August 2023

MHCC ACT Submission to the NDIS Review 2023

Acknowledgements

Acknowledgement of country

Mental Health Community Coalition ACT is located on Ngunnawal Country.

We acknowledge the Traditional Custodians of the land. We pay our respects to their Elders, past and present. We further acknowledge all Aboriginal and Torres Strait Islander Traditional Custodians and Country and recognise their continuing connection to land, sea, culture and community.

Acknowledgement of mental health lived experience

We also acknowledge the individual and collective expertise of those with a living or lived experience of mental health. We recognise their vital contribution at all levels and value the courage of those who share this unique perspective for the purpose of learning and growing together to achieve better outcomes for all.

Executive summary

Context

Mental ill-health is a population wide experience. It is something that any of us can experience during our lives, and is part of being human. Mental ill health, is experienced by different people and communities in different ways, with different levels of severity, and with different needs as a result. As a society we are constantly making calls about what we prioritise, what our governments fund and how we respond to different life experiences and types of need.

At present, on mental ill health, we do not yet have the balances right. Governments are sending funding in the wrong direction. We are funding acute and crisis driven mental health responses – without adequately addressing the factors that could reduce this need[i] [ii]. We are not responding to mental ill health in holistic ways that address the social determinants of mental ill health[iii] [iv]. Nor are we responding sufficiently to the inequalities present in our society which affect mental ill health, including the impacts for and increased risk of mental ill health experienced by specific groups in society[v] [vi] [vii] [viii] [ix]. This includes First Nations' communities[x] [xi] and others who experience intersectional barriers in our society[xii] [xiii] [xiv].

Whilst NDIS Individual funding packages have their place in responding to the impacts of mental ill health, especially for people who experience substantial and profound impacts of severe mental ill health, not everyone who experiences mental ill health or disability will want or need the level or types of support that an NDIS individual funding package can offer[xv].

We thus make with this submission a clarion call for the **need for increased focus on prevention**, on **early support** and on holistic approaches which recognise and **respond to the underlying social determinants of mental health**. All of these responses and alternative types of support/system improvements must be adequately funded. It is also imperative that there be **adequate investment in mainstream and disability supports, services and systems outside the NDIS (Tier 2)** such that the NDIS does not remain an "oasis in the desert"[xvi].

The NDIS has been transformative opportunity for many Australians, and it is important to focus on the benefits that an investment in the NDIS yields for all of us. We can be proud, as a nation, to have a scheme which is there to protect the human rights of any of us who find ourselves experiencing serious disability, including serious mental ill-health[xvii] [xviii].

While recognising the need to ensure that the NDIS is appropriately targeted to those who most need it, we urge a focus in public discourse on the positive, society-wide benefits of the NDIS – rather than on the financial costs of the NDIS[xix], on sustainability, cost blowouts and fraud. We are concerned that this kind of rhetoric "others" and denigrates people with disability by implying that people with disability accessing NDIS individual funding packages are a burden[xx] - and that it can also reinforce stigma and harmful stereotypes[xxi] [xxii].

There needs to be broader understanding about the importance of the NDIS in ensuring people with disability have the basics they need to live their lives[xxiii]. There needs to be greater awareness that for each dollar spent on the NDIS, there is a return of $2.25 to the Australian economy[xxiv]. Investing in the NDIS can mean that NDIS participants have access to improved quality of life (as each person assesses for themselves) but can also positively impact their families/carers[xxv]. On individual and family and community levels, it can mean improved health and wellbeing, improved social and community connections, or the person being able to pursue personal goals, such as employment, education or in relation to achieving their own version of an ordinary life[xxvi].

Given the significant numbers of people who experience mental ill health, and the diversity of what works for different individuals and families, the NDIS needs to be seen in context – as

one of the many social structures and supports that contribute to improving the experiences of people with disability and people with mental ill health across our community.

NDIS Access and Eligibility

For the smaller numbers of people with mental ill health or psychosocial disability for whom NDIS individual funding packages are designed to assist and who need to access them - it is imperative that the NDIS is accessible.

At present, people with mental ill health or psychosocial disability who apply for NDIS entry, are significantly less likely to be successful with their application than other NDIS applicants (an average of 47% across the last three quarters, compared with an average access rate of 76% for all applicants) [xxvii].

We recommend continued work to improve processes, to better understand and address these disparities and to improve the entry experience for the people the scheme was designed to assist.

We strongly recommend a codesign process with people with psychosocial disability, carers, and advocacy/representative organisations and other stakeholders to improve the access and assessment processes for people with psychosocial disability, and to address other barriers to access.

Improved processes should uphold a recovery focus, be trauma-informed, person centred and supportive to families, culturally responsive and ensure processes are accessible[xxviii]. Different processes may be needed to ensure equitable outcomes for all cohorts, especially for those experiencing intersectional barriers to entry.

NDIS internal and external appeal processes also need to be redesigned, to improve the participant experience and to ensure equity of access for people with mental ill health, mental illness and/or psychosocial disability.

Early intervention and support

Government mental health funding is being directed the wrong way. Despite the evidence around the benefits of early support and evidence that prevention in some instances can be possible, at present, much of mental health, disability and aged care funding continues to go towards acute and hospital care or tertiary level supports[xxix].   Whilst funding the acute and crisis care system is important, it is also important to provide adequate and secure funding for prevention and early support which are often being delivered by community mental health services.

Early support in relation to mental ill health changes lives and can substantially alter life trajectories.   We reiterate the importance of a **prevention** focus, and highlight the importance of **responding equitably** to the diversity in the community, and ensuring especially that the needs of **people at risk of intersectional harm are prioritised**.

Early intervention can and should include actions to **address the social determinants of mental ill health**[xxx].

MHCC ACT members report that the need in the community for prevention, early support and psychosocial support services remains high.

Quality, safeguards and regulation

We welcome and support implementation of the NDIS Psychosocial Disability Recovery-Oriented Framework[xxxi]. We also support the need for increased proactive approaches[xxxii] and more coordination on safeguarding, including from the NDIS Quality and Safeguards Commission, and increased funding for both systemic and individual advocacy**[xxxiii]**.

Our members additionally support an increase in targeted safeguarding approaches developed in partnership with people with disability known to be at extra risk, their carers, service providers, disability advocacy/representative organisations, government and other key stakeholders (including subject matter experts on anti-violence/anti-abuse work).

Our members call for the ACT specific "duplicate restrictive practices reporting issue" be urgently resolved. Providers should not have to engage in duplicate reporting of restrictive practice to both the ACT Senior Practitioner and also the NDIS Quality and Safeguards Commission.

They noted also the need to ensure provider oversight adequately balances the need for providers to be sufficiently participant wellbeing focussed, with the need to also streamline the regulatory and administrative burden that providers experience.

MHCC ACT members want NDIS funding models to change to ensure participants are not disadvantaged due to the impact of the administrative burden being experienced by providers from the NDIS.

At present, it also continues to be extremely difficult for providers to remain sustainable, operating purely within NDIS pricing structures[xxxiv]. Service providers advised during consultations that current pricing arrangements are insufficient to meet essential requirements such as supervision and professional development, investment in quality and improvement, and an adequate hourly rate to attract and retain people with required skills, experience, and qualifications[xxxv].

We welcome the proposed coordinated worker training across the care and support sectors, and notes it could have a significant and positive impact on quality of service.

Tier 2 and the NDIS

We encourages the NDIS review committee to be comprehensive in their conceptualisation of Tier 2, explicitly including the following as part of the definition:
- navigation support for people with disability seeking support inside and outside of the NDIS (or Aged Care funded) packages[xxxvi]
- funded disability support programs available to all and delivered outside individual NDIS funding packages (and Aged Care packages)[xxxvii] and
- targeted efforts supporting reduction of systemic barriers and inclusion of people with disability within mainstream services, businesses, and community groups[xxxviii, xxxix].

Currently, people with psychosocial disability have limited options for support outside of the NDIS. In our view, the best and most appropriate way to address the funding cliff between people inside and outside the scheme, is **to increase investment in supports outside the scheme**. We would especially encourage efforts to co-design Tier 2 and early support approaches with priority populations.

It is important that navigation services are available, that interface issues are addressed, and that there is clarity of roles between the different levels of governments and various stakeholders.

In line with Australia's Disability Strategy 2021-2031, there also needs to be a much more coordinated and concerted effort to ensure that mainstream services offer equitable access and quality of services to people with disability and their carers, in their full diversity, regardless of whether this is at the government, private business or community services level. In Tier 2, there need to be specific initiatives funded to work with mainstream services, private businesses and community services to support equitable access to and quality of supports for people with disability.

