Mind the Gap: The National Disability Insurance Scheme and psychosocial disability

Final Report: Stakeholder identified gaps and solutions

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Catholic Care NT
Centacare North Queensland
Central Coast Primary Care
Challenge Community Services
Clarity Psychology
Chorus
Clearwater (Me Well – Australian Disability Enterprise)
Flourish
Gugan Gulwan Youth Aboriginal Corporation
HelpingMinds
Lamp Inc.
Laynhapuy Homelands Aboriginal Corporation
Life Without Barriers
Mental Health Consumer Coalition ACT
Mental Illness Fellowship of Western Australia
MHCC (Mental Health Coordinating Council) NSW
MHCCACT (Mental Health Community Coalition ACT Inc.)
Micah Projects
Mind Australia Limited

Mind Works
Miwatj Health Aboriginal Corporation
NDS NT (National Disability Services)
NEAMI National
New Horizons
NMHCCF (National Mental Health Consumer and Carer Forum)
NT Mental Health Coalition
NWRH (North and West Remote Health)
Office of the Public Advocate QLD
One Door Mental Health
Queensland Alliance for Mental Health Inc.
RFQ (Richmond Fellowship Queensland)
Ruah Community Services
Salvo Connect Barwon
Selectability
Sisters Inside Inc.
St Laurence – Karingal
St Vincent De Paul – Family and Youth Homelessness and NDIS Mental Health Services
Tandem
The Benevolent Society
Toowoomba Clubhouse
Uniting Recovery
VACCHO (Victorian Aboriginal Community Controlled Health Organisation Inc.)
VICSERV (Psychiatric Disability Services of Victoria)
VMIAC (Victorian Mental Illness Awareness Council)
WAAMH (Western Australia Association for Mental Health)
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Executive summary

The National Disability Insurance Scheme (NDIS) is a major opportunity to create a network of person-centred supports that will assist individuals with disability to have choices and lead meaningful lives. The NDIS has the potential to provide significant positive benefits for people with psychosocial disability.

Right now, for people with psychosocial disability, there are gaps in implementation of the NDIS with - often stop-gap - solutions being implemented which are poorly coordinated and funded. This report reveals these gaps and proposes solutions as identified by consumers, carers and practitioners from the field who are highly committed to ensuring the best outcomes for people with psychosocial disability. Many of the gaps identified are not new and have been raised by peak bodies and in government-sponsored inquiries by the Commonwealth's Joint Standing Committee on the NDIS and the Productivity Commission. The experiences of the 58 expert stakeholders reported here reinforce and extend the earlier reports of these bodies.

The NDIS and Psychosocial Disability – who is served and who misses out?

The National Mental Health Commission Report *Contributing lives, Thriving Communities* estimates that of the 3.7 million Australians who experience mental illness, 690,000 Australians live with severe mental illness. The federal government has estimated that one third, or 230,000 people, need ongoing support, although it is unclear how this figure was derived[1]. However, the National Insurance Disability Agency (NDIA) estimates that at full roll out (2019-20) only 460,000 will be participants in the Scheme, with 13.9% or 64,000 people expected to have a primary psychosocial disability requiring support[2]. This means a significant gap of up to 91% of people with severe mental illness, or 166,000 - 626,000 people (depending on the figures used), will have to rely on non-NDIS community mental health services to meet their needs.

Current participation in the NDIS of people with a psychosocial disability is low and indicates multiple difficulties in the implementation of the Scheme.

Current participation in the NDIS of people with a primary psychosocial disability is low and indicates multiple difficulties in the implementation of the Scheme. Latest NDIA figures show that only 6.4% of Scheme participants have a primary psychosocial disability which is less than half the expected numbers. To date, 81.4% of people with psychosocial disability who requested access were accepted into the Scheme compared to over 97% for people with cerebral palsy, autism or intellectual disability[3]. These figures reinforce that people with psychosocial disability are missing out for many reasons and the NDIA is failing to engage appropriately with people experiencing psychosocial disability. This report also documents that when individuals do enter the Scheme they frequently receive inappropriate plans and are unable to find services to carry out their NDIS plan.

This report draws on the great wealth of knowledge held by services currently providing community based services for people who experience psychosocial disability across Australia and sets out the gaps and proposed solutions that they have identified.

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[1] Commonwealth of Australia (2015) *Australian Government Response to Contributing Lives, Thriving Communities – Review of Mental Health Programmes and Services.* Department of Health: Canberra.

[2] National Disability Insurance Agency (2017) *Attachment A: Key Data on Psychosocial Disability and the NDIS - as at 31 March 2017.* **https://www.ndis.gov.au/medias/documents/hda/h2c/8804425367582/Attachment-A-Key-Data-on-NDIS-and-Psychosocial-Disability.pdf**

[3] Commonwealth of Australia (2017) Joint Standing Committee of the National Disability Insurance Scheme *Provision of services under the NDIS for people with psychosocial disabilities related to a mental health condition.* Report, available online: **https://www.aph.gov.au/Parliamentary_Business/Committees/Joint/National_Disability_Insurance_Scheme/MentalHealth/Report**

The Gaps

Stakeholders identified gaps in two main areas:

1)   Administration of the Scheme for people living with psychosocial disability who are potentially eligible; including: a. Scheme engagement and application processes, and b. Scheme assessments, planning, plan activation and review.

2)   Service delivery to those living with severe mental illness who will not be eligible for the Scheme or for a multitude of reasons are not applying, and therefore need to keep receiving services outside of the NDIS.

