National Mental Health Commission
December 2022

Joint Standing Committee Inquiry
Submission on the Capability and Culture of the National Disability Insurance Agency (NDIA)

Australian Government
National Mental Health Commission

Introduction

The National Mental Health Commission (the Commission) provides cross-sectoral leadership on policy, programs, services and systems that support better mental health and social and emotional wellbeing in Australia. There are three main strands to the Commission's work: monitoring and reporting on Australia's mental health and suicide prevention systems; providing independent advice to government and the community; and acting as a catalyst for change.

The Commission's underpinning principle is the Contributing Life Framework. This framework acknowledges that a fulfilling life requires more than just access to health care services. It means that people who experience mental illness can expect the same rights, opportunities, physical and mental health outcomes as the wider community.

As developed by the Commission, Vision 2030 – a national blueprint for mental health and wellbeing in Australia - promotes the opportunity for people to be mentally well in their full social context. This includes supports for navigation, connecting, planning and coordination care, as well as psychosocial supports for carers and family members. Vision 2030 recognises the National Disability Insurance Agency (NDIA) as an important facilitator within the current mental health system to enable access and funding for many of the identified core components of care.

The Commission welcomes the opportunity to provide a submission to the Joint Standing Committee on Capability and Culture of the NDIA. This response presents a range of key issues and opportunities to specifically address the Terms of Reference published by the Committee. The Commission's feedback in this submission is focused on:

- People living with a psychosocial disability, while also recognising that more broadly, mental health experiences of living with a disability require greater integration in Australia's service and support systems.
- Increased integration of Lived Experience (peer) workers within the NDIA, particularly for people with psychosocial disability and providing increased support to navigate the National Disability Insurance Scheme (NDIS).
- Reducing stigma and discrimination among the workforce, recognising mental ill-health related stigma and discrimination remain barriers to people accessing appropriate and adequate care and supports.

Culture, including the policies, practices and structures, of the NDIA has a direct effect on the implementation, performance and people's interactions with the NDIS. To ensure that people with psychosocial disability and mental illness are treated with dignity, respect and value, and are able to access crucial and necessary supports, further work is required. The NDIA must ensure its culture and practices:

- are based on a model of disability that includes the impacts of mental ill-health, distress and trauma
- recognises, values and embeds parity of psychosocial disability with other forms of disability, including through systems, processes and staff knowledge and skills
- recognises and aligns in-practice with the potentially episodic nature of mental ill-health, trauma and distress, and recovery principles
- does not further contribute to people's experience of stigma and discrimination.

Should you wish to discuss this submission in further detail, please contact Alex Hains, Executive Director, Policy at alex.hains@mentalhealthcommission.gov.au.

Terms of Reference

The Joint Standing Committee will inquire into and report on the implementation, performance, governance, administration and expenditure of the NDIS, with particular reference to:

- the capability and culture of the NDIA, with reference to operational processes and procedures, and nature of staff employment
- the impacts of NDIA capability and culture on the experiences of people with disability and NDIS participants trying to access information, support and services from the Agency; and
- any other relevant matters.

The Commission's Response

A. The capability and culture of the NDIA, with reference to operational processes and procedures, and nature of staff employment

The Commission recommends that greater focus and attention is given to staff employment to attract and retain a suitably skilled and qualified workforce capable of understanding the needs of people with lived and living experience of mental ill-health, including people with psychosocial disability.

A network of person-centred supports can better assist people with psychosocial disability to live contributing lives. Ways this could be achieved include:

- Greater representation of people with lived or living experience of psychosocial disability and NDIS participants on relevant committee and reference groups. This ensures consistency and clarity of what lived experience work is and how to recruit Lived Experience (peer) workers to support NDIS participants.
- Greater inclusion of a Lived Experience (peer) workforce, including a commitment to training for workplaces to ensure the safety and inclusion of members of the Lived Experience (peer) workforce.
- Embedding rights-based workforce training that explicitly includes stigma and discrimination reduction education.