We request the review panel also

- ensure that the rights and needs of people with mental ill health/disability living in acute care settings (beyond when acute care is needed) such as hospitals, and forensic mental health systems are adequately responded to, ensuring better individual outcomes and reduced risk of prolonged exposure to infectious disease. This also ensures improved outcomes for the community with more effective use of hospital resources.
- make a series of targeted recommendations to improve the experiences of NDIS participants (and potential NDIS participants) at risk of justice involvement, in detention, or otherwise in contact with the justice system.

Psychiatric and Allied Health

It is important to address known sector-wide issues that impact people with mental ill health and/or psychosocial disability including NDIS participants and also carers. There are considerable barriers preventing equitable access to psychiatric and allied health supports, such as financial barriers, limitations in mental health workforce impacting service availability, and systems causing intersectional barriers to be amplified. For the wellbeing of people with mental ill health, and carers, and in support of the NDIS, barriers must be addressed and removed.

List of recommendations

Intersectionality

Recommendation 1:
That the NDIA partner with people with disability experiencing intersectional barriers, carers and advocacy and representative organisations to find ways to address intersectional disadvantage.

Access and Eligibility

Recommendation 2:
That the following Mental Health Australia recommendation be supported "that Australian Governments should make changes to the *NDIS (Becoming a Participant) Rules 2016* to clarify eligibility for people with psychosocial disability. The process to develop the changes should include consultation with people with psychosocial disability, carers and other key stakeholders."[xl]

Recommendation 3:
That there be continued co-designed work to streamline and improve NDIS application processes for people with psychosocial disability or mental ill health, to address barriers to access and to ensure that applicants are adequately supported through application processes.

Recommendation 4:
That the NDIS continue to work together with people with disability, carers, advocacy and representative organisations to redesign NDIS internal and external appeals processes to improve participant experience and to ensure that they are equitably accessible for people with mental ill health and/or psychosocial disability.

Early intervention and support

Recommendation 5:
That the NDIS review panel recommend that the NDIA review the data it holds in relation to the experiences of people with disability and the social determinants of health and mental health, and publish regular statistics, enable research and use its influence to contribute to positive social changes that address inequality and inequity.

Recommendation 6:
That the NDIS review panel increased transparency and governance between federal and state/territory governments in relation to

- the funding of mental health/psychosocial disability prevention and early supports across the lifespan and

- for resourcing to be strengthened in line with needs to enhance the effectiveness of all mental health supports which would then impact positively for NDIS resourcing purposes.

Recommendation 7:
That there be increased cross sector coordination in relation to early intervention and support services for mental health, disability, health, aged care systems etc, in relation to funding, workforce planning, quality assurance, regulation and more.

Recommendation 8:
That funding for prevention and early support via community-managed mental health services is increased commensurate with level of needs, and in such a way as to allow for stability of funding, program development and refinement over time, and enhancement of early intervention and support options in the community.

Quality, safeguards and regulation

Recommendation 9:
That the NDIA fund and implement the NDIS Psychosocial Disability Recovery-Oriented framework[xli], and that there be ongoing monitoring, to seek to ensure that it is consistently implemented.

Recommendation 10:
That the NDIS review recommends greatly increased investment in and significant strengthening of safeguarding initiatives.

Recommendation 11:
That funding for both systemic and individual advocacy for people with disability and mental ill health be significantly increased, such that it is available proportionate to need.

Recommendation 12:
That the effectiveness of oversight and regulation mechanisms be improved, whilst processes are simultaneously streamlined to reduce any undue administrative burden. This must include resolving duplicate restrictive practice reporting requirements in the ACT.

Recommendation 13:

That the NDIA continue to work in close partnership with people with disability, carers, advocacy and representative organisations, service providers and other key stakeholders to find ways to change NDIS funding models to better support safeguarding, quality service provision and participant rights.

Recommendation 14:
That the NDIS Review committee call for both:
- increases in national funding and support for a Peer and Lived Experience workforce and
- Federal, state and territory governments to explore quality, co-designed and coordinated worker training models across care and support sectors

Recommendation 15:
That the NDIS Review Committee call for urgent action to address challenges faced by the community mental health workforce in recruiting and retaining adequately skilled workers, including by:
- Investing in Tier 2 supports to enable community mental health organisations to ensure security of employment, career pathways and salaries commensurate with skills (and at levels that are competitive when compared with public sector salaries),
- Addressing the drivers of similar mental health workforce issues for NDIS providers, such as issues with NDIS funding models and pricing, training and professional development structures and the organisational sustainability of continuing with NDIS service provision, and
- Addressing and resolving the conflicts between the NDIS funding model and employment award conditions.

Recommendation 16:
That NDIS plans for people with psychosocial disability are more adaptable and flexible, to respond adequately to fluctuating needs.

Recommendation 17:
That the NDIA work to improve NDIS experiences, supports and planning with people with multiple disabilities and/or health issues, in recognition that barriers can interact and compound.

Tier 2

Recommendation 18:
That the NDIS review committee be comprehensive in their conceptualisation of Tier 2, explicitly including
- navigation support for people with disability seeking support inside and outside of the NDIS (or Aged Care funded) packages
- funded disability support programs available to all and delivered outside individual NDIS funding packages (and Aged Care packages) and
- targeted efforts supporting reduction of systemic barriers and inclusion of people with disability within mainstream services, businesses, and community groups[xlii, xliii].

Recommendation 19:
That there be a significant investment in Tier 2 supports outside the NDIS' individual funding packages, with the aim of people with mental ill health receiving early support with a focus on recovery, preventing pressure on the acute mental health system and only directing individuals to NDIS individual funding packages where needed.

Recommendation 20:
Co-design Tier 2 and early support approaches with priority populations.

Recommendation 21:
That case coordination/support be available for people/families in crisis and/or the most complex of circumstances, regardless of their NDIS status.

Recommendation 22:
That in Tier 2, there are specific initiatives funded to work with mainstream services, private businesses and community services to support equitable access to and quality of supports for people with disability.

Recommendation 23:
That investment in Tier 2 includes investment in supports for children, their families and communities, especially in contexts where there are inter-related psychosocial, disability and/or cognitive needs.

Recommendation 24:
That the NDIS develop mechanisms to proactively identify and resolve interface issues via methods that also ensure participant wellbeing is prioritised and participants in complex situations are not disadvantaged whilst issues are being addressed.

Recommendation 25

That the NDIS review panel make a series of targeted recommendations to improve the experiences of NDIS participants (and potential NDIS participants) at risk of justice involvement, in detention, or otherwise in contact with the justice system.

Psychiatric and Allied Health access

Recommendation 26

That the NDIS Review Committee examine and make recommendations to the NDIA and governments in relation to addressing broader systemic issues that impact on the ability of people with mental ill health and/or psychosocial disability to afford and receive quality early allied health, medical and psychiatric services.

*Note that many of the recommendations relevant to the psychiatric and allied health section, have already been included in earlier sections above.

Contents

About MHCC

The Mental Health Community Coalition of the ACT (MHCC ACT) is a membership-based organisation which was established in 2004 as a peak agency. It provides vital advocacy, representational and capacity building roles for the Not for Profit (NFP) community-managed mental health sector in the ACT. This sector covers the range of non-government organisations (NGO) that offer recovery, early intervention, prevention, health promotion and community support services for people with mental ill health.

Our vision is to be the voice for quality mental health services shaped by lived experience. Our purpose is to foster the capacity of the ACT community-managed mental health services to support people to live a meaningful and dignified life.
Our strategic goals are:

- Strong Services: To support providers to deliver quality, sustainable, responsive and recovery-oriented services
- Effective Sector: To reshape the mental health landscape to help providers better meet the needs of people with experiences of mental ill health and carers
- Valued Sector: To recognise and value the role of community-managed services in supporting people's mental health and wellbeing
- Effective Workplace: To be a dynamic peak body with robust governance, financial sustainability, active membership and engaged staff.

Language Use

Throughout this submission, we have opted to use:

- The term _people with experiences of mental ill health_, to refer to people with their own direct personal lived experience of mental ill health.
- Person-first language: the term _people with disability_, instead of the identity-first alternative "disabled people",
- The term _psychosocial disability_ as used by the National Disability Insurance Scheme to describe "a disability that may arise from a mental illness"[xliv] (noting that some people with experiences of mental ill health reported concerns about the origins and ambiguity of this term, the variety of definitions and the ways in which the term can at times be used to include and exclude).
- A definition of the term _intersectionality_ is included on page 16.
- the term _priority populations_ as a way to refer collectively to communities that evidence shows are at increased risk of experiencing inequality. The ACT Wellbeing framework lists the following priority populations: Aboriginal and Torres Strait Islander Peoples, Carers, Children and Young people, Culturally and Linguistically Diverse people, Gender, LGBTIQ+, Older Canberrans and People with disability. We also recognise Veterans, People from Rural/Regional/Remote Areas. Inequality can be magnified for people who face intersectional barriers[xlv].
- _Aboriginal and Torres Strait Islander people_ (in addition to using the terms _First Nations/First Peoples_).
- People from a variety of culturally diverse communities, with the term _culturally and linguistically diverse (CALD)_
- The acronym _LGBTIQA+_ to refer collectively to people who identify with one or more of Lesbian, Gay, Bisexual, Transgender, Intersex, Queer, Asexual, with the plus sign intended to include any other terms to describe identities linked with diversity of sexuality, gender, relationships or bodies[xlvi].
- The word _carers_ to mean family members and/or friends and/or neighbours who are informal and unpaid supports to the person with experiences of mental ill health/ person with psychosocial disability[xlvii]. Informal support networks can vary greatly (not everyone will have family members, friends or neighbours or have them in a supportive role).
- The term _support worker_ to mean people who are paid to undertake a caring role.