Scheme engagement and application process

- Poor knowledge of the Scheme amongst many people with psychosocial disability
- The language of disability and permanence does not fit well with the language of recovery and is alienating for people who do not wish to consider themselves as having a life-long disability but nevertheless would be eligible
- Poor support for applications, including culturally-specific support for Aboriginal and Torres Strait Islander people
- Social and geographical isolation, including language barriers stop people from finding out about and engaging with the application process. This is particularly problematic for people from Aboriginal and Torres Strait Islander backgrounds
- Difficulties around gathering evidence required for the application resulting from an individual's transience, illness, the necessity for very specific, costly types of evidence, the fluctuating nature of psychosocial disability and a lack of specialists to provide evidence
- Poor support from NDIS staff for people from culturally and linguistically diverse backgrounds
- Poor understanding among carers and family members about the Scheme and available supports
- Carer and family member expertise and advocacy is excluded by assessors and planners and their own support needs are not included in plans

Scheme assessments, planning, plan activation and review

- Poor quality of NDIS assessments due to a lack of understanding about psychosocial disability
- Inappropriate assessments such as assessments conducted by phone without the applicant knowing what the call was about, or without support people present
- Extensive time delays at each step of the process (e.g. assessment, planning, review) mean that ongoing support from other services during the application, planning and activation processes is needed but lacking
- Lack of culturally appropriate plans and lack of culturally appropriate services to activate these plans
- People lack support for planning (or supporters, including family and service providers, are prevented from contributing) so plans don't meet individual needs
- Expert assessments are ignored or plans do not otherwise align with an individual's identified needs
- No opportunity to review a plan before it is signed off
- Plans once made are not activated due to confusion, poor support coordination, or a lack of appropriate service providers
- Confusion about support coordination means that it is not included in plans: support thus uncoordinated
- Cost related issues mean that providers cannot afford to provide the services listed in client plans for the funding level that they receive from the NDIA
- Unscrupulous providers draw down on line items so there is no funding left to be used for other providers
- Reduction in plans following review due to poor understanding of psycho-social disability
- Limited support for the development of NDIS work within Aboriginal and/or Torres Strait Islander community-controlled service providers
- Limited support for people when their plans are being reviewed; and reviews conducted by phone
- Plans are inflexible and difficult to review quickly when situations change or people become unwell

Service context and support for those not eligible for the Scheme

- Organisations with expertise in psychosocial disability are collapsing, merging and selecting not to engage with the NDIS due to an inability to provide effective services within the NDIA costing structure
- Organisations are losing staff with expertise in psychosocial disability because the level of funding provided by the NDIA for instances of care does not match the cost of employing trained staff or providing training and supervision to new staff

- Poor transition between the existing block funding model and the NDIA means that funding is stopped before people are transitioned to the NDIS
- There is a dramatic loss of services for the vast majority of people living with mental illness. This creates a second class of people with psychosocial disability who now receive much poorer support because they are not eligible for the NDIS
- Funding is being transferred to the NDIS from programs where many existing clients are not eligible for the NDIS, which has led to a loss of services to people with severe mental illness
- Peer support, community-based rehabilitation and recovery services are not being funded

The Solutions

1. **Dedicated high-level leadership on psychosocial disability** within the NDIA which works with a well-resourced steering group to evaluate current practice and its effectiveness at meeting client needs, re-develop NDIS materials and processes to address ongoing implementation issues (such as those described here), work with federal, state and territory governments to monitor the impact on services, and provide direction on necessary levels of training and development for workers.
2. **The NDIA should develop a strategy for monitoring and reporting publicly** on rates of application, acceptance, plan activation, timeframes, plan contents and rates of review for people with psychosocial disability in relation to targets and other types of disability so that effective short and long term strategies can be developed to increase applications and address implementation issues as these arise.
3. A concerted **strategy and implementation plan specific to Aboriginal and Torres Strait Islander** people with psychosocial disability should be developed which should have structured, community-relevant indicators which can be measured.
4. **Funding should be provided to existing community-focused services already working in inclusive and culturally relevant ways with Aboriginal and Torres Strait Islander communities,** such as Aboriginal Medical Services (AMSs), Aboriginal Community Controlled Organisations (ACCOs) and mainstream agencies whose services have proven engagement with Aboriginal communities, so that they can support applicants in their initial and ongoing interactions with the NDIS.
5. **The federal Department of Social Services should work to better equip existing services to manage the transition to the NDIS.** This includes monitoring the impact on services and providing access to support to assist in redesign and adaptation of business models for the new context of work under the NDIS.
6. Funding should be available through the NDIA for **the training of key workers to better understand psychosocial disability, recovery and person-centred care,** and to work in a culturally responsive and appropriate way with people from Aboriginal and Torres Strait Islander communities.
7. Funding should be provided by the federal government to **services working with culturally and linguistically diverse communities** so that they can support applicants in their interactions with the NDIS.
8. There should be **ongoing independent pricing reviews** conducted by an independent pricing authority which consider whether payments for NDIS-related services are able to meet Social, Community, Home Care and Disability Services Industry Award (SCHACDS) wage levels and training, supervision and development needs of organisations.
9. **Funding for existing programs serving people with psychosocial disability** and slated to close (e.g. the Personal Helpers and Mentors Scheme (PHaMS), Partners in Recovery (PIR), Day to Day Living (D2DL)) should not be ceased until all clients have an enacted NDIS plan or they have transitioned to another funded program to meet their needs.
10. The NDIA should move quickly to **establish a specialist psychosocial disability gateway** to the NDIS to assess and work with applicants with a psychosocial disability.
11. **An NDIS item number should be developed** for medical practitioners to bill assessments to Medicare.
12. There needs to be a focus on **ongoing advocacy and support coordination** as standard for potential clients with psychosocial disability.
13. **Standard NDIS processes should include carers and family members** in assessment and planning and have carer needs included in plans unless applicants expressly choose not to do so.
14. The NDIA needs to develop **a responsive system of short-term review which can be put in place quickly to increase support in times of increased need.** This could be funded through a contingency funding item in plans.

The body of the report also details individual solutions suggested by stakeholders in relation to specific gaps identified

About the project

Consumer, provider and advocacy stakeholders with expertise gained through direct experience of working with clients in the NDIS trial and transition sites are ideally suited to collectively identify emerging and existing gaps or issues as well as providing a prioritised list of practical and relevant recommendations to resolve these issues. This project, which is a partnership between the University of Sydney Faculty of Health Sciences and Community Mental Health Australia, and funded by the Sydney Policy Lab, engages with those with the most expertise and practice or experience-based knowledge. This expert stakeholder group includes 58 organisations from each state and territory and includes specialist Aboriginal and Torres Strait Islander community-controlled organisations, carer and consumer advocacy organisations and services working with people from culturally and linguistically diverse backgrounds.

