likely to be traumatic and make my mental health worse, not better" [P026]

"Based on my own research and from what I've heard from other people, I know that the whole NDIS application process is a nightmare" [P088]

"Sometimes people who are stable and coping okay feel applying for the NDIS will make things worse and their mental health will go backwards due to the stress of dealing with the NDIS…" [W161]

"[it] exacerbates my anxiety and depression when I am trying to work it all out for myself" [P033]

c. Process triggers fear of rejection

Fear of rejection, exacerbated by prior experiences of rejection – from the NDIA and elsewhere – is another barrier to people applying. People explained that this fear comes from personal experience of rejection and the trauma that follows. Fear for some came from hearing about the bad experiences of others. Some feared that rejection of their NDIS application, if they did apply, **might lead to hopelessness and suicidality.**

Sample quotes:

"NDIS is not aware of the re-traumatising effect of a rejected application - so they are not careful about this at all" [W123]

"fear of the process (having heard that it is onerous and that others have been rejected)" [W073]

"I'm scared of being rejected and no longer having a backup plan" [P028]

"Every time I get rejected, I get really depressed and suicidal. It's too much on me" [P043]

"Don't know if I can cope with another trauma from the process and /or rejection" [P053]

"Some clients I have supported have been rejected. This results in clients not wanting to reapply" [W009]

"…worrying they will get knocked back" [W161]

"Fear of being denied entry into the scheme" [W173]

"Fear of being turned down" [W193]

6. THE APPLICATION PROCESS DOES NOT ACCOMMODATE FOR MENTAL ILLNESS AND PSYCHOSOCIAL DISABILITY

Respondents repeatedly said that the application process is not designed to accommodate the needs of people living with mental illness or psychosocial disability. They explained that the lack of accommodation built into the design of the application process deters people from applying for the NDIS. Barriers included: a) Process excludes people because of symptoms of mental illness and psychosocial disability, and b) Process excludes people with prior negative experiences and trauma histories. These are both detailed below with sample quotes.

Before exploring the detailed qualitative findings, we will briefly revisit the quantitative data relevant to this theme. Table 9 shows the proportions and rankings of survey statements by respondent type (i.e., people with psychosocial disability, family/friends and service workers) that are relevant to the 'NDIA does not recognise and accommodate for...' theme. The high ratings regarding for the item included in this section highlights a substantial challenge – at a time when people may require the most support, they are unable to access it because of perceived challenges with the process.

Table 9. Person/family-friend/worker - proportions and rankings (theme 6 related)

Item	Person		Family / Friend		Worker	
	Percent	Rank	Percent	Rank	Percent	Rank
Because my mental health is not great at the moment and this makes it hard for me to cope with applying for the NDIS.	77.4%	5	85.1%	5	74.1%	8

a. Process excludes people because of symptoms of mental illness and psychosocial disability

Respondents reported that the application process, including its complexity, the need to seek out help in order to understand and navigate the process, the need to revisit difficult times, seek and pay for assessments (often from strangers), and the need to document how much their disability impacts on life, all **fail to accommodate for the challenges stemming from people's mental ill health and related symptoms.** Illness and disability related challenges that respondents emphasised included **cognitive difficulties, anxiety, paranoia, financial difficulties, depression, and low threshold for stress.**

Sample Quotes:

"my partner would not be able to cope with applying" [F024]

"Because my wife suffers from PTSD and bipolar it was impossible with the amount of paperwork involved to get her to apply" [F027]

"The nature of my impairment means it is usually impossible for me to ask for help" [P026]

"both finances and my poor mental health condition have prevented me from obtaining a professional diagnosis" [P036]

"forms and documents overwhelm me" [P097]

"not having capacity either emotionally and/or cognitively" [W011]

"My transgender son suffers from extreme social anxiety and depression to the point that he cannot face the (to him) trauma of applying and going through the process of attempting to get support from NDIS" [F003]

"Many people have lived with the illness for a long time and do not want to 'dig up' how unwell they really are" [W173]

"I feel guilty for not being 'disabled enough' to receive support" [P016]

"being told I'm not sick enough" [P125]

"constant paranoia" [F025]

"People are too unwell to be able to access support from services or NDIS" [W062]

"Paranoia or distrust of signing service agreements and other paperwork" [W084]

"A lot of mentally ill people are paranoid about the NDIS or say they don't see the point in it" [W108]

"Some people with multiple complex mental illness or disabilities have very complex needs which the NDIS doesn't help. e.g. autism with PTSD" [W108]

b. Process excludes people with prior negative experiences and trauma histories

Prior negative experiences with government agencies and services were reported as stopping some people from making NDIS applications. Respondents saw the NDIA as **failing to recognise this common previous source of trauma or distress** experienced by people with psychosocial disability and ensuring that the application process accommodated for this. They said that NDIA needed to **adopt a trauma informed approach.**

Sample Quotes:

"Dealing with the government or its agencies distresses me" [P010]

"My experience with the entire disability sector makes me reluctant to apply for anything at all" [P029]

"I want to minimise my contact with any government related services due to previous bad experiences with Centrelink and job network providers" [P032]

"have experienced trauma through systems and are suspicious of systems" [W147]

"have spent 15 yrs pushed from pillar to post, misdiagnosed 5 times, DES provider does nothing, robodebt, ineligible for DSP" [P035]

"Trust. I don't trust the Government" [P104]

"I have seen the Mental Health system from the inside and I'm still alive...not because it saved me...far from it....it in fact gave me more reason not to trust it" [P051]

"I simply don't have the energy to fight another dysfunctional system" [P088]

"Previous negative experiences with other government agencies - were distressed and traumatised by the process" [W026]

"Distrust of government" [W060]

"Lack of trust in human service systems due to past trauma, not feeling heard in the past" [W076]

"have experienced trauma through systems and are suspicious of systems" [W147]

"Many clients are resistant to engaging with certain, or any, health services, in particular mental health services, due to previous negative experiences…" [W181]

7. THE NEGATIVE REPUTATION OF NDIA STAFF AND CULTURE

Respondents said that both peoples' direct experiences of NDIA staff and/or the stories about NDIA staff told by peers led them not to apply or withdraw from preliminary attempts to apply for the NDIS. In addition to direct staff related barriers, respondents spoke of aspects of NDIA culture that they believed created a barrier to people living with psychosocial disability engaging with the application process. Collectively these barriers include: a) Staff do not understand psychosocial disability – particularly its episodic nature; b) Staff are not respectful and lack empathy; c) Staff are inconsistent and incompetent, unqualified and lack essential skills; d) Lack of action by NDIA to address access barriers flagged by the community, and e) An inflexible NDIA culture that doesn't consult. Each of these are detailed below with sample quotes.

Note that there were no survey statement(s) that related to the 'The negative reputation of NDIA staff and culture' theme. Respondents however repeatedly emphasised within the survey that this was a barrier to applying.

a. Staff are unqualified and do not understand psychosocial disability – particularly its episodic nature

Respondents reported that some NDIA staff **do not understand psychosocial disability and the impact it has upon people's lives**. They said this lack of understanding **impacts both on the interactions** they have with potential applicants and on the quality of **decisions made**. They particularly emphasised a lack of staff (and NDIA) understanding of the **episodic nature** of psychosocial disability. Others were frustrated that, given this lack or limited understanding, NDIA staff ignored or went against expert assessments or recommendations.

Sample Quotes:

"NDIA staff appear to have no comprehension of psychosocial disability and will often make assumptions about capacity and make decisions that go against expert recommendations. This is hugely problematic" [W042]

"Lack of understanding by NDIS staff of the impact of mental illness..."[W049]

"Lack of understanding and expertise within the NDIS with regard to psychosocial disability...[W099]

"misunderstanding re psychosocial disability" [W033]

"NDIS understanding of psychosocial disability often hinders consumers from applying" [W085]

"Lack of faith in the skills of assessors to interpret clinical assessments" [W056]

"I've been told ... that my illness is episodic so I wouldn't qualify" [P046]

"'Psychosocial disability' is not recognised as being lifelong and enduring as it is episodic in nature" [W017]

"I made an enquiry at the NDIS office when it started about 3 years ago and was told it was not available for people with psychological/psychosocial disabilities" [P063]

"A lot of the coordinators have no knowledge about mental illness [W108]

"Complex needs are not understood...especially trauma/ PTSD/ coupled with Autism and BDP" [F022]

"There are also many instances of NDIS conflating disability, MH and trauma, and substance use...[W076]

"NDIS seems to be run by employees who are not very aware and naive towards mental health issues that most (if not all) disabled individuals experience. They do not understand that mental health professionals are experts in their field and have earned registration through continuing education" [W123]

"The NDIA not having awareness of disabilities" [W171]

b. Staff are not respectful and lack empathy

Respondents reported that people had directly experienced **disrespectful and non-empathetic interactions with staff** and for some this had led to or contributed to them withdrawing from the process of applying. Others had heard about these negative interactions with NDIA staff from the **recounts of others** and this contributed to them not applying for the Scheme. Some said that staff sometimes **treated personal information in disrespectful ways** and breached people's privacy.