We have made these choices to reflect frequent usage across Australian society.

We are mindful that different people will prefer different terms. Respect is intended to all.

Introduction

The current NDIS Review is an opportunity to reset: to look at the transformation of the care and support systems in the last decade, to learn from what is working well and to identify improvements needed.

It asks us to reflect on human rights, on inclusion, on social justice and on the myriad of barriers, experiences of discrimination and disadvantage that people with disability continue to face each day.

This review asks us to reflect on how care and support systems are intended to work, as opposed to how they do work. To consider the ways the NDIS interacts with other service systems, and how interfaces have evolved and been shaped. We are being asked to interrogate our assumptions and to challenge narratives. We are also being asked again to dream of the future ahead.

In preparing this submission, we made a conscious decision to respond considering the rights and experiences of people with disability of all ages (despite the unfair two-tiered age related inequities between NDIS level supports, and those available at present from the Aged Care system to older people with disability who did not enter the scheme before the age of 65). We also have sought to particularly consider priority populations and intersectional barriers.

We strive to ensure lived experience is at the heart of service development and provision in the ACT community mental health sector. We appreciate the expertise that lived experience with mental ill health and with recovery brings, and value learning with and from the experiences of people with experiences of mental ill health carers, and supporters.

We have focussed this submission on the experiences of people with experiences of mental ill health, people with psychosocial disability, carers and mental health/disability service providers.   The questions to which we are responding throughout the submission, were posed by members of the NDIS review panel to mental health organisations.

In preparation for this submission, we held two consultations:

- a hybrid in person and online consultation with MHCC Members (organisational representatives) on Friday 26 May 2023 in partnership with the National Disability Services ACT Territory Manager.
- An in person consultation with people with experiences of mental ill health on Monday 19 June 2023 in partnership with ACT Mental Health Consumer Network . Those who participated at this second consultation were paid for sharing their expertise.

This review also builds on the regular feedback we have obtained through Leadership meetings with services across the sectors, and continued conversations with people with experiences of mental ill health, carers and communities.

We endorse the submission by Mental Health Australia[xlviii], and the National Mental Health Consumer and Carer Forum[xlix].

Context:

Society and Mental Ill Health

Mental ill-health is a population wide experience. It is something that any of us can experience during our lives, and is part of being human.

Mental ill health, is experienced by different people and communities in different ways, with different levels of severity, and with different needs as a result. The impacts of mental ill health both for the person experiencing it, and for families and communities can be substantial.

As a society we are constantly making calls about what we prioritise, what our governments fund and how we respond to different life experiences and types of need.

At present, on mental ill health - we do not yet have the balances right. Governments are sending funding in the wrong direction. We are funding acute and crisis driven mental health responses – without adequately addressing the factors that could reduce this need. We are not responding to mental ill health in holistic ways that address the social determinants of mental ill health[l][li].   Nor are we responding sufficiently to the inequalities present in our society, including the increased risk of mental ill health experienced by people experiencing poverty, and many priority populations within society[lii][liii][liv][lv][lvi]. This includes First Nations' communities, people who identify with one or more LGBTIQA+ populations, people from CALD backgrounds, people with co-occurring disabilities and more[lvii][lviii][lix][lx][lxi].

We thus make with this submission a clarion call for the **need for increased focus on prevention**, on **early support** and on for a holistic approaches which recognise and **respond to the underlying social determinants of mental health**.

As Bruce Bonyhady, one of the NDIS Review panel co-chairs has stated - "the NDIS was designed to support approximately one in 50 Australians. We know that one in five Australians have a disability. And because of what happened when the scheme was introduced, which was that all governments put all of their funds essentially into the NDIS and weakened the supports around the scheme, it's now this oasis in the desert. So if we want a sustainable scheme, that desert has to be watered, there needs to be much, much better supports for people outside the NDIS."[lxii] As the ACT was a whole-of-population trial site for the NDIS, we felt these impacts strongly[lxiii] – then and in the near decade of experience since.

Whilst NDIS Individual funding packages have their place in responding to the impacts of mental ill health, especially for people who experience substantial and profound impacts of severe mental ill health, not everyone who experiences mental ill health or psychosocial disability will want or need the level or types of support that an NDIS individual funding package can offer. Recovery can be achieved in a variety of ways.

Currently, however, people with disability, and people with mental ill health or psychosocial disability have limited options for support outside of the NDIS. In our view, the best and most appropriate way to address the funding cliff between people inside and outside the scheme, is **to increase investment in supports outside the scheme**. We would especially encourage efforts to co-design Tier 2 and early support approaches with priority populations.

Challenging current narratives of the NDIS

The rhetoric and framing which have arisen over the last few years around the financial costs of the NDIS and the sustainability of the NDIS are deeply problematic. We urge a focus in public discourse on the positive, society-wide benefits of the NDIS – rather than the financial costs of the NDIS[lxiv], on sustainability, cost blowouts and fraud.   Narratives which focus solely on the financial costs of the NDIS implicitly characterise people with disability

(inclusive of those on the scheme due to impacts of mental ill health), as: "those that cost the government money"[lxv]. We are concerned that this kind of rhetoric "others" and denigrates people with disability by implying that people with disability accessing NDIS individual funding packages are a burden[lxvi] - and that it can also reinforce stigma and harmful stereotypes [lxvii lxviii]. This conceptualisation also harks back to outdated charity models of disability, and "us and them" thinking which excludes and ignores the rights of people with disability and mental ill health, and their autonomy and independence[lxix].

There needs to be broader understanding about the importance of the NDIS in ensuring people with disability have the basics they need to live their lives[lxx]. There needs to be greater awareness that for each dollar spent on the NDIS, there is a return of $2.25 to the Australian economy[lxxi].

The focus should be on working together to ensure NDIS participants have their rights and entitlements recognised and responded to[lxxii]. Investing in the NDIS can also mean that people with disability experience improved quality of life, both for people with disability themselves (as assessed by the person with disability) and can also positively impact their families/carers[lxxiii]. Whether this be in relation to improved health and wellbeing, improved social and community connections, or in the person being able to pursue personal goals, such as employment, education or in relation to achieving their own version of an ordinary life[lxxiv].

Prevalence of mental ill health in Australia

The National Study of Mental Health and Wellbeing released in 2022 found that "over two in five Australians aged 16-85 years (43.7% or 8.6 million people) had experienced a mental disorder at some time in their life"[lxxv]. They note also that "a person does not need to meet the criteria for a mental disorder to be negatively affected by their mental health"[lxxvi].

Some of us will experience the impacts of mental ill health for longer, or in more substantial or ongoing ways, including via severe mental ill health and/or psychosocial disability.

The Productivity Commission report on Mental Health advises that "an estimated 3% of the population **(800 000 people) have a severe mental illness**, 5% (1.2 million people) have a moderate mental illness, and 9% (2.3 million people) have a mild mental illness"[lxxvii]. They then reference research by Whiteford et al[lxxviii], that suggests that "one-third of adults in the severe group are estimated to have a persistent mental illness, requiring ongoing services to address their residual disability"[lxxix]. This equates to approximately **240,000** adults.

The most recent NDIS psychosocial data dashboard (to 31 March 2023), states there are **60,864** active NDIS participants listed with a primary psychosocial disability[lxxx]. Some NDIS participants who experience psychosocial disability (mental ill health) might not be included in this data as they have co-occurring disabilities, and have listed another disability as a primary disability. Some may have also chosen not to register their experiences of mental ill health with the NDIS. Even considering these factors - there is a significant disparity between figures of 240 000 and 60,864.

Intersectionality and Priority Populations

About intersectionality

Intersectionality is a term originally coined by Kimberle' Crenshaw that in contemporary terms "refers to the ways in which different aspects of a person's identity can expose them to [compounding and] overlapping forms of discrimination and marginalisation"[lxxxi]. Aspects of identity might include but are not limited to: gender identity, sexuality, cultural background, dis/ability, socioeconomic status, housing status and more[lxxxii].

