NDIS access barriers for people living with psychosocial disability:

Finding from national survey and interviews

FINAL REPORT March 2022

THE UNIVERSITY OF SYDNEY

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The Team:

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, 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 an associate 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 and thanks:

The extensive engagement of so many people, sharing their experiences, knowledge and perspectives has helped 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 thank the almost 400 people living with mental distress, mental illness or psychosocial disability, their family and friends and workers who advocate for and strive to support people to have access to the opportunities needed to live the lives they want and deserve.

Thank you also to the National Mental Health Commission for funding and supporting this project.

EXECUTIVE SUMMARY

Background:

The primary objective of the NDIS is to provide Australians living with disability with the reasonable and necessary supports needed to live an engaged and productive life. The NDIS is designed to support people with all types of disability including those living with psychosocial disability. However, NDIA 2022 quarterly report to COAG figures, as well as independent reports, evidence that many people living with psychosocial disability are still not applying to access NDIS support. Therefore, it is timely to examine reasons for this ongoing poor engagement and consider the barriers that need addressing to turn this low participation rate around.

Aim:

The overall aims of this project were to 1. Understand the barriers to applying to the NDIS for people living with psychosocial disability, and 2. To co-design potential solutions to these identified barriers with stakeholders.

Approach:

The project involves three phases and this report synthesises the findings from Phase 2.

Phase 1 is completed and involved a scoping review in which we identified and synthesised the existing literature reporting any barriers to applying for the NDIS for people living with psychosocial disability. Findings from Phase 1 informed Phase 2.

Phase 2 involved engaging stakeholders in sharing their experiences and perspectives via an online survey. The survey contained a list of potential barriers for people to rate in terms of whether they or their family member experienced this barrier and how often it was a barrier for people who workers supported. The survey also contained open ended questions for people to tell us in their own words what the main barriers are to applying for the NDIS. The results of this survey are the focus of this report.

Phase 3 will commence following this report. In this final phase we will engage with expert stakeholders to collaboratively and constructively identify pragmatic and real solutions to address and reduce the barriers that are identified within this report. These solutions will be drawn together into a set of expert stakeholder recommendations.

Findings:

Almost 400 people, 117 people living with mental distress, mental illness or psychosocial disability themeselves, 44 family and friends, and 187 mental health advocates and practitioners participated in the survey. An additional 38 people identified as belonging to multiple categories. Respondants respondents came from all states and territories.

The quantitative findings – ranking of barriers in terms of frequency

The main quantitative results from the survey are presented in the table below. This table includes all items that were agreed to by 75% or more respondents from any of the three respondent groups. Items that had very high levels of agreement across all groups included that the NDIS application process was perceived to be stressful, too hard, and too confusing, as well as it being difficult to identify what evidence was required. Another item that was very strongly affirmed was that individuals' mental health at the time impeded their ability to cope with the application process. Other items that were affirmed by over 75% of workers are also listed in the table. The lower agreement proportions from the person and family / friend respondent groups to these items is likely to be related to the fact that individuals facing these barriers to applying for the NDIS are likely to have not responded to this survey.

Perhaps surprisingly, there were few significant differences between metropolitan (Capital city) respondents and those in regional, rural and remote areas.