Sample Quotes:

"Staff need to have empathy and people skills. I cannot speak for other NDIA offices only the one I deal with" [W075]

"Lack of empathy towards people with psychological disorders" [W154]

"I have seen countless breaches of privacy, and inappropriate and disrespectful conversations, and it concerns me to think that I would be seen in that light" [P024]

"paternalistic attitudes to deal with - no real understanding of the problems in relation to trying to have a social life for person with p.schiz. as well as other aspects of her illness" [F025]

"Please find a way to make it better, easier for them to be seen as a person, a human being; not just an NDIS number to file away and provide them the help and funding and services that they need to 'live the life'; the life that many of us can take for granted at times" [W149]

"Staff at NDIA (in my rural town experience) can be condescending towards people and can become easily frustrated with clients. This is so annoying to see and hear. Staff need to have empathy and people skills. I cannot speak for other NDIA offices only the one I deal with" [W075]

"I do not trust that my information would be handled sensitively or with due respect" [P024]

"Fear of disclosure of information" [W087]

"I also know that the way that staff at the NDIS in particular (to a lesser extent, partner organisations) treat and view mental illness" [P024]

"having to share their story repeatedly to bureaucrats who have no empathy" [F013]

"NDIS appears so impersonal to my Participants" [W149]

"Last year on a 3 week visit to me, my son agreed to go to the NDIS office at [location] because he realises that he needs help and support. THIS WAS OUR EXPERIENCE: Behind the counter were two women [staff] sitting down chatting. There was no one else in the office. My son and I stood in the line to speak to an NDIS Representative. One of the women asked what we wanted. Son, [who is 47yrs] was overwhelmed even with the question. After a time when I could see he was struggling, I stepped forward and said 'My son is here to see about an application for the NDIS'. Both women almost in one raised voice said: 'Oh no it's not that easy you probably won't be eligible'. Said in raised voices, my son immediately panicked, turned to me and started yelling at me saying 'I told you this is no good' - and turned his back to walk out of the office which he did, then furious with me. The women's shocked faces told me their reaction to my son's outburst....they sat with their mouths open. I then said to them,

'My son has been entitled to receive NDIS for 4 years or more...it has taken me that long to get him into an office to apply'. Neither woman said a word." [F049]

c. Staff are inconsistent and incompetent

Repeatedly respondents said that staff were inconsistent – with **different staff giving different information, following different processes to one another, and making inconsistent outcome or eligibility decisions.** The level of **knowledge or understanding of mental illness and psychosocial disability is inconsistent.** While worker voice dominates here, people who would be potential applicants were also witness to inconsistencies when they saw which peers were and were not deemed eligible for the NDIS. Respondents also said that staff were often incompetent, emphasising **lack of follow-up with people, delays in processing applications and repeatedly lost paperwork and applications.**

Sample Quotes:

"Applications being rejected for people who it seems that the whole concept of the NDIS was developed to help" [P122]

"Unskilled staff working at the NDIS...I can't even begin to think about how many times different staff give different information about the same participant applying" [W022]

"NDIA staff are inconsistent with process and knowledge" [W064]

"Observing others with less disability receive funding over others that have more disabilities" [W075]

"...often make assumptions about capacity and make decisions that go against expert recommendations" [W042]

"lack of assertive follow up by NDIS when they can't make contact with the client" [W089]

"We have helped apply but very often people are knocked back even after Dr's and specialists have said support is needed" [W092]

"Many clients expressed how frustrating it has been to communicate with NDIS" [W190]

"NDIS losing paperwork, speaking too quickly over phone, not adapting communication techniques to each participant" [W022]

"Too little support for them from NDIS" [W149]

"The LAC's turn over often and they have a very poor product knowledge" [W079]

"LAC's and NDIA staff are inconsistent with process and knowledge.   We have experienced delays in processing applications since July 1st 2021. We also experience numerous lost documents and applications" [W064]

"We have followed the NDIS access guidelines, plus submitted supporting evidence. Only to be told, that a person who is 47 years old with diagnosed bipolar (2017) has not had documented CBT, therefore cannot be admitted to the NDIS" [W069]

"There are also many instances of NDIS conflating disability, MH and trauma, and substance use, and cherry picking information within Access requests (without allied health skill or knowledge of a participant) in ways that grossly disadvantage people with mental ill-health in the process..." [W076]

"Numerous situations where NDIS representative has requested further information, despite the information being in the application- Clearly not reading all information submitted" [W081]

d. Lack of action by NDIA to address access barriers flagged by the community

Worker respondents said that many of the **barriers to applying for the NDIS have been raised and documented already** and were frustrated by **lack of NDIA action** to address these. They called for **reform at the policy and management level.**

Sample Quotes:

"So many barriers, which have already been well documented over time. A lack of action to reduce barriers by NDIA management is a key feature" [W076]

"This is a very large topic and there is a lot of reform is needed in this space" [W015]

"In essence, the NDIA does not see themselves as the barrier to access and this is a fundamental issue" [W203]

"The system is broken and like a lot of bureaucracy it is designed to be difficult as a deterrent for people applying" [W159]

"There are no specifically funded programs or supports to help proactively identify people who would benefit from the NDIS and provide intensive support for them to apply" [W203]

"So all that to say that the reason people I have worked with are not applying for the NDIS is because the NDIS was not designed to accommodate people with psychosocial disability and this is an issue that exists at a policy level" [W203]

e. An inflexible NDIA culture that doesn't consult

A **lack of NDIA consultation and collaboration with NDIS stakeholders** was reported as a barrier to people with psychosocial disability applying to the Scheme. This lack of consultation included **consultation about the Scheme design and policies** as well as **consultations related to specific applications to clarify any misunderstandings.**

Sample Quotes:

"Lack of consultation with MH services has created poor fit with service user needs" [W076]

"The NDIA not being open enough with support services on informing them about what is expected from an access request form, especially for psychosocial disability" [W134]

"Inconsistent interaction between the mental health sector, justice disability systems, and the NDIS" [W138]

"Additionally, rather than an NDIS decision-maker seeking further clarification from practitioners, it will reject the application without providing reasons" [W126]

"They need to have an interview when declined to meet with them, speak with them on the phone to hear their pain, their mental state and how it fully impacts on their lives because NDIS just aren't getting it!!!!!!!!!!" [W149]

"You cannot just call and speak to a contact. The number is a general number. Applications get lost in the system" [W187]

8. DISCONNECT BETWEEN 'DISABILITY' AND 'RECOVERY'

Respondents said that **the NDIA language and acceptance criteria of permanent disability prevented some people from applying for the NDIS**. They said that for people or their clinicians and workers to evidence **'permanent disability' equated to being hopeless, disempowering and stigmatising and counter to the recovery-oriented focus** of the mental health sector. People do not want to identify as disabled and accept that their situation is permanent and thus do not apply. Further, even if people are prepared to accept the notion of permanence, it is difficult to prove permanence of psychosocial disability given the episodic nature of mental illness. Equally workers and expert clinicians and doctors do not want to frame a person's situation as a permanent disability and thus struggle to support applications with evidence required by NDIA (this aspect is also covered above in 3. Hard to obtain evidence required by the NDIA).

Before exploring the detailed qualitative findings, we will briefly revisit the quantitative data relevant to this theme. Table 10 shows the proportions and rankings of survey statement(s) by respondent type (i.e., people with psychosocial disability, family/friends and service workers) that are relevant to the 'fundamental disconnect of principles and language' theme. There were few items directly related to this in the questionnaire.

Table 10. Person/family-friend/worker - proportions and ranking (theme 8 related)

	Person		Family / Friend		Worker	
Item	Percent	Rank	Percent	Rank	Percent	Rank
Because my mental illness or psychosocial disability, is not permanent.	5.1%	32	26.1%	29	20.8%	31

Sample Quotes:

"The NDIS is deficit focused, i.e.,: in order to be eligible for funding, a respondent must first prove that they essentially have no hope of recovery and will be permanently and forever disabled by the condition they experience" [W032]

"Definitions of permanency of functional impact" [W132]

"Not wanting to be associated with 'having a disability' or 'needing support/carers'" [W084]

"Stigma of needing support for a 'permanent disability' not fitting the frame of recovery models" [W076]

"The focus on disability being the wrong focus compared to 'recovery'" [W139]

"After working with people in the recovery framework this is disempowering and stigmatising" [W187]

"Stigma about being a person with 'psychosocial disability' when they've been working on the premise of Recovery i.e., people can and do recovery from mental illness" [F047]

"Declaring someone has a permanent psychosocial disability seems counter to recovery-based practice where Hope is the key and the belief that people can live well no matter what is happening, that they can live well with symptoms and without symptoms" [W071]

"not fitting the frame of recovery models" [W076]

"the focus on disability being the wrong focus compared to 'recovery'" [W139]

"Firstly, often people with mental ill health don't identify with disability" [W147]

"The process is time consuming and the title reinforces that a person has a disability" [W118]

"Deficit based language" [W208]

"languages used in the application are negative and traumatizing" [W206]

"Another issue in accessing the NDIS is the requirement that the psychosocial disability must be permanent. This is in direct clash with the concept of 'recovery' which has dominated the mental health field in the last decade. Neuroplasticity, and the idea that people can learn new, adaptive coping styles, as well as access to medication, and non-judgmental support to help people in their everyday activities, underpins a lot of the well-researched recovery-oriented methods of addressing mental health issues, even those with lifelong (to date) struggles" [W067]

"Stigma about being a person with 'psychosocial disability' when they've been working on the premise of Recovery i.e., people can and do recover from mental illness" [F047]

9. PERSONAL BELIEFS, FEARS AND STIGMA

Respondents also described beliefs that people had about themselves and others, and concerns about what others would think of them as deterring them from applying to the Scheme. Barriers included: a) I don't deserve NDIS – I am not as needy as others; b) People/they don't identify or accept that they have a disability or mental illness; c) I fear of unknown consequences of engaging with government agencies or having an NDIS plan; and d) I fear being labelled or judged by others. These are detailed below with sample quotes.