Cultural change being supported by lived experience leadership

The *United Nations Convention on the Rights of Persons with Disabilities*, to which Australia has been a signatory since 2009, states that people with lived experience shall be consulted and actively engaged in developing legislation and policies that concern people with disability. More work is needed to further embed lived experience in decision-making or advisory roles to help lead transformations of mindsets, culture, and practice in the NDIA and NDIS.[1,2,3]

In its submission on the proposed NDIS legislative improvements and the Participant Service Guarantee (October 2021), the Commission recommended:

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[1] University of Melbourne School of Population and Global Health. MISRed Report: Reducing stigma and discrimination towards people with mental illness, Final summary and recommendations. 2021 (Apr).
[2] National Mental Health Commission. Workshop insights: Addressing stigma and discrimination in employment. Australian Government. 2021 (Nov).
[3] Loughhead M, Hodges E, McIntyre H, Procter NG. A Roadmap for strengthening lived experience leadership for transformative systems change in South Australia, SA Lived Experience Leadership and Advocacy Network and University of South Australia, Adelaide. 2021.

- the inclusion of lived experience in both co-design processes and Board membership, including lived experience of psychosocial disability.
- the appointment of more than one Board member with lived experience, with at least one member having lived experience of psychosocial disability.
- the NDIA to work with peak mental health bodies and consumer and carer representative organisations to ensure the adequate participation of mental health consumers and carers when co-designing any aspect of the psychosocial disability stream.

Integration of Lived Experience (peer) workers to better support and improve access to the NDIS for people with mental illness and psychosocial disabilities

The Commission recommends that as part of the ongoing implementation of the NDIS, increased and greater focus is placed on the utilisation of the Lived Experience (peer) workforce, both within the NDIA and in service organisations. This aligns with the recommendations of the Productivity Commission Inquiry into Mental Health (2020), which found that Lived Experience (peer) workers, employed on the basis of their lived experience of mental illness, are well placed to support people with mental illness during their recovery.

Lived Experience (peer) workers, especially those with experience of accessing psychosocial disability supports, are well placed to provide support to individuals throughout the access, planning and implementation processes. They should be available to support and translate the NDIS at point of assessment and planning, especially when a person does not have a known service worker or informal family support present.

Embedding Lived Experience roles to address negative reputation of NDIA staff and culture, and unsafe application processes for people with psychosocial disability and mental illness

Harmful and inappropriately designed application processes and harmful staff culture and attitudes often stem from organisational processes, policies and practices that are not co-designed, led and delivered by people with lived and living experience of mental ill-health.

Lived Experience roles are imperative to creating and embedding healthy and safe cultures and for allowing participants, including prospective participants, to feel comfortable engaging with a service. Lived Experience roles enable the breaking down of stigma and stereotypes, creation of safe spaces for community conversations, and promotion of human empathy, connection, recovery, and hope. Developing and implementing support structures for the Lived Experience (peer) Workforce should be a priority.

Driving cultural change within the NDIA is not the responsibility of Lived Experience (peer) workers, however this workforce can be useful in supporting cultural and practice change. Importantly, these roles should only be pursued where they are likely to be supported by organisational culture, leadership and readiness for change. A commitment to change, collaboration, and co-development is essential.[4] Poor planning, poor implementation and lack of appropriate supports for such roles can inadvertently lead to increased stigma and discrimination. Workplace culture that embraces diversity is a key enabler for the success of lived experience in both designated Lived Experience roles and non-designated roles. The National Lived Experience (Peer) Workforce Guidelines provide principles, information and practical resources that could be adapted to various setting to support considerations by leaders who wish to establish Lived Experience workforce roles in their organisations.[5]

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[4] Byrne, L., Wang, L., Roennfeldt, H., Chapman, M., Darwin, L., Castles, C., Craze, L., Saunders, M. National Lived Experience Workforce Guidelines. 2021, National Mental Health Commission.