The project involved a stepped process engaging stakeholders throughout. It included:

1. Stakeholder identification of gaps that are existing or emerging in relation to the operation of the NDIS and psychosocial disability
2. Stakeholder proposals of best policy solutions
3. Stakeholder review of merged proposed solutions

It was designed to create a 'safe' environment for stakeholders to raise issues and challenges as well as to propose workable solutions. Thus, it was agreed at the out-set that reporting would use a collective 'voice'. Information collected in stakeholder discussions is therefore not attributed to individuals or the organisations they represent.

This report

This document reports on the solutions provided by stakeholders to address gaps previously identified in relation to the implementation of the NDIS for people with psychosocial disability.

These solutions are positioned in relation to gaps identified via 1) discussions with, and submissions from, expert stakeholders and 2) a review of academic publications and other documents including policy submissions and publicly available reports.

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The gaps identified by expert stakeholders were substantially validated by an independent academic review of related publications, reviews and reports. Each grouped area of gaps or issues is followed by our expert stakeholder proposed policy solutions. Gaps and proposed solutions are presented in five sections:

1) Overarching solutions to systemic problems
2) The NDIS journey for people living with psychosocial disability
3) The NDIS journey for carers and family members
4) The NDIS journey for service providers
5) The gaps at the edge of the NDIS

Because the policy solutions presented in these sections come from stakeholders working within a broad range of organisational, cultural and geographical contexts they are not necessarily consistent with each other. The overview in the Introduction and Executive Summary attempts to bring them together cohesively in an overarching description of solutions. The report is deliberately outward looking and focused on implementation issues as experienced on the ground in service provision. As such it should be seen as a complement to internal NDIA work on psychosocial disability and does not attempt to understand internal NDIA perspectives.

Introduction

The National Disability Insurance Scheme (NDIS) is a major opportunity to create, for individuals with a disability, a network of person-centred supports that will assist them to live their lives in the way that they choose.

The Scheme is still in its implementation phases and it is important that gaps identified are viewed as a way to improve the Scheme rather than condemn it.

People with psychosocial disability are missing out in the implementation of the NDIS as gaps arise and solutions are poorly coordinated and funded. This report reveals the areas of implementation around which these gaps have formed as identified by organisations and services working within the field. Our identification of these gaps is not unique and most have previously been identified by peak bodies, consumers and those working within the sector, as well as within government-sponsored inquiries by the Joint Standing Committee on the NDIS and the Productivity Commission. In response to the gap in services left in the wake of the NDIS for those that are not eligible, the federal government promised in its May 2017 Budget $80 million in funding, but only if this figure were matched by state and territory governments[4].

The NDIS and psychosocial disability – key figures

The National Mental Health Commission Report *Contributing lives, Thriving Communities* estimates that of the 3.7 million Australians who experience mental illness, 690,000 Australians live with severe mental ill-health. The federal government in response has estimated that one third of those, or 230,000 people, need ongoing support, although it is unclear from where this figure is derived[5]. However the NDIA estimates that at full roll out (2019-20) the NDIS will only meet the needs of 460,000 people with any disability in total, with 13.9% or 64,000 of these people expected to have a primary psychosocial disability requiring support[6].

Latest figures show that only 6.4% of Scheme participants have a primary psychosocial disability, which demonstrates that people with psychosocial disability are entering the Scheme at less than half of what was expected.

This means that there is a significant gap of up to 91% of people with severe mental illness, or 166,000 - 626,000 people (depending on the figures used), whose needs will need to continue to be met by community mental health services outside of the Scheme.

Enrolments into the Scheme from people with a primary psychosocial disability are low and demonstrate that there are problems related to knowledge of the Scheme, application for the Scheme, and Scheme assessment. Latest figures show that only 6.4% of Scheme participants have a primary psychosocial disability, which demonstrates that people with psychosocial disability are entering the Scheme at less than half of what was expected. While the NDIA has estimated that 14% of NDIS participants in NSW will have a primary psychosocial disability, currently only 7% of participants in that state are identified as having a psychosocial disability. NDIA figures also show that over the Scheme's life 81.4% of people with psychosocial disability who requested access to the Scheme were accepted into the Scheme compared to over 97% for people with cerebral palsy, autism or intellectual disability[7].

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[4] Australian Government (2017) *Prioritising Mental Health – Psychosocial Support Services – funding.* **http://www.health.gov.au/internet/budget/publishing.nsf/Content/budget2017-factsheet28.htm**

[5] Australian Government (2015) *Australian Government Response to Contributing Lives, Thriving Communities – Review of Mental Health Programmes and Services.* Department of Health: Canberra.

[6] National Disability Insurance Agency (2017) *Attachment A: Key Data on Psychosocial Disability and the NDIS - as at 31 March 2017.* **https://www.ndis.gov.au/medias/documents/hda/h2c/8804425367582/Attachment-A-Key-Data-on-NDIS-and-Psychosocial-Disability.pdf**

[7] Australian Government (2017) Joint Standing Committee of the National Disability Insurance Scheme *Provision of services under the NDIS for people with psychosocial disabilities related to a mental health condition.* Report, available online:

These figures reinforce what we have been hearing from people working in the sector – that many people with psychosocial disability are not testing eligibility or are not being accepted into the Scheme. This relates to a failure of the NDIA to engage appropriately with a range of people with psychosocial disability.

We are also hearing that service gaps are appearing in and around the Scheme. Within the Scheme service delivery gaps relate to poor alignment of participant needs with NDIA plans, and multiple barriers to actualising participants' plans. These gaps both stem from a lack of NDIA expertise and understanding of the unique needs and challenges associated with psychosocial disability. Further, as funding from existing programs is transferred into the Scheme, people who are outside of it are losing the services for which they were previously eligible. There is significant concern that the existing services whose program funding will be transferred to the NDIS will leave people without support when they are forced to close. In the ACT where Partners in Recovery (PIR) was terminated as the NDIS was introduced it was estimated that 63 PIR participants would not be eligible for the NDIS out of a total of around 160 previously accessing PIR[8]. Services for this group of people living with psychosocial disability are drying up in order to fund the NDIS.