Intersectionality is a way of thinking about structural inequality, inclusion/exclusion and the dynamics of power in a society[lxxxiii]. In this submission, we call on the NDIS review team to call for additional attention to addressing the intersectional barriers people with mental ill health and/or psychosocial disability might experience.

MHCC ACT members advise that at present the NDIS must continue work towards addressing intersectional barriers in partnership with people with mental ill health/ psychosocial disability with diverse backgrounds/identities to ensure that rights are upheld.

Aboriginal and Torres Strait Islander People, Social and Emotional Wellbeing, and Disability

The Disability Royal Commission has highlighted the myriads of interacting and systemic barriers that First Nations people with disability face in having their rights upheld, and in accessing culturally responsive services/systems, including via the NDIS. Change is needed and outlined in the Disability Sector Strengthening plan, co-produced by First Peoples Disability Network and Australian federal, state and territory governments[lxxxiv].

We are aware that the NDIA is co-designing a First Nations' Strategy and action plan in partnership with First People's Disability Network[lxxxv], and calls on the NDIS review committee to ensure that efforts to progress this initiative are funded appropriately and are being prioritised by the NDIA. We emphasise also the continued importance of ongoing efforts to improve cultural awareness and cultural responsiveness across the broader disability sector and community.

Culturally and Linguistically Diverse Communities

People with disability and/or mental ill health from Culturally and Linguistically Diverse (CALD) Communities can also face diverse cultural and/or language barriers to accessing supports such as through the NDIS. There is strong diversity in Australia's multicultural makeup, and it is imperative that this diversity is represented in NDIA staffing levels, that the NDIS is responsive in relation to cultural differences and that people with disability from CALD communities are receiving the information they need in formats that are understandable, such that they can make informed decisions about their rights and whether accessing the NDIS or other supports best suits their needs.

LGBTIQA+ communities

There are many people with disability who identify with one or more of LGBTIQA+ communities, and who can face specific and compounding intersectional barriers accordingly. During consultations, MHCC ACT members identified the urgent need for mental health and NDIS funded services that are informed and respectful of gender, sexual and bodily diversity, emphasising especially the need for ongoing training/education and attitudinal change across the community, but especially in social and health systems.

> **Recommendation 1:**
> That the NDIA partner with people with disability experiencing intersectional barriers, carers and advocacy and representative organisations to find ways to address intersectional disadvantage.

Eligibility and the NDIS

1. Why must NDIS access experiences be improved for people with mental ill health/psychosocial disability?

A. The NDIS is not equitably accessible to all people with mental ill health/psychosocial disability who are likely to meet the eligibility criteria

NDIS Individual funding packages are intended to be available to people with mental ill health/psychosocial disability that meet specific criteria[lxxxvi]. Yet there continue to be significant numbers of people experiencing severe impacts of mental ill health/psychosocial disability, who perhaps would likely meet the criteria, who are not accessing the scheme[lxxxvii] [lxxxviii]. Whilst we recognise that NDIS independent funding packages are not always what all people in this circumstance are seeking and wanting[lxxxix] – it should nonetheless be accessible for those that do want/need this level and type of support. For people for whom alternative supports are more suited – it is imperative that those supports are available and adequately funded.

Mellifont et al (2022) identifies five over-arching barriers making it harder for Australians with psychosocial disability to apply to the NDIS[xc]:

- "social inequities acting as barriers to applying,
- stigma, trauma and previous negative experiences,
- barriers to finding supports needed to apply
- challenges understanding the relevance of the scheme
- experiences and symptoms of mental illness extending and exacerbating barriers."[xci]

There is also evidence about barriers from the Disability Royal Commission[xcii] about intersectional barriers for priority populations, including First Nations People with Disability, People with disability from culturally and linguistically diverse backgrounds, and more. It is imperative that these and other barriers be addressed.

B. NDIS access processes can have negative impacts for people with mental ill health or psychosocial disability

Applying for NDIS entry often involves a lot of time, effort and financial costs for applicants and their supporters[xciii]. Hudson (2020) found that "consumers' concerns regarding eligibility are exacerbated by having to manage both the negative associations of 'being labelled' [which can happen in the process of gathering the supporting documentation needed for application] and the outcome of rejection"[xciv].

They described **potential participants feeling disheartened, despairing, and invalidated**. As MHCC ACT members have heard repeatedly from people with lived experience of mental ill health over time: *"After all that work to apply, I can't even persuade the NDIS – the system meant to support me, that I have a disability (or mental illness) and that my experiences are real. . ."*

Member organisations have spoken with us about the observed **mental health toll for potential participants** when they received a negative NDIS application outcome, often accompanied by an inadequate list of ideas for alternative support, and highlight the importance of improving NDIS processes accordingly. Participants also spoke to us of the negative impact of planning processes which require them to repeatedly demonstrate that they have high levels of needs, as opposed to what the evidence shows works with people with mental ill health - taking a strengths-based focus[xcv].

C. Disparity in application outcomes

The eligibility data released by the NDIA via the Psychosocial disability participant dashboard: (31 March 2023)[xcvi] shows a significant difference in the eligibility experience of people with psychosocial disability applying to the NDIS over the last three quarters as compared with the entire population of those who have applied[xcvii]:

On average – over the three quarters to 31 March 2023 – less than half of applicants with psychosocial disability were successful in their application to the scheme (an average of 47% of applicants with psychosocial disability were found to be eligible, compared with an average of 76% of applicants across the entire scheme)[xcviii].   Greater analysis and transparency is needed to understand the reasons for this discrepancy. A process to access help that is resulting in almost half of applicants being turned away (whilst potentially experiencing harm by engaging with the process) is a process that needs significant improvement.

2. How can we clarify eligibility for the NDIS in relation to psychosocial disability?

A. Update the NDIS Rules

In the 2019 Review of the NDIS Act, the reviewer David Tune recommended that the NDIS Act and Rules be amended to: "provide clearer guidance for the NDIA in considering whether a psychosocial impairment is permanent, recognising that some conditions may be episodic or fluctuating"[xcix].   Whilst there were some changes that were progressed in 2022, the proposed changes to the Act had intended to include this, via changes to the powers of the responsible Federal Minister[c]. Expanding ministerial powers in this way proved to be of concern to the wider Disability community and advocacy services, and did not proceed[ci].

There continues however to be a need for clearer guidance for the NDIA in relation to permanence.

Recommendation 2

That the following Mental Health Australia recommendation be supported "That Australian Governments should make changes to the *NDIS (Becoming a Participant) Rules 2016* to clarify eligibility for people with psychosocial disability. The process to develop the changes should include consultation with people with psychosocial disability and carers and other key stakeholders."[cii]

B. Address barriers to NDIS entry, and make NDIS entry processes more accessible

Psychosocial disability is reported in the top four or five of the more common types of disabilities of NDIS participants, yet there continues to be lower than expected numbers of people with psychosocial disability who are NDIS participants[ciii].

A scoping review conducted by Mellifont et al (2022), indicates that many people experiencing psychosocial disability have not yet applied to the scheme[civ].

The experience for potential and current NDIS participants with NDIS access and eligibility must improve.

It is important to ensure NDIA assessors, and planners (both those working at the NDIA, and with Local Area Coordinators (LACs)) have good mental health and psychosocial disability knowledge and experience to ensure a **recovery focus**, **trauma-informed**, **person/family centred**, **culturally responsive** and **accessible** approach to their work[cv].

Given that people with disability also already have higher likelihood than the broader community of having experienced violence, neglect and exploitation[cvi], and may also face additional barriers related to experiences of discrimination, stigma, and/or intersectional

disadvantage, it is vital to **introduce more mitigating strategies to improve the human experience in applying for the scheme**.

C. Assistance with applying for the scheme:

Whilst Local Area Coordinators (LACs) are the designated pathway to seek help with NDIS applications, MHCC ACT member organisations report that the pressures on LACs to assist with planning processes often means that LACs by necessity have taken a "provide information and instructions only" approach.   This is often not sufficient for people in more complex circumstances, who need more active assistance with processes.
Active assistance could include help with tasks such as completing the NDIS application form, and assisting proactively in obtaining appropriate supporting documents from medical or allied health staff or others (including by accompanying people to appointments, and with consent, direct liaison with staff).

The National Community Connector program (2020-2021) offered community education, assertive outreach and person-centred assistance via various coordinating partners to priority populations experiencing barriers in applying to the NDIS or other services did successfully address some of these gaps for the period in which it existed[cvii].

Recommendation 3
That there be continued co-designed work to streamline and improve NDIS application processes for people with psychosocial disability or mental ill health, to address barriers to access and to ensure that applicants are adequately supported through application processes.

Lorelai's story

Lorelai, an NDIS participant who experiences mental ill health reported that she had had a planning meeting with a Local Area Coordinator approximately six weeks ago. She explained that she had subsequently received an email to advise that she would no longer be funded to participate in the social and wellbeing activities that had helped her remain well, and that her transport funding had also been reduced.   Lorelai was visibly distressed in relating this, and explained the impact on her had been very strong.

