Breaking down Barriers:

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

EXECUTIVE SUMMARY
The University of Sydney Team

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

Funders:

The National Mental Health Commission
www.mentalhealthcommission.gov.au

Acknowledgement of Expert Stakeholders:

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

Suggested citation for report and download link:


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Background:

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

Aims:

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

Approach:

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

Findings:

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

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

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

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

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

The quantitative findings – ranking of barriers in terms of frequency

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

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

- Because I think that applying for the NDIS will be too stressful or traumatic.
- Because applying for the NDIS is too hard.
- Because it is hard to know what evidence I need to be able to apply.
- Because applying for the NDIS is too confusing.
- Because my mental health is not great at the moment and this makes it hard for me to cope with applying for the NDIS.

In addition to the 5 barriers listed above, the “worker” respondent group (individual workers and organisations) identified three additional key barriers that were affirmed by over 75% of respondents. These were:

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

The Qualitative findings – what people said

As well as rating the list of barriers developed from the literature, stakeholders were asked to tell us what barriers were missing or not mentioned. Qualitative comments also provided more detail about the barriers developed from the literature. There were ten overarching themes identified from the analyses of these quantitative and qualitative datasets. These ten themes are shown in Figure 1 below. Each of these themes are detailed and multi-faceted. They are provided in-depth and with example quotes within this report.
Phase 3 - stakeholder identified recommendations to redressing NDIS access barriers for people with psychosocial disability

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

The seven key recommendations developed from stakeholder suggested solutions are summarised in Figure 2, and Table 3 below. Figure 2 depicts the stakeholder proposed barriers and the aligned recommendations that each address.
Table 3. Brief summary of Recommendations (see alignment to barriers in figure above and further detail in the body of this report)

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

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

**Concluding Comments:**

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