Overarching solutions proposed for all gaps

While stakeholders posed discrete solutions for a wide range of gaps (these are provided in each section below) there were common solutions which were posed across the nation and across organisational types.
These are summarised here:

Dedicated Leadership: Taken collectively the gaps related to the administration of the NDIS in relation to psychosocial disability point overwhelmingly to a lack of dedicated leadership within the NDIA specific to psychosocial disability. This is therefore our primary solution. **Dedicated leadership would involve a high-level lead officer responsible for psycho-social disability and the effective use of a steering group (not just advisory group) which includes people with a lived experience, carers, Aboriginal and Torres Strait Islander people and peak bodies working in the sector** to:

1. evaluate current practice and its effectiveness at meeting client needs
2. redevelop materials and processes throughout the NDIS so that they address ongoing implementation issues (such as those described here)
3. work with federal, state and territory governments to monitor the impact on services
4. provide direction on necessary levels of training and development for workers

Monitoring and dissemination: Currently only some information on rates of application, acceptance, rates of plan activation, timeframes, plan contents and rates of review for people with psychosocial disability is available as legislatively mandated, but this is not detailed enough to be useful for planning. **The NDIA should develop a strategy for monitoring this data in relation to targets and other types of disability so that effective short and long term strategies can be developed to increase applications and address implementation issues as they arise.** The data should also be shared publicly, for example through expanding its existing quarterly reports to include this information.
Public reporting will also allow services to develop adaptive responses and academic research to be undertaken to allow for the Scheme to continue to develop effectively.
This data should pay special attention to communities where uptake by people with psychosocial disability is lower and issues around implementation more acute. This includes Aboriginal and Torres Strait Islander communities where data should be collected and reported as per AIATSIS guidelines for Aboriginal and Torres

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https://www.aph.gov.au/Parliamentary_Business/Committees/Joint/National_Disability_Insurance_Scheme/MentalHealth/Report

[8] Community Mental Health Australia (2017) Submission to the Joint Standing Committee on the NDIS – The provision of services under the NDIS for people with psychosocial disabilities related to a mental health condition; Burdon, D. (2016), ACT mental health services and clients wait for an end to NDIS impasse, *Canberra Times,* October 21st 2016.

Islander research[9]. Special attention should also be paid to people from culturally and linguistically diverse backgrounds and living in rural and remote regions.

A dedicated strategy for Aboriginal and Torres Strait Islander people: **Due to poor engagement with the Scheme from Aboriginal and Torres Strait Islander people with psychosocial disability, particularly those living in rural and remote areas, a concerted strategy and implementation plan should be developed.** This should be specific to psycho-social disability with structured indicators which can be measured and linked to existing NDIA Remote Strategy and Aboriginal strategy. This is needed in order to encourage applications, address shared issues relating to program implementation, develop a culturally competent NDIS-related workforce and employ Aboriginal and Torres Strait Islander people as staff. There should be dedicated and responsible leadership of this program of work from with the NDIA. This plan should be linked to the *National Strategic Framework for Aboriginal and Torres Strait Islander Peoples' Mental Health and Social and Emotional Wellbeing[10]*.

Support for struggling businesses: Community mental health services are struggling to redesign in light of the new funding model which comes with the NDIS. **The federal Department of Social Services should work to better equip existing services to manage the transition to the NDIS.** This includes monitoring the impact on services and providing access to supports which will help them redesign their business models in relation to the new context of work resulting from the implementation of the NDIS. This should be in addition to more general funding for transition support.

> *Community mental health services are struggling to redesign in light of the new funding model which comes with the NDIS. **The federal Department of Social Services should work to better equip existing services to manage the transition to the NDIS.***

Training all workers in psychosocial disability: Many of the issues identified around access, eligibility and planning related to a perceived lack of understanding by NDIA staff, assessors and planners on the realities and current practices surrounding psychosocial disability. **Separate funding should be available through the NDIA for the training of these key workers to better understand psychosocial disability, recovery and person-centred care, and to work in a culturally responsive and appropriate way with people from Aboriginal and Torres Strait Islander communities.** The NDIA should be engaging the community sector and culturally-run services who have existing knowledge of psychosocial disability to develop and provide training. This is so the sector isn't drained of its expertise and the NDIA are getting direct on-the-ground knowledge in their training. However, training must not supplement genuine ongoing collaboration with the NGO sector.

Utilisation of existing community-focused services for Aboriginal and Torres Strait Islander people: Stakeholders were concerned that people from Aboriginal and Torres Strait Islander communities were not engaging with the NDIS because it lacked cultural relevance. To address this **there should be funding provided to existing community-focused services already working in inclusive and culturally relevant ways with Aboriginal and Torres Strait Islander communities,** such Aboriginal Medical Services (AMSs) so that they can support applicants in their initial and ongoing interactions with the NDIS.

Ongoing independent pricing reviews: Pricing-related issues were seen as a cause of gaps because services were unable to provide appropriate and fully funded services for the prices indicated in the NDIS price guide. **There was therefore strong support within the stakeholder commentary for ongoing independent pricing reviews** which consider whether payments for NDIS-related services are able to meet Social, Community, Home

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[9] AIATSIS (2012) *Guidelines for Ethical Research in Australian Indigenous Studies*. Available online: **http://aiatsis.gov.au/research/ethical-research/guidelines-ethical-research-australian-indigenous-studies**.
[10] Department of Prime Minister and Cabinet (2017) *National Strategic Framework for Aboriginal and Torres Strait Islander Peoples' Mental Health and Social and Emotional Wellbeing*. Commonwealth Government: Canberra. Available online: **https://www.pmc.gov.au/resource-centre/indigenous-affairs/national-strategic-framework-mental-health-social-emotional-wellbeing-2017-23**

Care and Disability Services Industry Award (SCHACDS) wage levels and training, management and development needs of organisations. This would be most effectively established if the Federal Government were to implement the recommendation of the Productivity Commission to establish an independent NDIS pricing agency.

Advocacy via culturally-relevant services: People from culturally and linguistically diverse backgrounds are not applying at levels expected. **There should be a concerted effort and relevant funding by the NDIA to engage with services already working in culturally relevant ways with different cultural and linguistic groups to spread the message about the NDIS and support people through the application process.** The funding of interpreters for all interactions where English language is a barrier to understanding.