Table 1. Barriers rated highly by all respondent groups

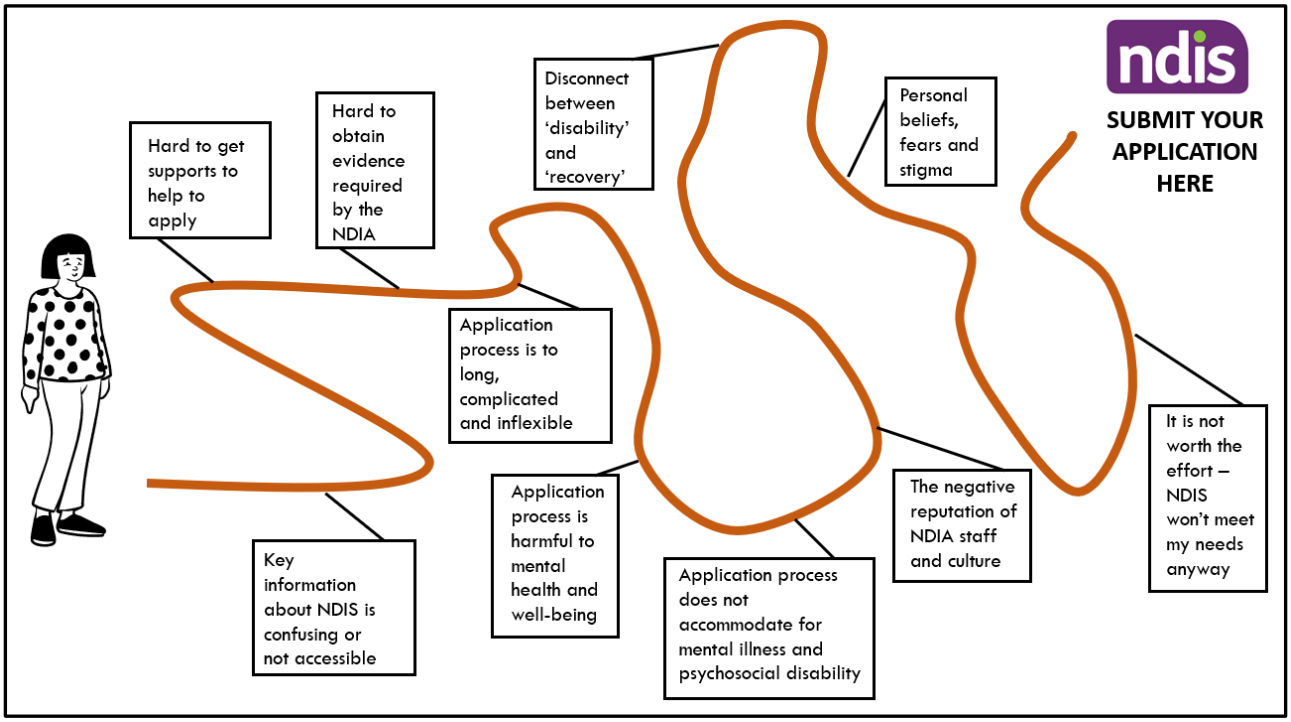
	Person		Family / Friend		Worker	
Item[a]	**Percent[b]**	**Rank[c]**	**Percent[d]**	**Rank[e]**	**Percent[f]**	**Rank[g]**
Because I think that applying for the NDIS will be too stressful or traumatic.	91.2%	1	97.6%	2	76.9%	6
Because applying for the NDIS is too hard.	86.1%	2	97.8%	1	92.9%	1
Because it 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 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 I cannot find out how to apply for the NDIS.	33.1%	20			79.7%	4

Notes: for full explanatory text, please see the full table presented in the main section of the report.

The Qualitative findings – what people said

There were ten overarching themes identified from the analyses of qualitative data – what people said. These ten themes are shown in the figure below and summarised following that. They are detailed further within the body of the report.

Figure 1. Barriers preventing people from applying to the NDIS



Themes in a little more detail:

1. KEY INFORMATION ABOUT NDIS IS CONFUSING OR NOT ACCESSIBLE

These barriers related to : a. Not knowing that that NDIS exists; b. Who would or would not be eligible; c. What evidence is needed; d. What supports and services would and wouldn't NDIS provide if eligible; e. What steps need to be navigated in the process of applying; f. How to get help to apply, and g. NDIA communication and language is confusing – including the website.

> *"I didn't think mental illness was covered by NDIS" [P107]*
>
> *"I did not know that it existed" [P002]*

2. HARD TO GET SUPPORTS TO HELP TO APPLY

> *"No organisations that will help with application process" [W196].*
>
> *"And services that could help, put you on a waiting list that can take weeks and months" [F048].*

These barriers related to : 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 and 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.

3. HARD TO OBTAIN EVIDENCE REQUIRED BY THE NDIA

These barriers related to : 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 f. Costs associated with gathering evidence are prohibitive.

> *"my Psychiatrist treats me as if they don't have the time to complete an application" [P024]*
>
> *"Lack of long-term medical evidence if people are transient" [W208].*

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

These barriers related to : a. Process is too long or too complicated, and b. Process is inflexible and impersonal.

> *"It's too overwhelming to do myself" [P085].*
>
> *"The monumental amount of effort involved in the application process is my primary reason for not persevering" [P016].*

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

These barriers related to : 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.

> *"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].*

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

These barriers related to : 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.