Before exploring the detailed qualitative findings, we will briefly revisit the quantitative data relevant to this theme. Table 11 shows the proportions and rankings of survey statements informed by respondent type (i.e., people with psychosocial disability, family/friends and service workers) that are relevant to the 'personal beliefs, lived experiences and stigma (self and societal)' theme. The most prominent barrier in this section was lack of trust in government agencies which was also borne out in the qualitative comments.

Table 11. Person/family-friend/worker - proportions and ranking (theme 9 related)

Item	Person Percent	Person Rank	Family / Friend Percent	Family / Friend Rank	Worker Percent	Worker Rank
Because I do not trust government agencies like the NDIS agency.	45.9%	13	53.7%	16	41.5%	18
Because other people need the NDIS support more than I do.	40.7%	16	23.9%	32	21.8%	30
Because I do not want to be labelled as a person with a disability.	11.9%	29				
Because I do not have a psychosocial disability.	5.0%	33	25.5%	30	28.4%	24
Because I do not have a mental illness	3.3%	34	18.8%	36	17.9%	32

a. I don't deserve NDIS – I am not as needy as others

People themselves, family members and workers said that for some people a belief that they were not worthy of the NDIS, that they didn't deserve it, or that others were more needy and deserving stopped them from applying for the NDIS. Some described a sense of shame or guilt for getting things for free because of their mental illness or disability.

Sample Quotes:

"I think I probably just don't deserve help" [P030]

"I would need to prove myself worthy of even applying for the NDIS" [P020]

"…feeling that he was not deserving and shouldn't get things for free just because of his mental health issues. This is also part of the reason why he also won't apply for Centrelink" [F020]

"I still struggle with a sense of being unworthy of the support and the shame of feeling like a burden on the health care system" [P122]

"Believing they are not worthy of NDIS" [W180]

"Appropriateness of my having support when others are more needing" [P016]

"Internalised stigma/beliefs about not needing or deserving support (e.g. "others have it much worse")" [W132]

"I think I'd feel guilty taking govt money" [P017]

b. People/they don't identify or agree that they have a disability or mental illness

Workers and family members said that their family member or some people they work with do not want to apply for the NDIS because **they do not identify with, or agree that they have, a disability and or a mental illness.**

Sample Quotes:

"I do believe there is also a small part of him that thinks by accepting financial support is accepting his mental health issues rather than working on 'getting better'" [F020]

"My family member does not want to access services through NDIS; doesn't view herself as someone with a disability; thinks that she can manage to do things herself (even though she can't)" [F023]

"My family member does not feel the NDIS has anything to offer him-counts himself as a high performing person with a diagnosed disorder" [F011]

"They do not agree that they have a disability" [W016]

"Don't believe they require assistance with their psychosocial disability" [W003]

"at times, denial of a mental illness or need for support" [W053]

"Not wanting to be associated with 'having a disability' or 'needing support/carers'" [W084]

"people not recognising their permanent and significant mental health challenges as being a disability" [W011]

"Some people don't acknowledge mental illness" [W111]

"Some people don't believe they have a psychosocial disability [W039]

"still be coming to terms with their diagnosis, and potential limitations to their life" [W026]

"people not recognising their permanent and significant mental health challenges as being a disability [W011]

c. I fear the consequences of engaging with government agencies or having an NDIS plan

Repeatedly respondents said that people were not applying for the NDIS because they feared the potential consequences. These potential consequences varied but included fear of having their disability pension reviewed or removed, losing concession cards, losing trusted and valued current mental health supports and losing their independence. Described above, some feared flow-on impacts such as losing custody of their children.

Sample Quotes:

"a fear of the unknown is often a barrier" [W181]

"I am also worried that engaging with the NDIS may result in possibly having my DSP reviewed and losing the basic level of stability it provides me" [P044]

"they think it will affect their Centerlink payments" [W136]

"People are scared of losing pension or concession card" [W169]

"… I don't want to become dependent" [P051]

"Not wanting to lose/change current supports that they will not be able to access if eligible for NDIS" [W113]

"People worry that it will affect their pension" [W169]

"Even if I was to apply and be approved to receive assistance, I would not feel like I could rely on it as it could be reviewed and taken away. I would rather never use a service and find other ways to deal with issues than begin to use a service only to have it taken away" [P044]

"I've had clients that don't feel they need the extra support. Clients are happy with their current supports and don't want to jeopardise it" [W181]

"Because they will lose a supportive and appropriate non-NDIS service" [W208]

"they don't trust something new, they think they will have to all the work" [W136]

"Concern about effect on Centrelink payments" [W072]

"Fear of losing pension" [P109]

d. I fear being labelled or judged by others

A number of respondents said that people avoided applying for the NDIS because they **did not want to be labelled as disabled** or to be **'connected' to a stigmatised group.** A number of people talked about the **shame** associated with the label of being disabled and said they didn't want others to 'see' them differently.

Sample Quotes:

"Fear!! of being labelled" [P051]

"I'd be labelled as a bludger according to my family" [P060]

"Many do not want to be labelled and do anything to not be part of the stigmatized group" [W162]

"Social stigma of psychosocial disabilities not being a 'real' disability, in my case my lived experience of personality disorder and mental illness" [P056]

"particularly when there is so much shame attached to it as I really value people seeing me as a successful and capable person" [P024]

"Stigma of needing support for a 'permanent disability'" [W076]

"Stigma in the community regarding psychosocial disabilities" [W109]

"Labelling oneself as emotionally disabled is a strange and potentially shaming experience" [F033]

"Stigma about being a person with psychosocial disability…" [F047]

"there is a level of shame felt by the Aboriginal clients I work with - not admitting they need help or have a mental illness/disability" [W071]

"Often shame and stigma ate the biggest limiters after financial and access issues" [W142]

"Many do no want to be labelled and do anything to not be part of the stigmatized group" [W162]

"The Shame factor" [W194]

"being labelled" [W202]

"Some are nervous about being labelled as having a "disability" and the associated stigma that may cause" [W209]

10. IT IS NOT WORTH THE EFFORT – NDIS WON'T MEET MY NEEDS ANYWAY

There were many respondents who said the people were not applying for the NDIS because they didn't believe that if they were eligible, an NDIS plan would meet their needs. There were two overarching reasons given for this: a) My plan would not include the things that I need, and b) I would not be able to use my plan because services do not exist or there is not enough money to cover service costs. Both are described below with sample quotes.

Before exploring the detailed qualitative findings, we will briefly revisit the quantitative data relevant to this theme. Table 12 shows the proportions and rankings of survey statements informed by respondent type (i.e., people with psychosocial disability, family/friends and service workers) that are relevant to the 'It is not worth the effort – NDIS won't meet my needs anyway' theme. The most prominent result in this section is that a barrier that is NOT generally present is that people don't need to apply for NDIS because they already have enough services.

Table 12. Person/family-friend/worker - proportions and ranking (theme 10 related)

	Person		Family / Friend		Worker	
Item	Percent	Rank	Percent	Rank	Percent	Rank
Because I do not think the NDIS will improve my supports.	42.7%	15	47.7%	18	36.8%	22
Because I have enough services already.	3.1%	35	2.1%	46	2.4%	39

a. My plan would not include the things that I need

Many respondents said that people were not applying for the NDIS because they had heard from others that **the things that they really needed support with were not approved 'items' or services** within NDIS plans. Some highlighted that they had heard that NDIS said that **Health rather than NDIS was responsible for providing the supports that they needed** such as therapies. Others talked about the **inflexibility and lack of individualised plans**.