Ongoing funding for existing services: Because of the risk that individuals will be left with no support due to the funding of current programs moving to the NDIS, **the funding for existing programs serving the needs of this group and slated to close (e.g. PHaMS, PIR, D2DL) should not be ceased until all clients have either had their plan enacted within the NDIS or they have transitioned to another program which can meet their needs.** Transition should be carefully monitored so that individuals are not left in a place with no community-based support where they are forced to draw support from clinical services and acute care.

Establishment of a psychosocial disability gateway: Many of the gaps identified resulted from the poor fit of psychosocial disability with the structures developed by the NDIA to meet the needs of other types of disability. Stakeholders therefore felt that **the NDIA should move more quickly to establish a specialist psychosocial disability gateway to the NDIS to assess and work with applicants with a psychosocial disability.** This specialist branch should have a multi-disciplinary approach to its staff and the hiring of staff which should include social workers, OTs, mental health nurses, psychologists and support workers who have trained/worked within mental health programs/services. The psychosocial gateway would provide direct points of expert and accessible contact to reach out and assist and support people to overcome barriers to engaging with the Scheme, navigating the complexity of the assessment, planning and commissioning processes. Additionally, some individuals with psychosocial disability will require a prolonged planning engagement over multiple meetings in order to build the rapport and trust necessary for the development of a suitable plan. This extended engagement/planning process should also be a part of the specialised psychosocial gateway.

Creation of a Medicare number for NDIS assessments: A gap was identified around the cost and quality of assessments of psychosocial disability by GPs and specialists. **A specific NDIS item number should be developed so that medical practitioners can bill assessments to Medicare.**

Advocacy as an essential part of the NDIA approach to psychosocial disability: Many people with psychosocial disability were viewed as failing to engage with the program, the application process and, if plans were developed, could not enact the plans or coordinate services, meaning that plans were unused. In order to address this **there needs to be a focus on ongoing advocacy and support coordination as standard for potential clients with psychosocial disability.**

Involvement of carers and families as standard: Carers and family members were seen to be excluded from the NDIS and their needs were not routinely included in planning, which meant that they were left with support compared to the previous mental health support systems which included programs like Mental Health Carer: Respite. A solution was to **include as standard processes unless applicants expressly choose not to: 1) the involvement of carers and family members in assessment and planning and 2) the inclusion of carer needs in plans.**

Responsiveness to fluctuating illness: Unlike previous programs such as Partners in Recovery (PIR) the NDIS was seen as poorly responsive to the fluctuating needs of people with psychosocial

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disability. **The NDIA needs to develop a responsive system of short-term review which can be put in place quickly to increase support in times of increased need.** This could be funded through a contingency funding item in plans.

The next section of the report focuses on individual areas where gaps have arisen and associated solutions identified by stakeholders.

Gaps identified and solutions proposed

The NDIS journey for people living with psychosocial disability

We start by detailing the issues and challenges arising along the NDIS journey for people living with psychosocial disability themselves. Challenges arise from before a person engages with the Scheme and extend through to plan reviews and servicing of plans for those who were successful in receiving a package.

Many people are not applying (or choosing to test their eligibility) or are withdrawing their applications

Our conversations with stakeholders found that many people with psychosocial disability, across states and territories, are not engaging or applying at all. Others are withdrawing mid-way through the application process. Reasons provided for this lack of engagement and withdrawal were consistent from stakeholders we spoke to across all regions:

a.   **Lack of understanding or knowledge of the Scheme.** Stakeholders explained that many people living with psychosocial disability have no knowledge or understanding of the Scheme. This is particularly the case for those who are homeless and in hard-to-reach communities. There is no funding for assertive outreach in order to engage and inform these hard-to-reach, yet most likely to meet NDIA eligibility criteria, people. It is likely that many from this group of potential participants will need to hear the message about the NDIS several times before they absorb it and are prepared to engage with the NDIS.

b.   **Overwhelming complexity of the process.** Stakeholders reported that people with psychosocial disability are often unable to navigate the complexity of the application process alone and do not have advocacy/support to do so. Even with support, there are repeated examples across the country of people commencing applications but withdrawing due to what they experienced as a highly stressful and at times traumatising process.

c.   **A lack of specific support for Aboriginal and Torres Strait Islander people.** Aboriginal and Torres Strait Islander people living with psychosocial disability are often not applying. In large part, this is because there is a lack of Aboriginal workers to provide the pre-planning support in order for them to understand and engage in the Scheme in a culturally appropriate way. See also below.

d.   **A lack of culturally appropriate support for people from culturally and linguistically diverse backgrounds.** Different cultural concerns and attitudes to mental ill-health mean that conversations around psychosocial disability and access to the NDIS may be more difficult in certain cultural contexts.

e.   **Costs of acquiring reports.** Collecting acceptable evidence often requires people to pay for private consultants and specialist assessments to provide evidence of functional impairment and permanence of disability. These costs deterred or made applying impossible for some. In short, the poverty created by the disability was a barrier to application. The Joint Standing Committee has also raised this

concern regarding other areas, including children[11]. In some cases GPs have refused to provide reports because there is no Medicare code available to cover the work.

f.   People unaware that current services will terminate. Stakeholders relayed stories of people stating that they didn't want to apply because they were happy with their current services and did not understand or believe that funding for these services were being transitioned into the NDIS and would therefore not be available to them in the future.

g.   Anxiety, fear and illness-related barriers. Some people are not applying because of anxiety or fear about the Scheme. Sometimes this was based on a lack of information such as a fear of losing what they had before if they applied. At other times symptoms of their mental illness such as paranoia and anxiety were triggered.

An inherent part of their condition for many people living with psychosocial disability is "lack of insight" or "lack of awareness". The formal medical term for this medical condition is anosognosia. This is leading to many people who would benefit enormously from NDIA support choosing not to apply.

h.   Poor NDIS related support services. We heard repeated stories of excessive time delays in getting through the 1800 NDIS help line for clients and carers who needed help with the assessment form or had other NDIS related enquiries.

i.   Language of disability and permanence. Stakeholders highlighted the barrier created by the conflict and confusion around language. The language of permanent and lifelong disability is contrary to the mental health system's focus upon hope, recovery and living well. Mental health systems are increasingly driven by a recovery paradigm. Recovery in this context does not equate to cure, but rather living a personally meaningful and valued life. While the NDIA uses the language of recovery in some brochures, this is contrasted jarringly with language about permanence and life-long disability[12]. Evidence underpins the importance and value of these hopeful messages in contrast to messages of permanence. Stakeholders reported that many people, and younger people particularly, did not want to believe that their condition is 'permanent' and thus avoid applying because of this. This was particularly a problem for people from culturally and linguistically diverse backgrounds.