[5] Byrne L, Wang L, Roennfeldt H, Chapman M, Darwin L, Castles C, Craze L, Saunders M. National Lived Experience Workforce Guidelines. 2021, National Mental Health Commission

Education and training of workforce to reduce harmful systemic cultures

People with lived or living experience of mental ill-health commonly report stigma and discrimination from professionals in the health, mental health and disability support systems. Unfair treatment at an interpersonal level has been reported by people with psychosocial disability and mental illness when trying to engage with the NDIS. To gain a deeper understanding of the barriers for people with psychosocial disability, the Commission funded the University of Sydney's Centre for Disability Research and Policy to investigate the current experience for people with psychosocial disability. The *Breaking down Barriers: Co-Designed recommendations to reduce stakeholder identified NDIS access barriers for people with psychosocial disability (Breaking Down Barriers)* report identified the negative reputation of NDIA staff and culture as one of the primary barriers to accessing the NDIS.

For the NDIA workforce, education on stigma and discrimination should be embedded within existing education and training approaches, including in pre-service training, staff onboarding and ongoing professional development. Education and training need to go beyond general mental health literacy and awareness, to incorporate evidence-based approaches such as contact-based initiatives, to develop shared experiences and common understandings around mental ill-health. Training needs to be tailored to different cohorts and different settings, to develop skills and provide practical guidance on role-specific actions and behaviours to reduce stigma in relation to mental ill-health. It also needs to involve an appropriate level of nuance and detail to distinguish between different types of experiences of mental ill-health, including those experienced by people with complex mental health need. There is also a role for supporting the development of reflective practice amongst professionals.

B. The impacts of NDIA capability and culture on the experiences of people with disability and NDIS participants trying to access information, support and services from the Agency

The journey for people with psychosocial disability often begins well before any engagement with the NDIS and navigating the NDIS system is challenging. The Commonwealth Mental Health Programs Monitoring Project, Tracking Transitions of People in NDIS 2019 report found:

- There are a high proportion of people with psychosocial disability who have not applied for the NDIS and a high proportion of people who have applied and been found ineligible.
- Of all people found ineligible more than half did not appeal or re-apply because:
    - they were fearful of the application process
    - their mental health was too poor or unstable
    - they were dealing with more urgent priorities (for example, housing)
    - an inability to provide all the evidence required by the NDIS.

The *Breaking down Barriers* report identified that many people with psychosocial disability are not applying for NDIS support. As a result, people with psychosocial disability continue to miss out on the supports and services that can play a significant role in supporting people to live an engaged, meaningful and productive life. Stakeholders described ten broad and interconnected NDIS access barriers for people with psychosocial disability. These included:

1. Key information about the NDIS is confusing or not accessible
2. It is hard to get supports to help to apply - formal (services) and informal (family and friends)
3. It is hard to obtain evidence required by the NDIA
4. The application process is too long, complicated, and inflexible
5. The application process is harmful to mental health and wellbeing
6. The application process does not accommodate for mental illness and psychosocial disability
7. The negative reputation of NDIA staff and culture
8. The disconnect between 'disability' and 'recovery'
9. Personal beliefs, fears and stigma

10. It is not worth it – the idea that the NDIS won't meet a person's needs.

Seven recommendations were identified, reviewed and refined by stakeholders. These recommendations are practical, lived-experience-informed actions to address NDIS access barriers faced by people living with psychosocial disability. Key recommendations include the development of navigator positions (staffed in-part by those with lived experience of psychosocial disability) and embedding training for NDIA and partner staff to improve their ability to interact and engage with individuals with psychosocial disability.