Sample Quotes:

"NDIS does not fund gym memberships even though this would be a major factor in improving my level of wellness and alleviate depression" [P001]

"I'm unable to find anything that the NDIS funds which would provide me with any support" [P029]

"NDIS cater more for physical disability with limited understanding of psychosocial disability and or mental health issues. When a plan is in place your choice is limited for therapies" [F002]

"The services do not seem to cater all that well to people with a mental illness" [P032]

"Some have seen the support provided to others and 'don't like how it looks'" [W071]

"Potential changes to the NDIS which have been proposed within the last year make it sound very much like the Morrison Government is actively seeking to prevent people like me from receiving NDIS supports, and to arbitrarily remove NDIS supports from people like me who already have them" [P030]

"People whose main struggle is executive functioning are essentially barred from supports as a result of 'rationing' services with onerous admin" [P035]

"Have seen so many other people with mental illness who have been assisted to get an NDIS plan but then don't get the help they need because the NDIS won't fund the things they need because they say it's the responsibility of Health!!" [F042]

"Of the people who have signed up, the NDIS isn't flexible enough to suit their needs" [W108]

"That it's a waste of time and I'll go through all the bullshit and then the experience of being on the NDIS will be traumatic and unhelpful anyway" [P086]

"The main thing I need is long-term psychotherapy for complex trauma and from what I can tell, this isn't something I'm likely to get through the NDIS" [P088]

"This is the covert strategy applied by the NDIS to save costs and lock people out of the supports they legitimately need" [P045]

b. I would not be able to use my plan because services do not exist or there is not enough money to cover service costs

A number of respondents, **particularly those from rural and regional areas,** said that people believed that even if they did get the things that they needed and wanted in their plans, that there would be **barriers to them being able to actually use or 'activate' the plan.** These barriers were: 1. that there are **not services available to provide aspects of the plan** ('thin markets'), and 2. that even if there were services, that the **funding within their plan would be insufficient** to meet the service costs.

Sample Quotes:

"lack of appropriate supports in remote locations" [W091]

"The lack of services in regional areas is a deterrent, why bother applying for services that don't exist" [W071]

"Besides when they give barely any support or funding, is it even worth it? It's such a big fight to get it, and I probably won't even get the help I need" [P043]

"a lack of services even if a package could be applied for" [W091]

"Biggest barrier in rural areas... the lack of services and professionals should a package be made. Essentially it makes the NDIS redundant the majority of the time" [W091]

"The government also needs to pay additional attention to rural areas that experience limited specialist services and inconsistent GP availability" [W009]

"It is left to market forces to function" [W096]

"Thin Markets is one of the main reasons and the lack of services to rural and remote communities" [W052]

"Lack of mental health trained NDIS supports in regional and remote areas" [W208]

CONCLUDING COMMENTS

This Section and phase of the project (Phase 2) has revealed the breadth and depth of barriers to accessing the NDIS for people with psychosocial disability as reported by key stakeholders. While we are aware of the many recent efforts being made by the NDIA to address these barriers (including the release of the NDIS Recovery Framework), the testimonies and experiences of stakeholders highlight that more needs to be done.

NEXT STEP

The next phase of the research project involved: a) obtaining stakeholder informed solutions to each of the ten barriers that were identified in this phase of the project; and b) collaboratively formulating a suite of policy recommendations.

PHASE 3. SOLUTIONS proposed by stakeholders to address NDIS access barriers for people with psychosocial disability

This section details the aim, methods, results and concluding comments for Phase 3 of the research project.

AIM

To identify stakeholders' proposed solutions to remove or reduce the barriers to applying to the NDIS (as identified in Phase 2) and to synthesise these suggested solutions into a practical set of recommendations.

METHODS

Phase 3 was an iterative co-designed process in which we returned to stakeholders to identify and propose workable, realistic and practical solutions to the previously identified barriers to applying to the NDIS. We sent the following email to all stakeholders who had expressed interest:

> *Dear Stakeholders*
>
> *In Phase 2, we identified what is stopping more people living with psychosocial disability from applying for the NDIS – the barriers.*
>
> *In this phase, we are seeking to collaboratively identify solutions to those barriers. To make this step as easy for people as possible, we have cut and pasted the barriers into the attached 'Solution Tables' document. We are inviting you, to help us to identify workable, realistic and practical solutions to each of the barriers in the 'PROPOSED SOLUTIONS' column of the tables. The more specific you can be the better. If you are a worker rather than an individual service user or family member, you are welcome to do this with other colleagues from your organisation.*
>
> *For some areas you might not have practical or policy related solution to recommend. For some, you might feel that you have already given relevant recommendations in a section above – please just say something like "addressed above".*

Stakeholders sent through detailed responses. While some responses came from individuals, many responses were from organisations where teams had collaborated on the development of their recommendations. The research team then thematically synthesised all responses into a set of draft recommendations.

These draft recommendations were then sent back to stakeholders for review and to provide final comments. Alongside the draft recommendations, we reported on whether similar recommendations had been made previously and provided a critical review of any related current plans or activities.

> *Dear stakeholders,*
>
> *Thank you all for your ongoing engagement with this National Mental Health Commission funded project – identifying the barriers (and solutions) for people living with psychosocial disability accessing the NDIS.*
>
> *This project has involved a few steps and we are up to the final one – inviting you to give any final thoughts and feedback.*
>
> *Here is a quick reminder of what has happened already:*
> *Step 1: you told us about BARRIERS to applying for the NDIS (and we pulled everyone's feedback together).*
>
> *Step 2: you told us what the best SOLUTIONS would be to address those barriers (and we have pulled everyone's solutions together into 7 core recommendations).*
>
> *NOW: we are sharing these 7 RECOMMENDATIONS with you so that you can provide us with any last-minute feedback or thoughts.*
>
> *This report starts with two versions of a summary – the recommendations in brief and the barriers that they link to (we would like to know which is easier to follow!!)*
>
> *After that, each recommendation is provided in more detail.*
>
> *Throughout this report, we have placed PURPLE boxes where we ask you for your feedback. You might only have feedback on some parts – please just add comments where you have things you would like to tell us.*
>
> *We will then incorporate all of your feedback and suggestions before releasing the final stakeholder informed report.*

Finally, the research team collaboratively discussed the comments and feedback received about the synthesised list of recommendations and updated them based on stakeholders' feedback. Almost all feedback supported the recommendations as they were, so only very minor amendments were made.

RESULTS

There were two rounds of feedback identifying solutions with 23 stakeholders responding to the first and 14 adding additional feedback in the second round. Stakeholders included representatives from government, peak bodies, and service provider organisations as well as people living with mental illness and their families.

A thematic synthesis of the detailed stakeholder responses resulted in seven key recommendations. Each of these are detailed below. We also report on their alignment with recommendations made in previous key reports (e.g., Mind the Gap and the Tune Review) and frameworks (e.g., NDIS Psychosocial Disability Recovery-Oriented Framework), and both flag and critique related plans or actions underway.

Recommendation 1: Build, maintain and disseminate accurate, up-to-date and easily accessible information

Update, enhance and build upon best currently available information (possibly the reimagine website - https://reimagine.today/). Resource and maintain the updating of a single national source of information. Enhance the dissemination of this information including easy to read downloadable one-pagers that can be printed and paper-based fliers to maximise accessibility.

This will increase awareness and clarify that people living with psychosocial disability stemming from long-term mental illness have the right to access and benefit from NDIS supports.

These materials should be:
- co-designed with people with lived experience and be easy to read/understand
- widely disseminated, including being accessible to people living in regional, rural and remote areas
- in multiple formats (internet, social media, television, posters, flyers etc)
- in multiple community languages
- informed by evidence-based approaches to reducing stigma and discrimination towards people with psychosocial disability
- using recovery-oriented language
- regularly maintained with up-to-date information

Materials should be co-designed for both the general public and also specifically targeted towards individuals with mental illness or psychosocial disability and their families.

Materials for the general public should include information about:
- what the NDIS is
- how the NDIS fits within the broader system of supports (health and social services)
- what psychosocial disability is and that the NDIS is available to people living with psychosocial disability
- how NDIS has helped people living with psychosocial disability
- positive psychosocial disability focused stories to show the benefits of having an NDIS package
- normalising the perception of accessing NDIS for people with psychosocial disability so that it is viewed as a right similar to other community and mainstream services

Materials for individuals with mental illness and their families should include accessible and clear information about:
- what psychosocial disability is and that the NDIS is available to people living with psychosocial disability. This will assist people to more easily assess whether their experiences are likely to be considered a psychosocial disability
- eligibility requirements so that individuals have a clearer understanding of their likelihood of being accepted
- the "permanence" criteria in relation to the episodic and fluctuating nature of psychosocial disability
- the evidence gathering and application process
- who to contact to get help to gather evidence and apply (the Navigator – see recommendation 3)
- their rights including the right to privacy/confidentiality, the right to not experience discrimination when applying for or accessing the Scheme

HAS THIS RECOMMENDATION BEEN MADE BEFORE? ARE THERE ALREADY PROPOSALS FOR ACTION?

The need for clearer, accessible information about the NDIS, psychosocial disability, eligibility requirements and permanent disability has been repeatedly raised in previous reports (e.g., Tune Review and Mind the Gap Report). The new (late 2021) NDIS Psychosocial Disability Recovery-Oriented Framework sets an agenda for improved provision of information to better support the decision-making experiences of NDIS participants with psychosocial disability (Principle 4). The Framework is not explicitly focused on information relating to applying to the Scheme, but rather information for those already accepted into the Scheme. Implementation of the Framework requires a lens that extends to the application process.

WHAT EXISTS OR IS HAPPENING ALREADY, AND WHY IS THIS NOT ENOUGH?