> *"not having capacity either emotionally and/or cognitively" [W011].*
>
> *"constant paranoia" [F025].*

7. THE NEGATIVE REPUTATION OF NDIA STAFF AND CULTURE

These barriers related to : a. Staff are unqualified and do not understand psychosocial disability – particularly its episodic nature; b. Staff are not respectful and lack empathy; c. Staff are inconsistent and incompetent; d. Lack of action by NDIA to address access barriers flagged by the community, and e. An inflexible NDIA culture that doesn't consult.

> *"Staff at NDIA (in my rural town experience) can be condescending towards people and can become easily frustrated with clients… Staff need to have empathy and people skills…" [W075].*
>
> *"Lack of consultation with MH services has created poor fit with service user needs" [W076].*

8. DISCONNECT BETWEEN 'DISABILITY' AND 'RECOVERY'

> *"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…" [W071].*

9. PERSONAL BELIEFS, FEARS AND STIGMA

These barriers related to : a. I don't deserve NDIS – I am not as needy as others; b. People/they don't identify or agree that they have a disability or mental illness; c. I fear the consequences of engaging with government agencies or having an NDIS plan, and d. I fear being labelled or judged by others.

> *"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].*
>
> *"People worry that it will affect their pension" [W169]*
>
> *"I'd be labelled as a bludger according to my family" [P060].*

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

These barriers related to: 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.

> *"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].*

Concluding comments:

This report evidences the bredth and depth of barriers that are still being experienced by Australians living with mental ill health when they consider or are encouraged by others to apply for the psychosocial stream of the NDIS. We are cognisant of the many recent efforts being made by the NDIA to address these barriers, including the very recent NDIS Recovery Framework. However, the amount of engagement in this survey (almost 400 people) and the testimonies and experiences shared evidence that more needs to be done. The next step of this project will be to engage with the same stakeholders – people living with mental distress, mental illness or psychosocial disability themeselves, their family and friends and mental health advocates, and practitioners. Together, we will develop stakeholder identified and prioritised solutions to many of the barriers identified within this report.

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Acknowledgements

We would like to warmly thank the many people with psychosocial disability who shared their experiences and perspectives regarding NDIS access issues. Thank you also to the advocacy and service workers (formal supports) as well as family and friends (informal supports) who gave up their time to inform this study.

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 who completed a survey

Language

Language is important and often contentious. Here we would like to clarify the language we have chosen to use throughout this report.

When referring collectively to those who completed the survey, we have used the terms *respondent or respondents*. This has been used rather than participants to distinguish between survey completers and NDIS participants (people who have an NDIS plan).

When referring to someone living with psychosocial disability, mental illness or mental distress, we have used the word *person*. *Family members and friends* are referred to as that, rather than carers. Finally, we have collectively referred to those who are paid to support people or advocate for them as *workers*.

PROJECT BACKGROUND AND AIMS:

Context

Many Australians who are living with psychosocial disability are not applying to access NDIS support. It is therefore timely to examine the reasons for this ongoing poor engagement with the Scheme. Our team at the University of Sydney was engaged to undertake and co-produce a comprehensive examination of the NDIS access issues facing people living with psychosocial disability.

This project involves three phases. The first phase of this project involved undertaking a scoping review of the literature that included peer-reviewed publications and grey literature (e.g., reports, newspaper articles). This scoping review addressed the following question: What are the barriers to assessing the NDIS for people living with psychosocial disability? Eleven themes were identified in the review. These included:

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

These themes informed the second stage of this project, upon which this report is based. This second phase involved the development of a national survey to seek the perspectives and experiences of people who live with psychosocial disability, mental ill health or mental distress, their family/friends, and people working in an advocacy or service organisation that supports clients with psychosocial disability to apply for the NDIS. It is the results of this survey that are the focus of this report.

Aims

The aim of the survey (Phase 2) was to understand key stakeholder perspectives on the barriers to accessing the NDIS for people living with psychosocial disability. The aim for Phase 3, that will follow over the next few months, is to co-design with key stakeholders a set of recommendations to address the NDIS access barriers for people living with psychosocial disability identified within this report.

METHODS

National online survey

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 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 basic 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 that 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.

RESPONDENTS

There were 386 people who participated in the online survey. Self-reported demographic details are provided in Figures 2 to 5 below. Further details about respondent demographics are available in Appendix 1.