She explained that she had already been under extreme pressure to get by whilst her new plan was being prepared, and that she was devastated at the impact this new plan was likely to have on her social wellbeing and her health. We discussed the option to appeal the decision – but she advised that the idea of it, even with help offered from an advocate, was all too stressful and overwhelming, and that she didn't know if her health would allow her to go through with it.

*Some details of this story have been changed to protect the identity of the participant concerned.

D. Improve NDIS appeals processes for people with mental ill health and/or psychosocial disability.

MHCC ACT members have long expressed concerns about the accessibility of the NDIS appeals processes, especially for people with mental ill health and psychosocial disability[cviii] [cix]. We welcomed the attention and efforts to improve the NDIS internal and external appeals processes over the last year, and the Independent Expert Review (IER) program. Some MHCC ACT members working with clients on NDIS appeals in the ACT advised that

referrals to access IER had been unsuccessful, and there was a mismatch between the improvements advertised in the media, and the experience of current clients.

We urge continued attention to NDIS appeals processes to ensure that they are accessible, timely in response and fit for purpose for people with mental ill health or psychosocial disability.

Recommendation 4:
That the NDIS continue to work together with people with disability, carers, advocacy and representative organisations to redesign NDIS internal and external appeals processes to improve participant experience and to ensure that they are equitably accessible for people with mental ill health and/or psychosocial disability.

Early Intervention/ early support

3. What should early intervention look like for psychosocial disability?

A. Early intervention, mental ill health and psychosocial disability

When thinking of early support, we agree with Mental Health Australia[cx] that it is important to consider needs across the lifespan not solely mental health support and assistance **early in life**, but also **early post onset of symptoms** at whatever age they might occur, and for people with fluctuating or episodic experiences, **early in episode[cxi].**

We highlight the importance of a **prevention** focus, of personal **recovery**, and the person at the centre of the circumstance having **choice and control** over if, when and how they access supports or services to the greatest extent possible.

We emphasise also the importance of **responding equitably at levels proportionate to need**, and the importance of working together with people and communities who experience intersectional barriers to find the best ways to **address intersectional barriers**.

Early support can change lives and can substantially alter life trajectories. Early intervention in episodes of psychosis[cxii cxiii], early intervention in relation to personality disorder[cxiv], early support in relation to other experiences of mental ill health, all have been shown to have positive impacts for life and wellbeing.

B. Early intervention and the social determinants of mental ill health

Early support and intervention should include actions that address the social determinants of mental ill health, whether this be in relation to housing/homelessness, food insecurity, poverty and financial stress, discrimination, experiences of violence and safety, or more[cxv] [cxvi]. The World Health Organisation publication on the social determinants of mental health nominates a key principle: **proportionate universalism**, which emphasises "it is important that actions be universal yet calibrated proportionately to the level of disadvantage"[cxvii].

Whilst the NDIA may sometimes be constrained in the ways that they can directly address some of the broader social determinants of health and mental health, the NDIA should be required to support and enable research, to publish data that can highlight inequality and inequities as they impact on people with all types of disabilities (including psychosocial disability) and to use their influence to further systemic solutions. For example: we would envisage the NDIA would have access to data about the number of NDIS participants with psychosocial disability who have experienced homelessness in the last year, and would also hold information about what worked to resolve homelessness issues for those who are now in secure housing. We would also envisage the NDIA would also hold data on the needs and

experiences of NDIS participants who are currently detained, in contact with or at risk of contact with justice systems. De-identified data on these and other topics related to the social determinants of mental health should be made urgently available for research, including via the National Disability Research Partnership.

Recommendation 5:
That the NDIS review panel recommend that the NDIA review the data it holds in relation to the experiences of people with disability and the social determinants of health and mental health, and publish regular statistics, enable research and use its influence to contribute to positive social changes that address inequality and inequity.

C. Prevention of mental ill health and psychosocial disability

Whilst mental ill health can't necessarily be prevented, whether mental ill health develops into a mental health condition sometimes can. An evidence review on primary prevention of mental health conditions conducted for VicHealth in 2020 found that "mental health conditions are not inevitable, and that there is considerable scientific evidence to show that many conditions can be prevented from occurring"[cxviii].

At present, much of mental health, disability and aged care funding continues to go towards acute and hospital care or tertiary level supports such as NDIS individual funding packages and residential aged care, rather than towards early support and intervention either in mental health, disability, aged care sectors or beyond[cxix].

Rosenberg et al[cxx] highlight the challenges of achieving effective prevention and early intervention focuses in mental health care when funding and governance responsibilities for mental health support is split between the federal and state or territory governments[cxxi], and when many prevention/early intervention arrangements occur in community managed mental health services many of which are experiencing precarious rather than consistent funding[cxxii]. Funding security for community mental health supports must be urgently addressed.

Recommendation 6:
That the NDIS review panel increased transparency and governance between federal and state/territory governments in relation to
- the funding of mental health/psychosocial disability prevention and early supports across the lifespan and
- for resourcing to be strengthened in line with needs to enhance the effectiveness of all mental health supports which would then impact positively for NDIS resourcing purposes.

D. Need for increased coordination between government, service systems, and communities

As concepts of mental ill health and psychosocial disability are connected, so too should planning for early intervention across mental health, health, disability and all the other related service sectors (including but not limited to youth, aged care, housing, justice etc), in relation to funding, workforce planning, quality assurance, regulation and more.

Recommendation 7:
That there be increased cross sector coordination and collaboration in relation to early intervention and support services for mental health, disability, health, aged care systems etc, in relation to funding, workforce planning, quality assurance, regulation and more.

E. Role of the Community managed mental health sector

In relation to mental health funding specifically - our view is that government mental health funding is being directed the wrong way. The bulk of mental health funding continues to go into the acute care system (which tends to focus on assisting people when they have reached a crisis point), instead of to the community managed mental health services that are often doing the preventative and early support work[cxxiii]. Whilst funding the acute and crisis care system adequately is important, it is also important to provide adequate funding for prevention and early support to circumvent the pressure on the acute system.

The community managed mental health sector, incorporates not for profit organisations, non-government organisations, for purpose organisations and more[cxxiv]. Community Mental Health Australia (CMHA) advises "The defining characteristic of these organisations and their services are that they form in response to unmet need in communities and are innovative, flexible and responsive in finding person-centred solutions to what are often complex and diverse health and social problems."[cxxv]

CMHA lists the following categories of community managed mental health services:

- "Helpline and counselling services
- Accommodation support and outreach
- Self-help and Peer Support
- Employment and Education
- Family and Carer Supports
- Information, Advocacy and Promotion
- Leisure and recreation"[cxxvi]

MHCC ACT members report that the need in the community for prevention, early support and psychosocial support services remains high.

Recommendation 8:
That funding for prevention and early support via community-managed mental health services is increased commensurate with level of needs, and in such a way as to allow for stability of funding, program development and refinement over time, and enhancement of early intervention and support options in the community.

F. Addressing stigma and discrimination

We highlight the continued need to urgently address stigma and discrimination through the community. We await with interest the National Stigma and Discrimination Reduction Strategy (currently in development)[cxxvii].

Quality, Safeguards and Regulation

4. What are the most effective, proportionate and risk-based approaches to quality, safeguards and regulation (including provider regulation?)

A. Implementation of the NDIS Psychosocial Disability Recovery-Oriented Framework

We support implementation of the NDIS Psychosocial Disability Recovery-Oriented Framework[cxxviii]. Achieving full implementation of this framework (in tandem with other recommendations outlined through this submission) would significantly improve the quality of experience of people with mental ill health/ people with psychosocial disability in contact with the NDIS.

Recommendation 9:
That the NDIA fund and implement the NDIS Psychosocial Disability Recovery Orientated framework[cxxix], and that there be ongoing monitoring, to seek to ensure that it is consistently implemented.

B. Strengthening Safeguarding in support of human rights

Quality and safeguarding efforts must support the **human rights of all people with disability in their full diversity**[cxxx] [cxxxi] being adequately and equitably upheld.

We agree with the NDIS review panel in relation to the need to strengthen and increase connections, coordination and efforts between federal and state/territory governments and all stakeholders on safeguarding topics[cxxxii].

We agree with the need for an **improved balance between universal approaches on safeguarding, with targeted efforts in support of people known to be at greater risk** of violence, abuse, neglect, exploitation and other harms[cxxxiii].

We agree that safeguarding is a shared responsibility[cxxxiv].

We emphasise the need for an **especial focus on co-designing new approaches to safeguarding**, both with people with disability and their supporters in general, but also with priority populations: people and communities that face intersectional barriers, in particular, with Aboriginal and Torres Strait Islander people/communities, with people from CALD backgrounds and people who identify with one or more of LGBTIQA+ communities. Such co-design efforts should also involve advocacy and representative organisations and other key stakeholders.