Extensive, complex and time-consuming internet searches by our research team has identified that there is a plethora of NDIS information sources. These multiple, inconsistent, almost all out-of-date sources of 'truth' creates confusion and complexity. A single, accurate source of information that can be consistently accessed is needed.

Main limitations of the information currently available are:

- information generally covers what NDIS is, some covers what psychosocial disability is, none really explains the steps that a person with psychosocial disability needs to take to apply for the NDIS
- most information is not psychosocial disability specific
- information is hard to access and not widely known about by people with psychosocial disability
- information is internet-based and thus access is limited to those who have and use technology
- most is not written in easy-to-read English

Our assessment is that the reimagine website (https://reimagine.today) is currently the best source of information available. This is supported by the number of other sites that link people back to Reimagine for information. The recommendations above need to be actioned to enhance Reimagine or other selected single source. Continued funding will also be required for maintenance, updating and further co-development of this source of information.

Recommendation 2: Co-develop and co-deliver systemic training and establish workforce support champions

Co-develop and co-deliver continually available <u>training for health and community service providers</u>. GPs, public, community and private mental health, disability and social services require ongoing access to training about the psychosocial stream of the NDIS so that they can provide accurate and helpful support, advice and evidence to people who are considering or are applying for the NDIS.

Create "<u>support champion</u>" roles (coaching, championing and advice) that are external to Health, but similar to those already developed within many state and territory Health and Local Health Districts (Disability Strategy Manager & NDIS Lead – Northern Sydney Local Health District for example).

a. **Training**

Training must be widely accessible to a range of service providers such as hospital and private based specialists, GPs, public, community and private mental health, disability and social services. Training should be co-developed, co-delivered and co-evaluated by people with lived experience of psychosocial disability to increase the capacity of the broader health, mental health and community-support sectors to:
- recognise their responsibility to identify, encourage and support appropriate clients to apply for the NDIS
- clearly understand the application process and eligibility requirements including what evidence is required within applications and the language and focus required by the NDIA within expert reports.
- dispel misinformation about the NDIS and who is eligible
- provide well-informed support to NDIS applicants that is trauma-informed, respectful, and individualised. This is important throughout the application process, but particularly important when writing reports that cover individuals' previous traumatic experiences.
- clearly understand the types of support and services that are available through the NDIS.

Notes. 1. To ensure people do access available training, models for time-reimbursement and provision of Continuing Professional Development (CDP) points need to be explored. Flexible delivery options should be offered (e.g., online training). 2. Incentives need to be developed in partnership with PHNs to ensure this training is valued and attended. 3. This recommendation relates to training for health and community service providers who support and provide evidence for people applying for the NDIS – NOT NDIA/NDIS staff – that is covered in Recommendation 6 below.

b. **Support Champions**

The purpose of support champions is to provide a coaching, championing, and advice provision role to support and build workforce capacity. These positions already exist in many Health districts/networks, but equivalents are needed to support providers who 'sit' outside of Health – GPs, community managed organisations, private practitioners.

Note. While the PHNs appear to be the natural location for these roles, mechanisms to ensure quality consistency across the country is needed (many stakeholders highlight the great difference in supports and quality of service between PHNs).

HAS THIS RECOMMENDATION BEEN MADE BEFORE? ARE THERE ALREADY PROPOSALS FOR ACTION?

The need for targeted and consistent training of health professionals and the building of consistency in the evidence provided in disability reports for people with psychosocial disability have been raised in the Tune Report and Mind the Gap reports.

WHAT EXISTS ALREADY, AND WHY IS THIS NOT ENOUGH?

Training: An extensive internet search has evidenced that there has historically been an array of training modules or online courses run to educate GPs, and/or other health providers on the NDIS. However, access to these appear to have been limited (only accessible to a particular PHN 'community' for example), and very little seems to be recorded and thus currently accessible. Additionally, very few were specifically focused on how to support the access or application processes for people with psychosocial disability. The Flinders Transition Project (funded for 2 years) seems well placed to play a role in the development of targeted training that is focused on supporting the access or application process.

Support Champions: Numerous state health departments have established effective NDIS support leads or champions. Expansion of these approaches or positions to support workforces outside of state health services is needed.

Recommendation 3: Establish Navigator positions – independent and psychosocial specific

Create a clear, independent NDIS Psychosocial specific Navigator role to assist individuals, family members and service providers throughout the NDIS application process.

Navigators are an accessible point of contact for a) individuals considering applying for the psychosocial stream of the NDIS, b) family members (supporting families and including them in the process where possible) and c) service providers inquiring about the eligibility process and evidence requirements specific to the psychosocial stream of the NDIS. The following are important aspects of the role:

- Navigator roles are widely publicised so that people with psychosocial disability are aware of their existence. Navigator roles are adequately resourced to ensure their sustainability.
- Navigators should be a specialised role only working with people in the psychosocial disability stream
- Navigators are highly skilled and knowledgeable about both psychosocial disability and the NDIS
- Navigators need to be independent from both NDIA and NDIS service providers to avoid potential conflicts of interest.
- Navigators need to be recovery-oriented, trauma informed, skilled in rapport building and have accessible communication skills that break down language barriers and reduce confusion and distress.
- there are adequate numbers of Navigators (including Navigators with lived experience of psychosocial disability) and these are well dispersed across the country
- additional funding is provided for Navigators to ensure that permanent roles are created and other services are not diminished
- a single national psychosocial disability specific Navigator access phone number exists where people can seek specific advice and get connected directly to their local Navigator
- Navigators provide direct and 'hands on' support to 'walk' with people throughout the entire evidence gathering and application process
- Navigators have the autonomy required to be flexible and to provide individualised supports.
- Navigators are physically located in community-based places that many people do and can access easily (GP clinics, health centres etc).
- Navigators have assertive outreach capacity – connecting with people not currently engaged with health or mental health services but who may be eligible for NDIS
- as a part of assertive outreach, Navigators host public events with hard-to-reach communities to introduce and raise awareness of the NDIS
- Navigators advise on the eligibility requirements, types of supports and services available through the NDIS, and progress of applications.
- Navigator roles are held accountable to standards of quality and service and there is an independently commissioned review of Navigator quality, impact and acceptability to stakeholders

Who should set up and manage these navigators?
Stakeholders repeatedly emphasised that the various 'navigator-type roles' that currently exist are constrained by the population served and interests of the organisation or agency within which they are embedded. Independence is a central part of this recommendation. This means that navigators should not be employees of the NDIA and should not be embedded within any individual NDIS service provider organisation. Potentially suitable organisations to set up and manage the navigators include:

> independent mental health consumer, carer and / or non-government peak bodies; advocacy organisations; Aboriginal Community Controlled Health organisations (ACCHOs) and multicultural mental health organisations that do not provide direct NDIS support package related services. Opportunities for collaboration and networking among navigators should be encouraged in sharing and supportive settings.

HAS THIS RECOMMENDATION BEEN MADE BEFORE? ARE THERE ALREADY PROPOSALS FOR ACTION?

The need for navigators to help people living with psychosocial disability to access the NDIS has been raised in several reports including: The Tune Review; Mind the Gap; The Productivity Commission Report on NDIS costs; and the Mental Health Australia (MHA) Report on the temporary Community Connectors initiative.

WHAT EXISTS ALREADY, AND WHY IS THIS NOT ENOUGH?

The research team and stakeholders have identified various and differing current and previous (but all temporary) NDIS navigation supports for people with psychosocial disability. Just one example was the short-term funded National Psychosocial Support Transition (NPS-T). The limitations of these existing navigation supports impact on equity of access and include:

- there are many existing, variably set up, variably funded, variably named, short-term navigators
- they are not independent – all have an agenda linked to funding and 'location'
- most are not wide enough in scope – no assertive outreach for example
- all have limited scope in terms of who they can support

MHA has done an excellent report on the previous Community Connectors initiative (https://mhaustralia.org/sites/default/files/docs/mental_health_australia_-_ndis_community_connectors_-_final_report_-_oct_2021.pdf) and this should inform the development of these roles. There is a current (and yet again short term) initiative (ACDC Project – CMHA) – learnings from this project should feed into the development of navigator roles.

> ## Recommendation 4: Cover out-of-pocket expenses
>
> **Create funding streams or models of reimbursement to ensure that people have equitable access to the experts required to provide evidence of psychosocial disability without incurring out-of-pocket expenses. ***
>
> A specific NDIS Medicare Benefits Schedule that provides enough 'incentive' for GPs, and private allied health/clinical providers to invest the additional time required to access historical evidence, conduct assessments and complete the NDIA required report without charging individuals a 'gap' cost.
>
> OR
>
> An alternative to creating an NDIS specific Medicare Benefits Schedule is to have a pool of funds for evidence of disability assessments available to individuals who are not supported by public mental health services. Individuals would access these funds in order to purchase the expert assessment they need (Navigators would manage and provide access to this funding source).
>
> Stakeholder support was found for both options. Those favouring the Medicare Benefits Schedule identified this option as being "more straightforward" and 'carrying less stigma' as reasons for their support. It was also suggested that a pool of funds would be, "be most beneficial for some participants...especially for the out-of-pocket costs."
>
> *Note. These out-of-pocket costs are not incurred by people accessing public mental health services because costs are covered through an all of governments agreement (Applied Principles and Tables of Support to Determine Responsibilities NDIS and other service – APTOS).*

HAS THIS RECOMMENDATION BEEN MADE BEFORE? ARE THERE ALREADY PROPOSALS FOR ACTION?