> *Stakeholders highlighted the barrier created by the conflict and confusion around language. The language of permanent and lifelong disability is contrary to the mental health system's focus upon hope, recovery and living well.*

Some professionals are not willing to label illnesses as permanent for young people (because of negative stigma associated with such a diagnosis) which means that young people are then left without the support they need. Young people also lack the resources to fund alternative assessments (Commonwealth Ombudsman, 2017)[13].

j.   Finite pre-planning support. Stakeholders expressed concern for future access to the Scheme with the pre-planning support funding coming to an end as NDIA moves to full roll-out. Again, the lack of and need for ongoing, culturally appropriate pre-planning support was particularly highlighted for Aboriginal and Torres Strait Islander people living with psychosocial disability.

k.   The "social and geographical isolation" felt by many people with mental ill-health, particularly Aboriginal and Torres Strait Islander people living in remote and regional communities, may make

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[11] Commonwealth of Australia (2017) Joint Standing Committee into the National Disability Insurance Scheme. *Provision of services under the NDIS Early Childhood Early Intervention Approach*. Report. December 2017.

[12] E.g. National Disability Insurance Agency, *What is Psychosocial Disability?*
https://www.ndis.gov.au/psychosocial/products

[13] Commonwealth Ombudsman (2017) Submission by the Commonwealth Ombudsman. Joint Standing Committee on the NDIS. The Provision of services under the NDIS for people with psychosocial disabilities related to a mental health condition.

engagement for effective assessment particularly difficult, meaning that these people do not access the NDIS[14].

l.   **Translation services are not consistently available** for pre-planning meetings.

Solutions posed (note gaps relating specifically to Aboriginal and Torres Strait Islander people and solutions are also discussed separately below)

Better information systems put together by the NDIA for explaining NDIS to people who are potentially eligible in order to encourage applications:

- Ongoing, centralised (run by NDIA) information, that is easy to understand and specific to psychosocial disability for each region prior to roll-out and ongoing as rollout takes place and more workers join the assessment, planning stages
- It is necessary for assertive outreach that explains the NDIS in relation to psychosocial disability to go into culturally and linguistically diverse communities to encourage applications. There is necessity for ongoing advocacy arrangements to be made to facilitate this as current ones may be terminated where state or territory governments end advocacy funding when NDIS introduced
- Funding of psychosocial disability peer support for culturally and linguistically diverse communities to assist with building knowledge of the NDIS. This funding should go through existing NGOs already working in these communities
- Better (more coordinated) use of existing resources e.g. reimagine today **https://reimagine.today/** and accompanying workbook. Resources should be available in different languages. Resources should be developed using accessible language and with click through explanations of key terms in easy to read formats

The NDIA should work with people, organisations, places of worship, and community services already working with culturally and linguistically diverse communities.

- Targeted and culturally appropriate media campaigns and information sessions are needed for Aboriginal and Torres Strait Islander people
- The NDIA should work with people, organisations, places of worship and community services already working with culturally and linguistically diverse communities, so that the message about the NDIS reaches these communities, through their existing networks. The NDIA should target media relevant to different cultural and linguistic groups
- Better use of the existing peer-support workforce to spread information about the NDIS. There are existing materials which could be modified for this purpose. For example the MHCC in NSW has a professional development module that can be adapted for use: **http://www.mhcc.org.au/sector-development/workforce-development/peer-workforce-development.aspx**
- Localised information-based services should be implemented through PHNs targeting people they already engage with who are socially and geographically isolated and delivered concurrently with existing programs e.g. a community wheels service, social groups/clubs

Better information on the NDIS put together by the NDIA in collaboration with PHNs to family members and practitioners already working with the target group:

- Targeted free training of professionals (GPs, allied health) in settings which make sense – such as within their own workplace, e.g. 15 minute consultation-length training for GPs

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[14] Community Mental Health Australia (2017) Submission to the Joint Standing Committee on the NDIS – The provision of services under the NDIS for people with psychosocial disabilities related to a mental health condition; Community Mental Health Australia (2017) Submission to the National Audit Office. Decision-making controls for sustainability – National Disability Insurance Scheme access. **http://cmha.org.au/wp-content/uploads/2017/06/ANAO-decision-making-controls-for-sustainability-NDIS-access-CMHA-submission.pdf**.

- National marketing to the general population which is clear and accessible
- Local Area Health Networks and GPs should receive training around the likelihood that they will be approached for assessments for people seeking to participate in the NDIS and there should be appropriate referral pathways established as well as agreements for doctors and other health practitioners to be reimbursed by Medicare for providing those reports and assessments
- There should be an education campaign aimed at GPs and psychiatrists to encourage people likely to be eligible not to regard NDIS support as stigmatising

Information about the termination of existing programs and transition to the NDIS:
- It needs to be very clear to services currently providing for this group which services will not be receiving ongoing funding and they need to know of end dates so that they can work backwards from them with client needs in mind
- Services already working with people with severe and complex mental illness need to specifically identify and work with the people who will be impacted. There should be a person-centred approach to transition. The benefits of the NDIS need to be explained on an individual basis, working with an individual's strengths and without spreading fear about service closure and loss of support. Information should specifically state what will happen and when for clients. Workshops should also be funded by PHNs on the end of services for clients and provide details about support for transition and other programs available

Creating an environment more conducive to receiving applications:
- Courteous people with knowledge of the NDIS and psychosocial disability should be handling NDIS phone and in-person support. Kindness is important. This contact point should be a person (not a recorded information service) and this person needs psychosocial expertise. There could also be a role for a peer-support group to take this on

> *Courteous people with knowledge of the NDIS and psychosocial disability should be handling NDIS phone and in-person support. Kindness is important.*