We note also the need to continue to improve ways to **address thin markets** and to ensure that there are **provider of last resort arrangements** available (providers specifically funded to assist when all other arrangements are not working)

We recognise that the Disability Royal Commission final report will soon be released, and is likely to significantly shape paths forward.

Recommendation 10:
That the NDIS review recommends greatly increased investment in and significant strengthening of safeguarding initiatives

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C. Developmental measures for safeguarding

In the NDIS Participants safeguarding proposals paper[cxxxv] it is suggested that developmental safeguarding measures, i.e. "strengthening the capability of people with disability, workers and providers to reduce the risk of harm and promote quality"[cxxxvi] is an important area where focus is needed.

Whilst we agree that a focus on developmental safeguards is valuable, we urge the NDIS review panel to simultaneously pay close attention to structural, systemic and organisational power dynamics and assumptions to protect against the possibility that a focus on participants improving their own safety could move narratives into unsafe "blame-the-victim" terrain, as has too often occurred over time in discussions about topics such as violence, especially in relation to domestic and intimate partner violence[cxxxvii] [cxxxviii].

D. Complaints, Proactive action and Advocacy

Whilst **improved and accessible complaints mechanisms** in relation to the NDIS, and NDIS services are also needed, waiting until complaints emerge is not sufficient for safeguarding purposes.

The Joint Standing Committee Inquiry into the NDIS Quality and Safeguards Commission final report recommended: "**increased proactive approaches,** including regular face to face contact, with vulnerable participants and visits to service provider sites"[cxxxix] (emphasis added). We strongly support the need for proactive approaches. We also recognise that having **different options for proactive outreach** is important, as different options are needed in different circumstances, as are a variety of mechanisms and approaches including advocacy and representation support.

Recommendation 11:
That funding for both systemic and individual advocacy for people with disability and mental ill health be significantly increased, such that it is available at levels proportionate to need.

A Lived Experience Story

A person with experiences of mental ill health decided to attend a respite service for a few days post a hospital admission, as a way to transition back to being in the community. He advised that he experienced restrictive practice (being locked into an apartment with no ability to egress), and also quality of care issues in relation to this service.

He raised concerns about these issues with the NDIA Quality & Safeguards Commission, but was unhappy with the outcome. Whilst this person was able to self-advocate (and lodged complaints with other appropriate authorities, which were much more thoroughly investigated), he highlighted the privilege that he holds from his educational and work backgrounds, noting concerns for others accessing this and similar services, including those not able to self-advocate as easily (he advised staff told him that a previous resident was non-verbal, and consequently "less trouble").

He highlighted how challenging it can be to know what service quality will be like ahead of time, questioned oversight and the qualifications, level of experience and training of staff.

*Some details of this story have been changed to protect the identity of the participant concerned.

E. Registration, and regulation

On **NDIS registration** – as has been apparent via multiple Disability Royal Commission hearings – NDIS registration and quality of service provision are not always aligned[cxl]. It is also important to improve the ways regulation across service systems works together, as many organisations are seeking to comply with multiple regulatory frameworks simultaneously. MHCC ACT members are interested in NDIS registration approaches being streamlined, however the details of proposed models would be required for them to be able to provide additional feedback on merits or otherwise of proposed approaches.

Our members also emphasise the need to improve approaches with registered and unregistered providers. They advise that despite recognising the value of registration, and what the associated regulatory checks can offer in terms of safeguarding participants rights, they are aware of a number of providers considering de-registering with the NDIS or exiting different areas of service provision, due to the undue regulatory burden experienced to achieve and maintain registration, which means there can be unfair advantages experienced by unregistered providers.

Insufficient regulation of unregistered providers can also be an issue when there are high risk supports, such as accommodation support, where unregistered providers can have insufficient reporting requirements for safeguarding purposes.

An ACT jurisdictional regulation issue
In the ACT, NDIS providers have to report restrictive practices both through the ACT Senior Practitioner and also to the NDIS Quality and Safeguards Commission, however are not funded for jurisdictionally based regulatory burden. MHCC ACT members requested that this **duplicate-reporting issue** re restrictive practices be resolved, but in ways that do not weaken safeguards.

MHCC ACT members in consultation spoke also of the need for regulation and oversight mechanisms **that ensure that participant rights and wellbeing are prioritised by all service providers, no matter the complexity of a participant's needs or circumstances**.

Recommendation 12:
That the effectiveness of oversight and regulation mechanisms be improved, whilst processes are simultaneously streamlined to reduce any undue administrative burden. This must include resolving duplicate restrictive practice reporting requirements in the ACT.

F. Impact of funding models and administrative burden on service quality

MHCC ACT members spoke of the limitations of the funding models and pricing structure to adequately recruit/retain disability support workers with the required skills, experience, and qualifications, and provide suitable ongoing training and supervision of disability support workers.

Administrative challenges have been reported consistently in relation to the operations of the NDIS –they were emphasised in the 2014 Joint Parliamentary Standing Committee Inquiry[cxli], the 2017 Productivity Commission NDIS Costs report[cxlii] and the 2019 Tune Review of the NDIS Act[cxliii][cxliv]. Researchers have also found the scheme to be "administratively cumbersome overall" [cxlv]., and have highlighted that the people with disability from already marginalised groups are disproportionately impacted[cxlvi].

Service providers advised that funding limitations and administrative requirements directly impacts on quality of service provision, and that specific skills were often needed to meet regulatory requirements.

In the ACT, providers advise that the inadequacy in some areas of NDIS pricing structures over time has resulted in some NDIS providers either discontinuing services or scaling down and reducing their service offering, which ultimately limits participant choice around which providers they can access. Other providers have casualised their workforce and/or reduced workforce supports and supervision to enable a viable business model. National Disability Services reports service providers experiencing similar themes[cxlvii]

A service provider who wants the focus to be on participant experience and services, captured the tensions during consultations: "*it feels like we are an administrative business with a side hustle of supporting people, at times*". They emphasised that this is not what they want to be, and highlighted an interest in improving funding models to better address this issue.

Recommendation 13:
That the NDIA continue to work in close partnership with people with disability, carers, advocacy and representative organisations, service providers and other key stakeholders to find ways to change NDIS funding models to better support safeguarding, quality service provision and participant rights.

G. Workforce and worker training, supervision and support

We also endorses the key workforce issues and findings outlined in the NDIS Review workforce paper "Building a more responsive and supportive workforce"[cxlviii].

Addressing workforce issues for the community mental health workforce is pivotal to being able to achieve early support and diversion from acute care assistance. In relation to the ACT – we have recently produced an ACT community-managed mental health workforce profile for 2023, which identified that most of the workforce were women (approximately 61%), that almost 70% were less than 45 years of age, almost 50% had insecure employment, either being on fixed term temporary or casual contracts[cxlix]. Organisations interviewed for that profile, identified inadequate funding to recruit appropriately qualified staff and staff wellbeing/burnout as topics of concern[cl].

We would welcome efforts to increase and improve the experience of the wider 'care and support' workforce, to improve training and supervision for support and other workers, and to **increase the peer worker workforce**. Peer workers can play an important role in demonstrating recovery and in contributing to reductions in stigma and self-stigma[cli]. A service provider highlighted that to make peer worker programs successful, it is imperative that workplaces are inclusive, supportive and with reasonable adjustments available. For the wellbeing of peer workers and clients, there also needs to be clear training, leadership on, and boundaries around, circumstances in which it is appropriate to share lived experiences and to ensure that people are comfortable with, trained and supported in ways to do so safely for all involved[clii].

We encourage consideration of all topics that may assist in improving recruitment and retention of workers, and improving the quality of support that people with psychosocial disability receive.

Coordinated worker training across the care and support sectors could have a significant and positive impact on quality of service, however would need to be adequately recognised in pricing structures. We would encourage any such training to explicitly increase human rights knowledge (and how to support rights being upheld), increase cross-sectoral knowledge and increase understanding of and skill in working with individuals and families facing intersectional barriers (specific community-led education from Aboriginal and Torres Strait Islander communities, from LGBTIQA+ communities, from Culturally and Linguistically Diverse communities etc). We would also welcome greater awareness across sectors in

relation to working in trauma-responsive ways, in disability inclusive ways (anti-stigma, anti-discrimination, disability rights also supported decision making), and in relation to mental health recovery. Some training would need a local focus. Any such training designed to increase quality and safeguarding, is specialised training that can't be simply included in current training components which just cover basic orientation type training for workers.

We noted that the NDIS Review workforce paper mentions only a few care and support sectors (such as disability, aged care, veterans)[cliii]. We would encourage quality, co-designed and coordinated training to be made available across a much broader set of care and support sectors - including sectors (and training topics) as diverse as the housing/homelessness sector, alcohol and other drugs sector, mental health sector, child youth and family sector, aged care sector, anti- domestic, family and sexual violence sectors and more.