The need to address out-of-pocket expenses associated with applying to the NDIS is raised by both the Tune and the Mind the Gap reports.

WHAT EXISTS ALREADY, AND WHY IS THIS NOT ENOUGH?

Existing Medicare Benefits Schedules disincentivise GPs and other private practitioners (psychiatrists, occupational therapists, psychologists etc) from doing the assessments and paperwork required to provide evidence of a patient's disability and its functional impact. This is due to the rebate not covering the actual time taken. When they do agree to support the person's application by providing evidence, patients are charged gap-payments to cover the time required beyond the Medicare billable time. These costs can be very extensive and prohibit people from seeking evidence and thus applying for the NDIS.

Recommendation 5: Commission and fund an independent evaluation of the application process specifically for people with psychosocial disability

Independent evaluation of the impacts of a) recent legislative changes, b) the future implementation of the Recovery Framework and c) adoption and future implementation of the recommendations within this report, on the experiences of the NDIS application process for people living with psychosocial disability.

The evaluation needs to address the following questions:

- has the process become less adversarial and more collaborative: adopting a person-centred and recovery-oriented process that focuses on supports that can improve applicants' lives rather than on labels and deficits?
- has the process been re-designed with a focus on trauma-informed approaches?
- has the process been made as simple as possible and is there clear and understandable advice provided to support the person in the application process?
- has the process become more transparent so that people are clearly informed about why they were assessed as eligible or not?
- has the amount of evidence required been revised and minimised, especially evidence required to "prove" previous traumatic experiences?
- has the 'type' of evidence accepted by NDIA been reviewed and greater respect and recognition been afforded to evidence provided by community mental health workers, family members and others with extensive knowledge of a person but who are not currently accepted as an 'expert'?
- has the NDIA worked collaboratively with other agencies (e.g., Centrelink, Department of Veterans' Affairs) to address policy-related barriers that impede people's ability to gain access to historical information such as medical records from other departments (information access barriers are currently restricting clinicians from preparing required reports to support access requests)?
- have clearly measurable KPIs been set and monitored to ensure the application process is safe, timely and equitable?

This evaluation needs to be funded and independent with findings made publicly available.

HAS THIS RECOMMENDATION BEEN MADE BEFORE? ARE THERE ALREADY PROPOSALS FOR ACTION?

The need for improvements to the NDIS access process for people with psychosocial disability (and other disability types) has been repeatedly raised across all major reports. The NDIA have very recently (March 2022) established an Information Gathering for Access and Planning (IGAP) project. This initiative will involve working with people with disability and the broader disability community to co-design a new person-centred model of gathering information for access and planning decisions. It will be important for this stakeholder recommended evaluation to examine whether the needs of people with psychosocial disability were adequately recognised and addressed within the IGAP project.

WHAT EXISTS ALREADY, AND WHY IS THIS NOT ENOUGH?

Actions have happened at a policy and legislative level and the IGAP, while predominantly framed as a 'project to build a shared understanding', presents a possibility for positive action. In terms of legislation, the passing of the National Disability Insurance Scheme (Participant Guarantee and Other Measures Bill 2022) in late March is relevant. This Act includes two significant changes on psychosocial disability – the replacement of psychiatric condition with psychosocial disability in section 24 (1) (a) and revised wording at the end of section 24 that specifies that impairments related to psychosocial disability may be taken to be permanent despite the episodic or fluctuating nature of the impairments.

This stakeholder recommended independent evaluation should examine whether these recent legislative changes and the IGAP project result in an enhanced experience for people with psychosocial disability applying for the Scheme.

Recommendation 6: Co-develop (or identify) and co-deliver recovery and psychosocial disability training for a) NDIA staff, b) NDIA partner staff (LACs), and c) NDIS service provider staff (community managed/controlled organisations)

All staff within these 3 distinct workforces have access to recovery-oriented and trauma-informed psychosocial disability training and education that has been co-designed, co-developed and co-delivered with people with psychosocial disability.

- training needs to be co-designed, co-developed and co-delivered with people living with psychosocial disability.
- training needs to have a recovery-oriented focus, address stigma, discrimination and misunderstandings of psychosocial disability.
- due to high staffing turnover within the NDIA, NDIA partner and NDIS service provider organisations, education and training (for both service providing and administrative staff) needs to be adequately resourced and continuous.
- while we emphasise staff members who work at the NDIS application coalface given the focus of this project, the reputation of the broader NDIA and NDIS workforce filters down to those considering applying (and can create a barrier). Training is therefore important across the NDIA/NDIS workforce.
- training should be provided as a part of orientation or onboarding activities and on a regular basis to ensure that all staff remain up to date.
- training should be mandated – not optional – NDIA, NDIA partner, and NDIS service provider staff all need to be able to attend training in paid work time (with organisations funded to cover these costs to ensure no additional financial pressure is placed on organisations) or for individuals to be able to claim funding for the time involved in attending training to ensure viability.
- training should inform trainees about the support needed by people with cognitive impairment and intellectual disability as well as people with psychosocial disability who have a forensic history.
- training should be independently evaluated to assess its effectiveness.

HAS THIS RECOMMENDATION BEEN MADE BEFORE? ARE THERE ALREADY PROPOSALS FOR ACTION?

The Tune report and the Mind the Gap report recommended that recovery-oriented training in psychosocial disability be provided to NDIA staff. The same training, as well as supervision and communities of practice for all support workers working with psychosocial NDIS participants was a key recommendation of the Recovery Oriented Psychosocial Disability Support Project final report conducted by Mental Health Victoria (Mental Health Victoria (MHV), 2021, 'NDIS Recovery Oriented Psychosocial Disability Support Project: Final Report', Recovery Oriented Psychosocial Disability Support (ROPDS) Project – Growing National Workforce Capability, MHV, Victoria)

A commitment to the roll-out of recovery-oriented workforce training of NDIA and NDIA partner workforces is a key pillar of the Recovery Framework (Principle 6). It would be good to see this focus extend to the 3rd workforce – NDIS service provider organisations and their support workers who are engaged to work with psychosocial NDIS participants.

WHAT EXISTS OR IS HAPPENING ALREADY?

External to the NDIA and the NDIS, there have been a plethora of recovery-focused training opportunities and courses (for just some examples, see The Future Horizon report (pages 27-33 https://www.mhvic.org.au/images/documents/The-Future-Horizon.pdf).

Many of these existing, co-developed and co-delivered training opportunities could be adopted or adapted to suit.

WHAT IS WRONG WITH THESE CURRENT OPTIONS/PRACTICES? WHY ARE THESE NOT ENOUGH?

We could not find evidence of any co-developed and co-delivered training in psychosocial disability and recovery-oriented practice approaches being delivered to NDIA or NDIA Partner staff. Anecdotally some time-limited pockets of training have been delivered to NDIS support workers, but given the high staffing turn-over, this training needs to be continual.

Recommendation 7: Commission and fund an independent review of NDIA culture and workforce issues

Review the impact of implementing the NDIS Psychosocial Recovery-Oriented Framework agenda on NDIA staffing practice and cultural issues

Organisational leadership issues and cultural issues within the NDIA need to be addressed. An independent review is needed to critically examine and report on progress toward the NDIS Psychosocial Recovery-Oriented Framework agenda. The independent review needs to be a transparent, co-designed, collaborative process that partners with stakeholders, particularly people living with psychosocial disability. It needs to examine the following:

- have the cultural issues within NDIA that contribute to fear and reluctance for individuals to apply been identified?
- has there been an increase in the proportion of staff with lived experience of psychosocial disability?
- are employees with lived experience of psychosocial disability represented and accommodated at all levels of the organisation?
- are "enforcement" and "compliance" staff working from a trauma-informed, person-centred perspective?
- have recruitment/selection criteria changed to include, and value lived experience and attributes such as communication skills, respect, empathy and recovery orientation?
- are people with lived experience of psychosocial disability included as recruitment panel chairs and members?
- has a workforce strategy been developed to address staff retention so that knowledge and expertise is not lost?
- are NDIA complying with privacy and confidentiality requirements (including seeking appropriate and specific permissions for sharing information)?
- Has the NDIA designed, implemented, and publicised systems that encourage feedback and complaints and ensured that these are addressed and contribute to continual improvement?

Note: A detailed implementation plan for actioning the NDIS Psychosocial Recovery-Oriented Framework needs to be made publicly available.

HAS THIS RECOMMENDATION BEEN MADE BEFORE? ARE THERE ALREADY PROPOSALS FOR ACTION?

The Tune and Mind the Gap reports are just two examples of previous recommendations to address cultural issues existing within the NDIA workforce. Both called for training and increased representation and employment of people with a lived experience of psychosocial disability as central methods of enhancing culture.

WHAT EXISTS OR IS HAPPENING ALREADY, AND WHY IS THIS NOT ENOUGH?