- There should be NDIS-specific advisors with knowledge of psychosocial disability to assist applicants in places where NDIS applications are made (e.g. Centrelink)
- Currently Centrelink is set up so people are not encouraged to attend (encourage online applications, long waiting times, may be linked with past denials of support). The NDIA needs to work with Centrelink to address these problems or provide an alternative access point. Psychosocial disability-specific peer workers should be available to support and 'translate' the Scheme at point of assessment and planning, especially when a person does not have a known service worker or informal family support present
- There should be a dedicated phone information line handling psychosocial disability-related enquiries
- Information on the application process in plain language should be available through Aboriginal and Torres Strait Islander-controlled organisations and other health and community workers that people already know and trust
- Psychosocial training for NDIS-related workers (information providers, assessors and planners) is needed so that they understand the barriers that psychosocial disability might pose to engagement and application submission and provide more empathetic support
- There should be a strategic change in the wording of eligibility requirements within NDIS information for psychosocial disability from "permanent" to the language of "persistent, chronic or enduring". These alternative terms would be more suitable in the mental health context

Making the application process more accessible:
- Have a single entry point for applicants to provide information for proving eligibility rather than multiple points where the same information has to be given

Psychosocial disability training for NDIS-related workers (information providers, assessors and planners) is needed so that they understand the barriers that psychosocial disability might pose to engagement and application submission and provide more empathetic support.

- Could use data sharing (with consent) to just collect the information from other systems passively
- Form needs to be checked for accessibility. Currently the forms are too long and too difficult to navigate
- Extra funding for advocacy for hard to reach groups e.g. rural and remote groups. Currently some advocacy for appeals and complaints in metro areas but not rural and remote
- System responsiveness needs to be increased because of sudden changes in need level for people with psychosocial disability which may make them need to enter the Scheme quickly. Transient arrangements need to be put in place where this is not possible
- Advocacy for people from culturally and linguistically diverse communities is needed to encourage people to apply and to support them through the process. There should be bilingual planners and LACs in target areas, but this should not mean that interpreters are not available and routinely used where necessary
- The culturally and linguistically diverse NDIA strategy should consider psychosocial disability specifically
- Translation of materials. Bilingual information sessions. Interpreters available with knowledge of NDIS and how to speak about psychosocial disability in a culturally relevant way. It is a right for people to be able to access information in a language that they can understand
- There should be a dialogical approach to access where individuals are able to discuss their concerns and needs with people who are interested in developing an understanding of the individual's situation and explain from that basis how the NDIS may meet their needs
- The NDIA and LACs should develop ongoing relationships with community workers, community leaders and others (e.g. Community Participation Officers in LGAs, Emergency Department workers and the Police) who are connected to isolated individuals with disability and their families in order to identify participants and barriers to engagement

Advocacy is important for targeting groups that are applying less:
- Intensive applicant support and independent advocacy to consumers and their families to access and navigate the NDIS
- Advocates, including peer workers already working with people from culturally and linguistically diverse backgrounds, should be provided with ongoing NDIS training to assist people to engage with the Scheme

Raising understanding about psychosocial disability within the NDIA and the information it produces:
- A dedicated NDIA lead for psychosocial disability needs to draw on the knowledge of the advisory group to work on language and processes around the NDIS to make them more appropriate to psychosocial disability and the recovery model. This should include reviewing and changing the language used in documentation across the Scheme – this will educate staff and make the program more accessible
- LACs must have training in psychosocial disability. Acknowledgement that some people need significant help with the process (not one size fits all) and that this may need to be a slow, back and forth, face-to-face process and take between 30-100 hours
- Inclusion of people with a lived experience of psychosocial disability on the NDIA Board and throughout the organisation
- There should be a genuinely independent and critical evaluation of the Scheme aimed at identifying difficulties and making strategic recommendations from the point of view of those accessing,

supporting and providing it. It should ensure that the Scheme aligns with the National Mental Health standards

Pre-planning support should be better utilised and offered by the NDIA working with PHNs and existing organisations working with the target group:

- Pre-planning support should continue because new people with psychosocial disability will always come into the Scheme
- The federal government should provide additional funding for the existing mental health non-government sector to provide pre-planning support
- Support workers or case managers already working with this group should assist in pre-planning
- Translation services for Aboriginal and Torres Strait Islander languages should be funded by the NDIA and available for pre-planning meetings otherwise plans will not meet participant needs
- The Queensland Government funds the participant readiness outreach project **http://qldalliance.org.au/participant-readiness-initiative-extended/.** This program, or an equivalent project, needs to operate in other states and territories. Federal funding would help with consistency around these types of programs or people in one state or territory will end up having a better experience or greater access to the program than others

Barriers to access by Aboriginal and Torres Strait Islander people

There are multiple barriers in the way of Aboriginal and Torres Strait Islander people to know about and apply for the Scheme. The barriers result from:

a. *A lack of culturally-specific support services* to enable NDIS involvement. There is also a lack of specific Aboriginal and Torres Strait Islander community-controlled NDIS providers (in the ACT there are no Aboriginal and Torres Strait Islander specific NDIS providers).

b. Aboriginal people, living in both city and rural contexts, as a community of people particularly disadvantaged though *lack of awareness of the Scheme.*

c. *The language of disability* is a barrier for Aboriginal people. In some regions is also a need for translation services to be provided.

d. Many Aboriginal and Torres Strait Islander people *feared engaging in government services and asking for support*, because of a distrust about government programs stemming from past poor treatment or compulsive programs. This was particularly where children were involved, due to generational histories and experiences of child removal.

e. *Social and geographical isolation* encountered by Aboriginal and Torres Strait Islander people in urban, rural and remote communities. An active "outreach model" owned by communities has been effective in engaging isolated communities, as can be seen in the example of Palm Island[15].

f. There is a *lack of an Aboriginal and Torres Strait Islander support unit within the NDIA.*

g. For Aboriginal and Torres Strait Islander people *health is linked to social, emotional and cultural wellbeing.* Disability is an added experience to Aboriginal social disadvantage.