More detail on this report can be found at: Breaking down Barriers: Co-designed recommendations to reduce stakeholder identified NDIS access barriers for people with psychosocial disability (usyd.edu.au)

NDIA culture inhibiting access to NDIS for people with mental illness and psychosocial disability due to lack of understanding of the nature of disability and illness

The *Breaking down barriers* report highlights cultural issues of the NDIA as prohibiting people with mental illness and psychosocial disability from accessing the NDIS. A key recommendation from the report is the need to co-develop and co-design recovery and psychosocial disability training for NDIA staff and partner staff. This would ensure that all staff are able to provide recovery-oriented, trauma-informed services.

Many individuals with psychosocial disability who are attempting to access NDIS services have experiences of interpersonal and institutional trauma that can impact their ability to engage with others. As such, it is necessary that NDIA staff and partners are able to take a trauma-informed approach to ensure that they are not engaging in insensitive and alienating interactions that create additional barriers of access for those with lived experience of mental ill-health and psychosocial disability.

Robust training programs centred on the provision of recovery-oriented and trauma-informed services are required to improve the NDIA and subsequent NDIS culture. This will improve capabilities to support people with psychosocial disabilities and complex mental health needs.

Psychosocial Disability Recovery-Orientated Framework

The Commission acknowledges work is underway to support improved understanding of and responses to psychosocial disability, through the recent introduction of the NDIS Psychosocial Disability Recovery-Oriented Framework. However, the impact of these changes is yet to be seen, and more work is required to monitor and unpack what they might mean in practice for people with lived or living experience of mental ill-health.

The Commission recommends the Psychosocial Disability Recovery-Orientated Framework is prioritised for implementation, alongside the NDIS Review, announced in October 2022. The Framework has involved robust consultation, input and development to ensure that the experiences of individuals living with psychosocial disability are the basis for reform and the improvement of services.

C. Other relevant matters

Understanding the nature, extent and impact of harmful culture through regular data collection

More regular collection of population-level data measuring the prevalence and experiences of psychosocial and mental health-related stigma and discrimination in Australia is urgently required. This is particularly true of structural stigma, which is understudied as well as intersectional and cross-cultural experiences. The Commission recommends the NDIA collect more regular and more granular information about people's experiences, both qualitative and quantitative. This would support improved understandings of and responses to diverse lived experiences, and better locate where negative reputation, or harmful experiences, of NDIA staff and culture stems from. It would also reduce the likelihood of broad-brush assumptions, ultimately building a more robust evidence base.

Expediate the reduction and elimination of restrictive practices

Changes to structural factors such as laws, policies and practices can be important drivers of behavioural and cultural change.

Experiences of coercive and restrictive practices can be inherently traumatising and can result in emotional and physical harm for people receiving care, support people, and the workforce. These practices also reinforce the stigma and public fear that surround mental ill-health, perpetuating the message that if a person needs acute psychiatric care, they'll be 'locked up' or punished, rather than treated with dignity and respect.

The Commission endorses the NDIA's position to move toward the reduction and elimination of restrictive practices. Not only would this better align with Australia's human rights obligations, it may also leverage cultural change within the NDIA.

To reduce and ultimately eliminate restrictive practices, the NDIA needs to embed cultural values and practices that maximise people's autonomy, agency and is respectful of dignity and risk. We strongly recommend recovery approaches and trauma-informed principles to assist services to reduce and eliminate the use of restrictive practices.

The Commission also endorses the 2022 Joint Statement on the Inappropriate Use of Psychotropic Medicines to Manage the Behaviours of People with Disability and Older People, which states:

> *The ACQSC, the NDIS Commission and the ACSQHC have agreed to work together to reduce the inappropriate use of psychotropic medicines through:*
>
> - *Raising awareness of the risks associated with inappropriate use of psychotropic medicines amongst healthcare, aged care and disability workforces*
> - *Supporting improvements to the availability and quality of behaviour support planning, and preventative and de-escalation strategies*
> - *Strengthening understanding and capacity for appropriate informed consent, prescribing, dispensing, administration and cessation of psychotropic medicines.*

The reduction of the inappropriate use of psychotropic medication needs to be prioritised and expediated. A progress update of the joint statement needs to be made, including provision of an implementation plan.