The new, yet to be implemented, NDIS Psychosocial Disability Recovery-Oriented Framework sets an agenda to tackle and address workforce cultural issues: Principles 1 (Supporting personal recovery), 2 (Valuing lived experience) and 6 (A stronger NDIS recovery-oriented and trauma-informed workforce). When actioned, these should drive a positive cultural shift. However, an independently funded review is needed to provide a transparent evaluation of whether implementation of the Framework occurs and if so, whether this activity leads to an enhanced NDIA workforce culture.

CONCLUDING COMMENTS

This final phase of the project has again demonstrated the value of learning deeply from expert stakeholder wisdom and the expertise that stems from lived experience. Just as stakeholders provided a depth of understanding in relation to current barriers during phase 2 of this project, in this final phase stakeholders were clear about the solution-focused approaches that could, if implemented, redress these barriers. There are seven key recommendations that stakeholders identified as being essential to making a practical difference to the accessibility of the Scheme. Adding weight to their feasibility and value, these recommendations have been made previously across other key reports that examined NDIS access including for example the Tune Review and the 'Mind the Gap' reports.

Stakeholders are asking for more than policymakers' awareness of the barriers that deny much needed NDIS access. Stakeholders are calling for immediate investment in these practical actions to 'break down barriers' to accessing NDIS support. Doing so will improve the lives of many thousands of Australians living with psychosocial disability who are currently unable to seek the supports they need through the NDIS.

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APPENDICES

Appendix 1 – Demographic summary of survey (Phase 2) respondents

	All (n = 386)		Respondent responded as							
			Person / consumer (n = 125)		Family member (n = 45)		Worker (n = 212)		Person and Family member (n = 4)	
	n	%	n	%	n	%	n	%	n	%
Type of respondent										
Person	117	30.3								
Family member	44	11.4								
Worker	187	48.4								
Person and Family member	13	3.4								
Person and Worker	9	2.3								
Family member and Worker	10	2.6								
Person and Family member and Worker	6	1.6								
What is your age										
18 to 24	14	3.6	7	5.6	2	4.4	5	2.4	0	0.0
25 to 34	91	23.6	34	27.2	0	0.0	56	26.4	1	25.0
35 to 44	79	20.5	32	25.6	4	8.9	41	19.3	2	50.0
45 to 54	105	27.2	28	22.4	13	28.9	63	29.7	1	25.0
55 to 64	81	21.0	22	17.6	17	37.8	42	19.8	0	0.0
65 to 74	11	2.8	1	0.8	7	15.6	3	1.4	0	0.0
75 or older	5	1.3	1	0.8	2	4.4	2	0.9	0	0.0
Which Australian state or territory do you live / work in?										
New South Wales	105	27.2	41	32.8	14	31.1	50	23.6	0	0.0
Victoria	91	23.6	31	24.8	7	15.6	52	24.5	1	25.0
Queensland	34	8.8	15	12.0	7	15.6	10	4.7	2	50.0
South Australia	61	15.8	7	5.6	5	11.1	48	22.6	1	25.0
Western Australia	38	9.8	13	10.4	7	15.6	18	8.5	0	0.0
Tasmania	11	2.8	2	1.6	2	4.4	7	3.3	0	0.0
Northern Territory	3	0.8	1	0.8	0	0.0	2	0.9	0	0.0
Australian Capital Territory	41	10.6	15	12.0	3	6.7	23	10.8	0	0.0
Missing	2	0.5					2	0.9		
Where do you live? / Where do you mostly work										
Capital city	220	57.0	87	69.6	20	44.4	112	52.8	1	25.0

	All (n = 386)		Person / consumer (n = 125)		Family member (n = 45)		Worker (n = 212)		Person and Family member (n = 4)	
					Respondent responded as					
	n	%	n	%	n	%	n	%	n	%
Regional city	111	28.8	22	17.6	22	48.9	65	30.7	2	50.0
Rural or remote	52	13.5	16	12.8	3	6.7	32	15.1	1	25.0
Missing	3	0.8	0	0.0	0	0.0	3	1.4	0	0.0
Do you identify as Aboriginal and/or Torres Strait Islander?										
No	365	94.6	118	94.4	44	97.8	199	93.9	4	100.0
Yes	19	4.9	7	5.6	1	2.2	11	5.2	0	0.0
Missing	2	0.5	0	0.0	0	0.0	2	0.9	0	0.0
What is the proportion of the people that you work with who are Aboriginal and/or Torres Strait Islander?										
None							23	10.8		
Very few							158	74.5		
Around half							23	10.8		
Most							3	1.4		
All							4	1.9		
Missing							1	0.5		
Is English your main language?										
No	14	3.6	3	2.4	1	2.2	9	4.2	1	25.0
Yes	371	96.1	122	97.6	44	97.8	202	95.3	3	75.0
Missing	1	0.3	0	0.0	0	0.0	1	0.5	0	0.0
What is the proportion of people that you work with whose main language is not English?										
None							32	15.1		
Very few							130	61.3		
Around half							20	9.4		
Most							19	9.0		
All							10	4.7		
Missing							1	0.5		

Appendix 2 - Persons – Proportions and Ranking

Item	Yes	No	Not sure	Total	Percent[a]	Rank
Because I think that applying for the NDIS will be too stressful or traumatic.	114	11	4	129	91.2%	1
Because applying for the NDIS is too hard.	105	17	6	128	86.1%	2
Because it is hard to know what evidence I need to be able to apply.	104	19	6	129	84.6%	3
Because applying for the NDIS is too confusing.	97	25	7	129	79.5%	4
Because my mental health is not great at the moment and this makes it hard for me to cope with applying for the NDIS.	96	28	5	129	77.4%	5
Because I have had previous experiences of trauma and I worry that applying will re-traumatise me.	83	40	6	129	67.5%	6
Because it costs too much to get someone like a doctor to do an assessment to prove that I have a permanent psychosocial disability.	78	40	11	129	66.1%	7
Because I do not know about any support services that can help me to apply.	78	45	6	129	63.4%	8
Because services do not have the time to help me to apply for the NDIS.	54	48	27	129	52.9%	9
Because I do not have family or friends who can help me with an NDIS application.	63	62	4	129	50.4%	10
Because I do not really understand what the NDIS is about and how it can help me.	59	62	8	129	48.8%	11
Because I do not always use mental health services, so it is hard to get someone to write a letter to prove I have a permanent psychosocial disability.	58	65	6	129	47.2%	12
Because I do not trust government agencies like the NDIS agency.	50	59	20	129	45.9%	13
Because services do not know how to help me to apply for the NDIS.	45	57	27	129	44.1%	14
Because I do not think the NDIS will improve my supports.	47	63	19	129	42.7%	15
Because other people need the NDIS support more than I do.	50	73	6	129	40.7%	16
Because I started applying, but stopped because I found it too stressful.	51	75	3	129	40.5%	17
Because there is no help to apply for the NDIS that respects my LGTBQI+ identity.	26	39	17	82	40.0%	18
Because applying for the NDIS is not a priority for me right now as I have other more urgent priorities.	41	78	10	129	34.5%	19
Because I cannot find out how to apply for the NDIS.	39	79	11	129	33.1%	20

Item	Yes	No	Not sure	Total	Percentᵃ	Rank
Because there is no one who can write a letter to prove I have a psychosocial disability.	36	82	11	129	30.5%	21
Because if I do talk to my doctor about the NDIS, I worry that they will treat me differently.	31	87	11	129	26.3%	22
Because my doctor or mental health worker does not understand the NDIS.	29	82	18	129	26.1%	23
Because there is no help to apply for the NDIS that respects and understands my culture.	17	55	9	81	23.6%	24
Because I do not think my doctor or mental health worker understands what a psychosocial disability is.	23	95	11	129	19.5%	25
Because my friends or my family do not think I should apply for the NDIS.	20	95	14	129	17.4%	26
Because I do not really know what a psychosocial disability is.	21	100	8	129	17.4%	27
Because my doctor or mental health worker does not think that I should apply for the NDIS.	14	95	20	129	12.8%	28
Because I do not want to be labelled as a person with a disability.	14	104	11	129	11.9%	29
Because I did not know that the NDIS existed until recently.	15	114	0	129	11.6%	30
Because my doctor or mental health worker does not think I have a permanent psychosocial disability.	10	104	15	129	8.8%	31
Because my mental illness or psychosocial disability, is not permanent.	6	111	12	129	5.1%	32
Because I do not have a psychosocial disability.	6	113	10	129	5.0%	33
Because I do not have a mental illness	4	119	6	129	3.3%	34
Because I have enough services already.	4	125	0	129	3.1%	35

Notes:
Colour coding explanation: Red 100% to 75% of respondents agree; Orange 74.9% to 50% of respondents agree; Yellow 49.9% to 25% of respondents agree; Grey 24.9% to 0% of respondents agree
ᵃ This is the percentage of respondents reporting "Yes". This figure excludes responses of "Not sure".