Recommendation 14:
That the NDIS Review committee call for both:
- increases in national funding and support for a Peer and Lived Experience workforce and
- Federal, state and territory governments to explore quality, co-designed and coordinated worker training models across care and support sectors.

Recommendation 15:

That the NDIS Review Committee also call for urgent action to address challenges faced by the community mental health workforce in recruiting and retaining adequately skilled workers, including by:

- Investing in Tier 2 supports to enable community mental health organisations to ensure security of employment, career pathways and salaries commensurate with skills (and at levels that are competitive with other sectors),

- Addressing the drivers of similar mental health workforce issues for NDIS providers, such as NDIS funding models and pricing, training and professional development structures and the organisational sustainability of continuing with NDIS service provision, and

- Addressing and resolving the conflicts between the NDIS funding model and employment award conditions

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H. Existing NDIS participants and carers

For existing NDIS participants with psychosocial disability and mental ill health, people with experiences of mental ill health reported that NDIS plans need to be more adaptable and flexible to respond adequately to fluctuating needs.

During consultations, people with experiences of mental ill health and service providers spoke to the importance of security of funding of NDIS plans year to year. Security of funding in NDIS plans allows for people with mental ill health/psychosocial disability to flourish, without fear that when their health improves (for example, as a result of supports that are working) that funding and supports will then be then suddenly reduced or removed too soon, putting psychosocial health and hard earned wellbeing gains at risk, or causing relapse. The importance of skill and capacity building in addition to support for carers was also highlighted.

The present system of NDIS change of circumstance processes take too long to be suitable to meet early intervention needs. The structure of NDIS packages also need to be more flexible, such that participants can choose to move funds between funding buckets more easily to meet their needs.

During MHCC ACT consultations with members for this submission, the following program was highlighted as supportive both of young people, but also of their carers:

> *Good practice with funding constraints example*
>
> *The University of Canberra's WOKE program, a mental health support program which "empowers young people by teaching skills to manage difficult and distressing emotions, communicate needs in relationships and to change behaviours that are getting in the way of the life they want"[cliv], and delivers therapy support based on Dialectical Behaviour Therapy (DBT) has proved invaluable to 15-21 year olds and their families[clv], however at present does not have the security of ongoing funding[clvi].*

> **Recommendation 16:**
> That NDIS plans for people with psychosocial disability are more adaptable and flexible, to respond adequately to fluctuating needs.

I. People with co-occurring mental ill health and/or multiple disabilities/health issues.

We are aware that people with mental ill health and other co-occurring disabilities often report that the NDIS does not adequately recognise and respond to the compounded impact of having multiple disabilities and/or health conditions. The continuing requirement to nominate primary or secondary disability is arbitrary and does not fit with the reality of people's experiences.

> **Recommendation 17:**
> That the NDIA work to improve NDIS experiences, supports and planning with people with multiple disabilities and/or health issues, in recognition that barriers can interact and compound.

Tier 2 and the NDIS

5. What should Tier 2 look like for mental health? How can government address the current cliff between people in and out of the scheme?

A. Defining Tier 2

In the 2011 Productivity Commission report that led to the establishment of the NDIS, the term "Tier 2" was largely focussed on provision of information, and navigation assistance to people with disability and their carers regardless of the person's NDIS status[clvii clviii].

The intent was to ensure "appropriate support from any system"[clix clx].

The term Tier 2 is interpreted in a variety of ways, with agreement varying as to whether it refers – or should refer – to[clxi]:

1. Information, referrals and fostering connections to mainstream and community supports[clxii], and/or
2. Funding for disability support programs or initiatives delivered outside the NDIS to non-NDIS participants and their carers[clxiii]; and/or
3. Targeted efforts to support reduction of systemic barriers and inclusion of people with disability within mainstream services and community groups[clxiv, clxv].

In our view – **all three of the above should be included in conceptualisations of Tier 2**, and we will incorporate each of these in this discussion accordingly. We propose the NDIS Review Committee do likewise.

Recommendation 18:
That the NDIS Review Committee be comprehensive in their conceptualisation of Tier 2, explicitly including
- navigation support for people with disability seeking support inside and outside of the NDIS (or Aged Care funded) packages and
- funded disability support programs available to all and delivered outside individual NDIS funding packages (and Aged Care packages), and
- targeted efforts supporting reduction of systemic barriers and inclusion of people with disability within mainstream services, businesses, and community groups[clxvi, clxvii].

B. *Importance of and benefits in funding Tier 2*

Quantifying exactly how much funding is covered by Tier 2 can be complex and figures can vary significantly depending on how Tier 2 is defined[clxviii]. It is evident however that the difference in funding for NDIS individual packages, and for people with mental ill health, psychosocial disability and other types of disability outside the Scheme is stark[clxix].

We re-state – in our view - the best and most appropriate way to address the funding cliff between people inside and outside the Scheme, is **to increase investment in supports outside the Scheme**, and in particular to address the drivers which are contributing to hardship and the human rights of people with disability not being upheld, including those highlighted already as socio-economic determinants of mental health.

Efforts to improve Tier 2 should continue to build on learnings from previous community mental health programs and must provide a diverse array of options to suit a diverse population and to allow for choice by people with experiences of mental ill health. There is an especial need to focus on the needs of people who face intersectional barriers, and those with complex and severe mental ill health/psychosocial disability who are not NDIS participants, or who are unable to meet the current eligibility criteria.

Recommendation 19:
That there be a significant investment in Tier 2 supports outside the NDIS' individual funding packages, with the aim of people with mental ill health receiving early support with a focus on recovery, preventing pressure on the acute mental health system and only directing individuals to NDIS individual funding packages where needed.

Recommendation 20:
Co-design Tier 2 and early support approaches with priority populations.

C. *Navigation and Case Coordination supports*

Navigation support in a future Tier 2 needs to re-instate the function that had originally been intended for NDIS Local Area Coordinators (LACs), i.e. **information, referral, and fostering connections to mainstream and community supports**[clxx]. Given the overlap in the likely target population for people with mental ill health or psychosocial disability, we encourage **analysis of how Head to Health centres and Tier 2 navigation support services could work** together, as part of system redesign.

There are natural limits to how many systems/supports any one individual or family/informal support network can deal with simultaneously, especially when in crisis or very complex situations. We highlight the need for **case coordination/support for people/families in crisis and/or the most complex of circumstances**

Recommendation 21:
That case coordination/support be available for people/families in crisis and/or the most complex of circumstances, regardless of their NDIS status.

D. Equitable access to and quality of supports

Many mainstream service systems, private businesses and community organisations do not consistently respond adequately to the needs of people with mental ill health and/or disability in their full diversity[clxxi]. Some needed services do not yet exist, in others there is significant organisational change needed to ensure that people with disability have equitable access to and quality of services[clxxii]. There needs to be dedicated efforts, mechanisms and resources targeted to ensuring ongoing shortcomings are adequately addressed[clxxiii].

We highlight the need for a wide range of approaches that are **flexible, and co-designed with different communities (in their full diversity)** such that they fit the different circumstances in different places across Australia.

Recommendation 22:

That in Tier 2, there are specific initiatives funded to work with mainstream services, private businesses and community services to support equitable access to and quality of supports for people with disability.

E. Support for Children and families

It is important also that support for children and families be adequately available.

Recommendation 23:

That investment in Tier 2 includes investment in supports for children, their families and communities, especially in contexts where there are inter-related psychosocial, disability and/or cognitive needs.

F. Interface issues

Whilst the NDIS has published operational guidelines to delineate areas of responsibility on interface issues[clxxiv], there are changing roles emerging between State/Territory and Federal Government, and more clarification continues to be required[clxxv].

Further work continues to be needed in the interfaces and interactions between the NDIS and the various mainstream service systems - whether these be - health, mental health, housing/homelessness, justice, child and family services, aged care or more[clxxvi], both nationally and also within each State/Territory. It is not acceptable to have people with disability and carers experiencing unfair barriers, or caught in the middle, without interim assistance, whilst there are protracted debates/arguments between service systems about which service system should assist.

Recommendation 24:

That the NDIS develop mechanisms to proactively identify and resolve interface issues via methods that also ensure participant wellbeing is prioritised and participants in complex situations are not disadvantaged whilst issues are being addressed.

G. Older People with Disability/ Mental ill health:

Another Tier 2 consideration - we highlight the structural age discrimination that is built into the entry criteria for the NDIS (people are eligible to apply only if under 65 years of age), and whilst the Aged Care Royal Commission had recommended that there be equity for people with disability receiving aged care[clxxvii], that at present this is not occurring.