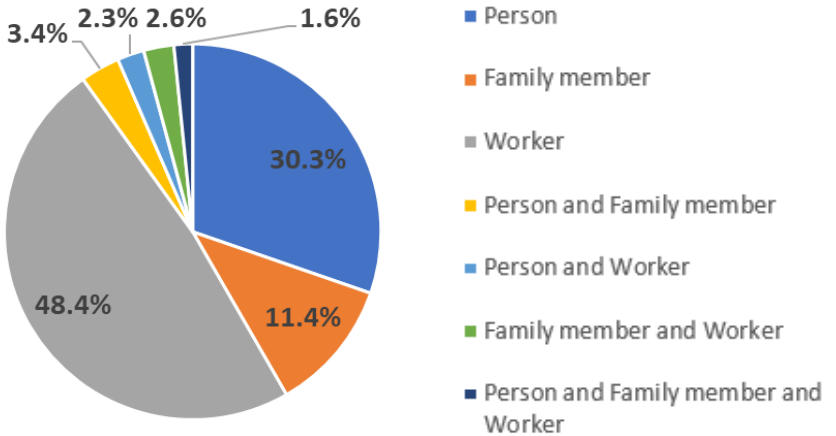

Figure 2. Respondents by type, %

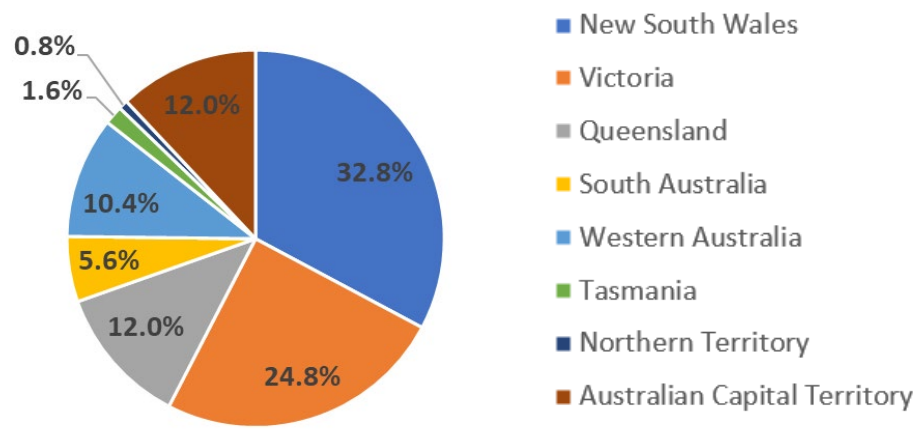

Figure 3. Person respondents by state, %

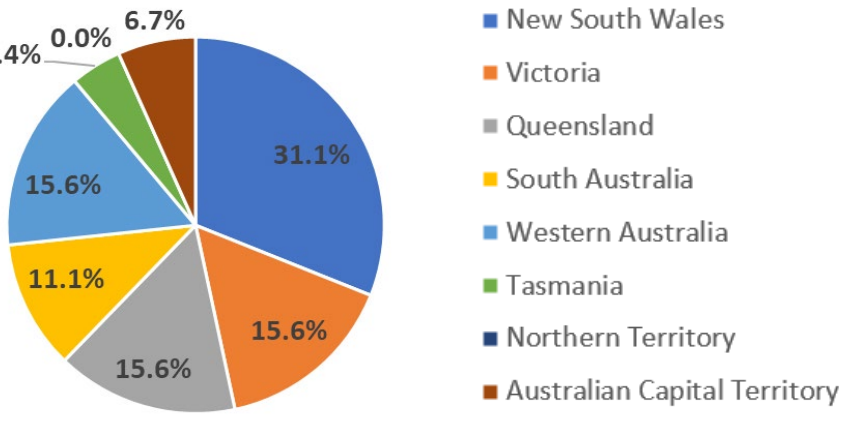

Figure 4. Family member respondents by state, %

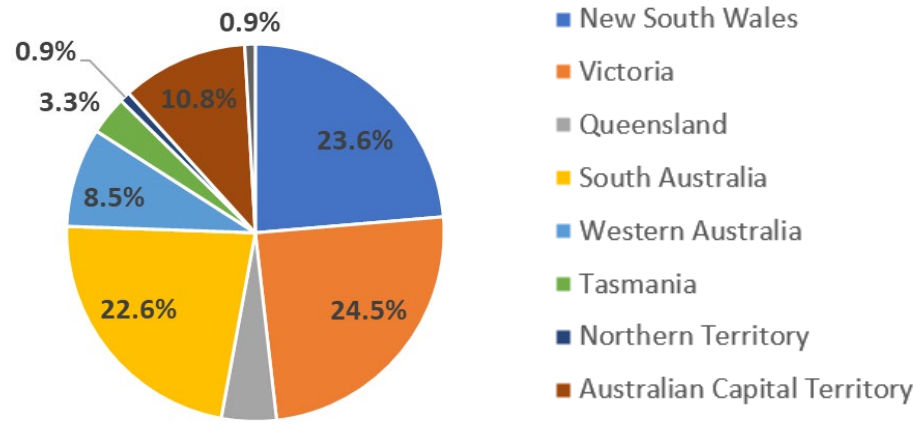

Figure 5. Worker respondents by state, %

FINDINGS

Overall Quantitative Findings

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

Table 2 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 1, a full set of results for each respondent group is presented in Appendices 2 to 4.

Table 2. Person/family-friend/worker - proportions and rankings

	Person		Family / Friend		Worker	
Item[a]	**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

	Person		Family / Friend		Worker	
Item[a]	**Percent[b]**	**Rank[c]**	**Percent[d]**	**Rank[e]**	**Percent[f]**	**Rank[g]**
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
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.

[R] Respondents who lived / worked in **regional, rural or remote areas** were significantly more likely to affirm this as a barrier as compared to respondents who lived / worked in metropolitan 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 wealthy of written data to described what stops some people, or makes it difficult for some people, to apply for the psychosocial disability stream of the NDIS.

A thematic analysis of responses to open survey questions 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 2 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 3. Person/family-friend/worker - proportions and ranking (theme 1 related)

	Person		Family / Friend		Worker	
Item	**Percent**	**Rank**	**Percent**	**Rank**	**Percent**	**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 result 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 3 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 4. Person/family/friend/worker - proportions and ranking (theme 2 related)

	Person		Family / Friend		Worker	
Item	**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 applying stalling or stopping. Others 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 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 '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 5. 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 and 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 gather 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 **previously 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 requires applicants to engaging 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 5 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 6. 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 **longwinded 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 6 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 7. Person/family-friend/worker - proportions and ranking (theme 5 related)