Appendix 3 - Family Member – Proportions and Ranking

Item	Yes	No	Not sure	Total	Percentª	Rank
Because applying for the NDIS is too hard for them.	45	1	3	49	97.8%	1
Because they think that applying for the NDIS will be too stressful or traumatic.	41	1	7	49	97.6%	2
Because applying for the NDIS is too confusing for them.	43	3	3	49	93.5%	3
Because it is hard to know what evidence they need to be able to apply.	38	5	5	48	88.4%	4
Because their mental health is not great at the moment and this makes it hard for them to cope with applying for the NDIS.	40	7	2	49	85.1%	5
Because it is hard to find out how to help them apply for the NDIS.	36	11	2	49	76.6%	6
Because they do not really understand what the NDIS is about and how it can help them.	32	14	3	49	69.6%	7
Because services do not have the time to help them to apply for the NDIS.	25	13	10	48	65.8%	8
Because they have had previous experiences of trauma and they worry that applying will re-traumatise them.	27	15	7	49	64.3%	9
Because it costs too much to get someone like a doctor to do an assessment to prove that they have a permanent psychosocial disability.	26	18	5	49	59.1%	10
Because they do not always use mental health services, so it is hard to get someone to write a letter to prove that they have a permanent psychosocial disability.	27	19	3	49	58.7%	11
Because they have had previous experiences of trauma and I worry that applying will re-traumatise them.	25	18	6	49	58.1%	12
Because I do not know about any support services that can help them to apply.	25	20	4	49	55.6%	13
Because I think that applying for the NDIS will be too stressful or traumatic for them.	26	21	2	49	55.3%	14
Because applying for the NDIS is not a priority for them right now as they have other more urgent priorities.	25	21	3	49	54.3%	15
Because they do not trust government agencies like the NDIS agency.	22	19	8	49	53.7%	16
Because services do not know how to help them to apply for the NDIS.	20	18	11	49	52.6%	17
Because they do not think the NDIS will improve their supports.	21	23	5	49	47.7%	18
Because there is no one who can write a letter to prove they have a psychosocial disability.	17	22	10	49	43.6%	19
Because they will not let me help them to apply.	20	26	3	49	43.5%	20
Because they started applying on their own, but stopped because they found it too stressful.	20	27	2	49	42.6%	21
Because my mental health is not great at the moment and this makes it hard for me to help them to apply for the NDIS.	20	28	1	49	41.7%	22
Because they do not really know what a psychosocial disability is.	17	26	6	49	39.5%	23
Because their doctor or mental health worker does not understand the NDIS.	15	29	5	49	34.1%	24

Item	Yes	No	Not sure	Total	Percent[a]	Rank
Because their doctor or mental health worker will not support them to apply.	14	29	6	49	32.6%	25
Because I started helping them to apply, but stopped because they found it too stressful.	14	34	1	49	29.2%	26
Because there is no help to apply for the NDIS that respects and understands our/their culture.	6	15	3	24	28.6%	27
Because I started helping them to apply, but stopped because I found it too stressful.	13	35	1	49	27.1%	28
Because they think their mental illness or psychosocial disability is not permanent.	12	34	3	49	26.1%	29
Because they do not believe they have a psychosocial disability.	12	35	2	49	25.5%	30
Because they did not know that the NDIS existed until recently.	12	35	2	49	25.5%	30
Because they think other people need the NDIS support more than them.	11	35	3	49	23.9%	32
Because I do not think the NDIS will improve their supports.	9	37	3	49	19.6%	33
Because I do not trust government agencies like the NDIS agency.	9	38	2	49	19.1%	34
Because their doctor or mental health worker does not understand what a psychosocial disability is.	8	34	7	49	19.0%	35
Because they do not believe they have a mental illness.	9	39	1	49	18.8%	36
Because there is no help to apply for the NDIS that respects their LGTBQI+ identity.	3	17	7	27	15.0%	37
Because I do not really understand what the NDIS is about and how it can help them.	7	41	1	49	14.6%	38
Because their doctor or mental health worker does not think they have a permanent psychosocial disability.	6	38	5	49	13.6%	39
Because their doctor or mental health worker does not think that they should apply for the NDIS.	5	36	7	48	12.2%	40
Because their other friends or family do not think they should apply for the NDIS.	4	38	7	49	9.5%	41
Because I do not think they should apply for the NDIS.	3	44	2	49	6.4%	42
Because I do not really know what a psychosocial disability is.	3	45	1	49	6.3%	43
Because I think that their mental illness or psychosocial disability is not permanent.	2	46	1	49	4.2%	44
Because I did not know that the NDIS existed until recently.	2	47	0	49	4.1%	45
Because I do not believe they have a psychosocial disability.	1	47	1	49	2.1%	46
Because they have enough services already.	1	47	1	49	2.1%	46

Notes:
Colour coding explanation: Red 100% to 75% of respondents agree; Orange 74.9% to 50% of respondents agree; Yellow 49.9% to 25% of respondents agree; Grey 24.9% to 0% of respondents agree

[a] This is the percentage of respondents reporting "Yes". This figure excludes responses of "Not sure".

Appendix 4 - Workers – Percentage agree and Ranking

Item	N[a]	Number agree[b]	Percent agree[c]	Rank
Because applying for the NDIS is too hard for them.	212	197	92.9%	1
Because applying for the NDIS is too confusing for them.	212	189	89.2%	2
Because it is hard for them to know what evidence they need to be able to apply.	212	177	83.5%	3
Because it is hard for them to find out how to apply for the NDIS.	212	169	79.7%	4
Because they do not know about support services that can help them to apply.	210	167	79.5%	5
Because it costs too much for people to get a specialist assessment to prove that they have a permanent psychosocial disability.	212	163	76.9%	6
Because they think that applying for the NDIS will be too stressful or traumatic.	212	163	76.9%	6
Because their mental health is not great at the moment and this makes it hard for them to cope with applying for the NDIS.	212	157	74.1%	8
Because they do not really understand what the NDIS is about and how it can help them.	212	148	69.8%	9
Because they started applying, but stopped because they found it too stressful.	212	129	60.8%	10
Because they do not always or consistently use mental health services, so it is hard to get specialists to write a letter to prove that they have a permanent psychosocial disability.	212	129	60.8%	10
Because there is no specialist available that can write a letter to prove they have a psychosocial disability.	212	128	60.4%	12
Because it is hard for support services to know what evidence people need to be able to apply.	212	116	54.7%	13
Because they do not really know what a psychosocial disability is.	212	112	52.8%	14
Because support services do not have the time to help them to apply for the NDIS.	211	102	48.3%	15
Because their doctors or mental health specialists do not understand the NDIS.	212	102	48.1%	16
Because they have had previous experiences of trauma and they worry that applying will re-traumatise them.	212	100	47.2%	17
Because they do not trust government agencies like the NDIS agency.	212	88	41.5%	18
Because applying for the NDIS is not a priority for them right now as they have other more urgent priorities.	211	83	39.3%	19
Because there is no help to apply for the NDIS that respects and understands their culture.	199	78	39.2%	20
Because they did not know that the NDIS existed until recently.	211	82	38.9%	21
Because support services do not know how to help people with psychosocial disability to apply for the NDIS.	212	78	36.8%	22
Because they do not think the NDIS will improve their supports.	212	78	36.8%	22
Because they do not believe they have a psychosocial disability.	211	60	28.4%	24

Item	N[a]	Number agree[b]	Percent agree[c]	Rank
Because they have had previous experiences of trauma and support services worry that applying will re-traumatise them.	212	56	26.4%	25
Because support services started helping them to apply, but stopped because their support worker left their job.	212	54	25.5%	26
Because there is no help to apply for the NDIS that respects their LGTBQI+ identity.	194	49	25.3%	27
Because their doctors or mental health specialists do not understand what a psychosocial disability is.	212	52	24.5%	28
Because support services think that applying for the NDIS will be too stressful or traumatic for them.	211	48	22.7%	29
Because they do not accept or believe that their mental illness or psychosocial disability is permanent.	211	46	21.8%	30
Because they think other people need the NDIS support more than them.	212	44	20.8%	31
Because they do not believe they have a mental illness.	212	38	17.9%	32
Because their mental health specialists do not think they have a permanent psychosocial disability.	212	36	17.0%	33
Because their family members do not trust government agencies like the NDIS agency.	212	34	16.0%	34
Because they do not want support services to help them to apply.	212	33	15.6%	35
Because their mental health specialists do not think that they should apply for the NDIS.	211	24	11.4%	36
Because their friends or family do not believe they have a psychosocial disability.	212	22	10.4%	37
Because their friends or family do not think they should apply for the NDIS.	212	16	7.5%	38
Because they have enough services already.	212	5	2.4%	39

Notes:

Colour coding explanation: Red 100% to 75% of respondents agree; Orange 74.9% to 50% of respondents agree; Yellow 49.9% to 25% of respondents agree; Grey 24.9% to 0% of respondents agree

[a] The overall number of workers who responding to this item (excluding those who responded "not applicable")

[b] The number of respondents s reporting "Often" or "Very often / Always" for each item.

[c] This is the percentage of respondents reporting "Often" or "Very often / Always" for each item. This figure excludes responses of "Not applicable".

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