The Mental Health Atlas of the ACT 2023[clxxviii], and the Capital Health Network ACT Needs Assessment 2021-2024[clxxix], both highlight the gap in mental health services available to meet the needs of older people (those over the age of 65 years), including those living in residential aged care facilities, many of whom might also be experiencing additional intersectional barriers in access to mental health support. When considering Tier 2, we urge consideration of support for people with mental ill health across the lifespan.

H. People with disability living in hospital beyond when acute care is needed, people who are homeless, or in forensic settings

We are aware that people with disability living in hospital beyond when acute care has concluded, especially those with co-occurring disability or health conditions or who are immune compromised, can face significant risks to their lives from an increased risk/likelihood of exposure to infectious disease[clxxx]. We welcomed the emphasis by Bill Shorten, Minister for the NDIS on seeking to ensure that NDIS participants in this situation receive urgent assistance to be discharged from hospital in a timely way[clxxxi]. We emphasise also the need for adequate Tier 2 services available to assist people with disability who are not NDIS participants (of all ages) in these circumstances too.

We also highlight the particular needs of people with psychosocial disability who are homeless, and people with disability in forensic mental health settings.

I. Justice System, Human Rights and Disability

People with disability (inclusive of those with psychosocial disability) are unfairly over-represented as detainees in Australia's prison system[clxxxii]. Aboriginal and Torres Strait Islander people (inclusive of those that identify or have lived experience as First Nations people with disability) are also unjustly over-represented in justice systems in Australia[clxxxiii]. The Productivity Commission noted that in terms of prevalence of mental ill health – people who have ever been in jail or homeless, have twice the prevalence of mental ill health compared with the rest of the population[clxxxiv].

Whilst coordinated efforts by the ACT government and ACT justice stakeholders to achieve change through the **ACT Disability Justice Strategy**[clxxxv] and related strategies are warmly welcomed – significant and transformational reform continues to be needed for people with disability and people with mental ill health through justice processes, in detention and post release, to achieve equitable justice and health outcomes[clxxxvi]. The NDIS, early support and Tier 2 reform have an important part to play in the changes being sought.

In relation to justice, disability and health –people who are incarcerated are known to have higher health and disability needs than typically occurs in the community[clxxxvii]. We thus highlight also the impacts that a lack of access to healthcare, including via Medicare and the Pharmaceutical Benefits scheme can have for people who are incarcerated[clxxxviii]. We urge action to address the undue impacts that this has on access to and quality of healthcare for people who are detained"[clxxxix].

Recommendation 25

That the NDIS review panel make a series of targeted recommendations to improve the experiences of NDIS participants and potential NDIS participants at risk of justice involvement, in detention, or otherwise in contact with the justice system.

Psychiatric and Allied Health services

6. How can NDIS participants have improved access to psychiatric support, noting there are often co-payments and many participants have low incomes?

To minimise impacts and to promote recovery it is important to address known sector-wide issues that impact for people with mental ill health and/or psychosocial disability including NDIS participants also carers.

MHCC ACT members report insufficient access to quality medical or allied health support and care and a lack of early support can mean more acute mental health care is required, and/or can mean impairments progress, with the need for increased NDIS support. Some people who might not have needed an NDIS package have impairments progress to the point that a package is required. Existing NDIS participants can require greater level of NDIS supports when suitable mental health care is unavailable or access to it delayed.

During consultations in the ACT, the following topics were raised:

- Clinical and allied health mental health staff shortages, and the need to support and build the workforce. Despite Canberra being a metropolitan centre, attendees reported continuing workforce challenges across many areas of the mental health workforce, including but not limited to: psychiatrists, psychologists, social workers, counsellors, GPs with expertise in mental health support, mental health nurses, recovery coaches, mental health support workers etc, with reports of people with experiences of mental ill health being on waiting lists, experiencing delays in receiving care and the impact of care not being available.

- Financial barriers: People with experiences of mental ill health and service providers highlighted that support is more readily available to those that can afford to pay privately for help, those who can pay significant co-payments, and those with both financial means and digital access to enable them to access support from interstate. Service providers highlighted that this is impacting people with low socio-economic status, as well as those with moderate incomes.

- Intersectional barriers are amplified: Mental ill health can be experienced at disproportionately higher levels by some individuals and groups of people experiencing intersectional barriers and disadvantage. The proportion of society who experience intersectional barriers is significant. Participants highlighted skills gaps amongst psychiatric and allied health workforce in working with priority populations such as LGBTQIA+ communities, Aboriginal and Torres Strait Islander communities, and people with co-occurring disabilities or differences and mental ill health (i.e. dementia and mental ill health, intellectual disability and mental ill health, acquired brain injury and mental ill health, neurodiverse people with co-occurring mental ill health etc).

- Barriers to Diagnosis: there are significant challenges in pathways to obtaining diagnosis both for mental ill health but also in relation to disabilities, health issues and neurodiversity differences including autism and ADHD.

When asked for what would help with the challenges, consultation attendees discussed

- A need for increased access to community mental health early programs and supports, and transdisciplinary models of support.
- The importance of a strong and supported Peer workforce in all areas of mental health support.
- Changes to Medicare rebates/ program funding, to seek to increase access to psychiatric, psychological or allied health care by reducing or eliminating co-payments

(whilst being cautious to guard against prices being inflated). Changes to increase Medicare coverage of eating disorder treatment was cited as having been very positive.

- <u>Functional Assessments, Diagnostic access</u>: People with experiences of mental ill health highlighted it would be useful for there to be more information about and easier access (cost and availability) to quality functional assessments completed by Occupational Therapists of their choice, also to diagnostic pathways for those that wish to pursue diagnosis.

- <u>Continued education for GPs and community leaders</u> in relation to the NDIS, and community resources and supports available. People with experiences of mental ill health highlighted that often a GP was a gateway into the service, and that it helped when they or their clinic were well informed about available supports.

Recommendation 26

That the NDIS Review Committee examine and make recommendations to the NDIA and governments in relation to addressing broader systemic issues that impact on the ability of people with mental ill health and/or psychosocial disability to afford and receive quality early allied health, medical and psychiatric services.

Conclusion

People with mental ill health and/or psychosocial disability were the last disability group accepted into the NDIS[cxc]. For most people who have experienced mental ill health, carers and supporters, engaging with the NDIS over the decade since, has not been easy[cxci].

For many, people with mental ill health and psychosocial disability amongst them, the NDIS has been life changing. Some people have been able to pursue their interests whilst building social networks, others have obtained employment, yet others have embarked on studies. It has encouraged people to realise their rights and entitlements and to progress towards their goals.

Yet there continue to be challenges in reconciling concepts of personal recovery, and what for many are episodic/fluctuating conditions, with the emotional and financial impacts of gathering evidence to fulfil the requirements of a deficit focussed access process that requires proof of permanency and substantially reduced functional capacity[cxcii].

There are challenges also with planning, re-assessment, and appeal processes, all of which need to be re-thought, in partnership with people with experiences of mental ill health/ carers and advocacy and representative organisations, to better suit their needs. The NDIS needs also to better understand the compounding and interactive nature of intersectional barriers and harm.

Whilst we can be proud of the NDIS as a system that has improved the treatment of people with a disability, there is still much to achieve before people with mental ill health/psychosocial disability consistently have the "transparent, responsive, respectful, empowering and connected"[cxciii], experience promised by the NDIS participant service charter. May this review allow for both the experiences of people with mental ill health/psychosocial disability without an NDIS funding package, and the experience of NDIS participants to significantly improve, as such improvements are pivotal in the future of the scheme.

Appendix 1: MHCC ACT Member List (as at June 2023)

A Gender Agenda
Access Lifecare
ACT Disability, Aged and Carer Advocacy Service (ADACAS)
ACT Mental Health Consumer Network (MHCN)
ACT Shelter
Advocacy for Inclusion
Alcohol Tobacco and Other Drug Association ACT (ATODA)
Anglicare NSW South, NSW West and ACT
Avenue Counselling
Barnardos
BPD Awareness
Canberra Youth Residential Service
Capital Health Network
Capital Region Community Services
Care Financial Counselling
Carers ACT
Central Counselling Services
Communities at Work
Connections Case Management
EveryMan Australia
Fearless Women
Grand Pacific Health (headspace)
Greenleaf Disability Service
Koomarri
Livability
Marymead CatholicCare Canberra & Goulburn
Menslink
Mental Health Foundation ACT
Mental Illness Education ACT (MIEACT)
Meridian ACT
Nexus Human Services
OzHelp Foundation
Perinatal Wellbeing Centre
Quest Group
Richmond Fellowship ACT
Rubies Nursing Care
SiTara's Story
St Vincent de Paul Society Canberra Goulburn
Stride
Think Mental Health (Head to Health Canberra)
Toora Women
Volunteering ACT
Wellcare
Wellways
Woden Community Service Ltd
Youth Coalition ACT
YWCA Canberra

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