	Person		Family / Friend		Worker	
Item	**Percent**	**Rank**	**Percent**	**Rank**	**Percent**	**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 7 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 8. Person/family-friend/worker - proportions and rankings (theme 6 related)

	Person		Family / Friend		Worker	
Item	**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 people's 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 were relevant to the 'The negative reputation of NDIA staff and culture' theme.

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 8 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 9. 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, ie: 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 9 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 10. Person/family-friend/worker - proportions and ranking (theme 9 related)

	Person		Family / Friend		Worker	
Item	**Percent**	**Rank**	**Percent**	**Rank**	**Percent**	**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 10 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 11. 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 report evidences the bredth and depth of barriers that are still being experienced by people living with mental ill health when they consider or are encouraged by others to apply for the psychosocial stream of the NDIS. We are cognisant of the many recent efforts being made by the NDIA to address these barriers, including the very recent NDIS Recovery Framework. However, the amount of engagement in this survey (almost 400 people) and the testimonies and experiences shared evidence that more needs to be done.

The next step of this project will be to engage with the same stakeholders – people living with mental distress, mental illness or psychosocial disability themeselves, their family and friends and mental health advocates, and practitioners or workers. Together, we will develop stakeholder identified and prioritised solutions to many of the barriers identified within this report.

Appendices

Appendix 1 – Demographic summary of survey respondents

			Respondent responded as							
	All (n = 386)		**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		

			Respondent responded as							
	All (n = 386)		Person / consumer (n = 125)		Family member (n = 45)		Worker (n = 212)		Person and Family member (n = 4)	
	n	%	n	%	n	%	n	%	n	%
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
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	Percent[a]	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	Percent[a]	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**

Item	Yes	No	Not sure	Total	Percent[a]	Rank
Because their doctor or mental health worker does not understand the NDIS.	15	29	5	49	34.1%	**24**
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

[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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