Solutions posed

The NDIA needs more direction specific to Aboriginal and Torres Strait Islander people with psychosocial disability:

- The NDIA needs to develop a specific strategy for Aboriginal and Torres Strait Islander people with psychosocial disability (in addition to their existing general strategy)

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[15] Community Mental Health Australia (2017) Submission to the National Audit Office. Decision-making controls for sustainability – National Disability Insurance Scheme access. **http://cmha.org.au/wp-content/uploads/2017/06/ANAO-decision-making-controls-for-sustainability-NDIS-access-CMHA-submission.pdf.**

- The NDIA should work to support Aboriginal Medical Services (AMSs) to develop specific support services e.g. the model being used in East Arnhem through an AMS called Miwatj Aboriginal Health Services as a solution
- ILC funding should be prioritised so that it is used for providing NDIS advice through organisations already working with these communities.
- Co-design of services so that they are appropriate for the needs of all those in remote communities
- Staff to be trained in Cultural Competency for better service delivery to Aboriginal and Torres Strait Islander people, including education on the Stolen Generation and trauma, and how to better understand their needs. This should not supplement community-controlled services delivered by communities in local languages
- The NDIA needs to reach out, connect with and fund existing Indigenous peak bodies such as the National Aboriginal Community Controlled Health Organisation (NACCHO), First Peoples Disability Network and so forth and work with them to develop a more relevant focus to the NDIS

Develop capacity within the Aboriginal and Torres Strait Islander communities to work in NDIS-related roles and provide leadership:
- The NDIA Reconciliation Action Plan should be drawn on as a set of principles for driving work in this area: **https://www.ndis.gov.au/html/sites/default/files/documents/16-087-RAP-WebPDF.pdf**
- The NDIA needs to develop a specific workforce plan for increasing the employment of Aboriginal and Torres Strait Islander people in NDIS-related roles
- Employment of Aboriginal and Torres Strait Islander staff and funding provided by the federal government to services so that they can build up their competency in working with Aboriginal and Torres Strait Islander communities. A specialised support team co-designed and led by leaders, consumers and carers will help with ongoing engagement

The NDIA needs to develop a specific workforce plan for increasing the employment of Aboriginal and Torres Strait Islander people in NDIS-related roles.

- Access and outreach needs to happen through services who have existing trusting relationships with communities
- Specific grants should be provided through the federal government to target providers already working within Aboriginal and Torres Strait Islander communities that can develop programs, supports etc. to meet the specific needs of the community
- Training and financial assistance to develop Aboriginal and/or Torres Strait islander community controlled NDIS providers

Specific advocacy and resources to encourage Aboriginal and Torres Strait Islander people's involvement in the NDIS:
- Encourage the expansion of existing programs such as that run by the First People's Disability Network: **http://fpdn.org.au/our-work/**
- Support line where individuals can receive specific Aboriginal and/or Torres Strait Islander-focused advice on psychosocial disability and the NDIS
- Information on the NDIS should be provided through information sessions provided by Aboriginal and Torres Strait Islander community controlled organisations. This could be developed specifically but can also draw on existing resources, for example Australian Indigenous Health InfoNet provides a diversity of resources and information including publications about a range of programs, projects and research. Available at: **www.healthinfonet.ecu.edu.au**
- Necessity for further NDIS resources and application processes for Aboriginal people and in community languages using interpreters if needed
- Shop fronts or locations where people can access the NDIS away from government (i.e. not at Centrelink which may have negative associations for people from past contact) and through existing trusted providers

- An holistic approach to assessment and planning should take place including, as relevant, an individual's family and community members. What is relevant will depend on the individual and their community
- There needs to be an understanding of, and respect for, using correct protocols and sensitivity when accessing Aboriginal and Torres Strait Islander communities and each has their own protocols and sensitivities
- Existing, successful engagement programs should be scaled up but with an acknowledgement that every community is different and programs must work inclusively with communities if they are to be relevant

The burden of evidence collecting, proving eligibility and eligibility assessments

The second step along the NDIS journey that has created particular barriers and challenges for people living with psychosocial was the process of proving that they met the NDIS eligibility criteria. The following issues and barriers particular to people with psychosocial disability were described by stakeholders:

A lack of evidence to support eligibility. Stakeholders across the country spoke of the complexity for this cohort of collecting the evidence required by NDIA to prove that they had a permanent, functional disability and thus met the Scheme's eligibility criteria. Evidence was particularly hard to obtain for people who are often disconnected from services and supports or don't have access to services and supports (such as people in rural, regional and remote areas), are transient and/or homeless, or face difficulties in accessing services and information such as with people with language barriers. The following factors were noted:

a. Difficulty in managing evidence for eligibility. Many people don't have the evidence required, some can't get the evidence, and for others the process of trying to get the evidence required for application was just too hard and this led to people deciding not to, or feeling unable to, apply despite the high likelihood of being found eligible.

b. Transience makes evidence hard to track down due to homelessness, incarceration or inconsistent engagement with services and GPs.

c. Only certain evidence counts. Stakeholders repeatedly spoke of the frustration of having a range of quality evidence such as years of case notes and other written history that they felt should be able to support a person's application but was deemed not acceptable evidence.

d. The psychosocial disability itself adds to the complexity of providing evidence due to mistrust or paranoia.

e. Many people with mental illness are not engaged with treatment and services which means that for many who likely fulfil the NDIS criteria for a package, an extended history of specialist evidence does not exist.

f. Permanence was a difficult eligibility criteria to prove. the transience of many people, their chronic disengagement or avoidance of support and services, and some people's anosognosia, or lack of awareness of having an illness, collectively create a particular challenge to collecting a longitudinal body of evidence for 'permanence' of disability.

g. There is a shortage, and in some areas a complete lack, of available specialists to get supporting evidence from. GPs, and other providers or services outside mental health, frequently do not understand that NDIS is accessible for people with psychosocial disability or do not understand what detail is required in an application. This is particularly a problem for remote and rural clients.

h. All of the complexity described above meant that for many people the burden of evidence collecting was overwhelming and distressing. They often had no support in the process.

i. Stakeholders commented that fluctuating mental ill-health and functional impairment which is not always visible complicated people's ability to collect acceptable documentation and evidence of 'permanence' from specialists. it was common that a person would only be able to make it to specialists for an assessment on a 'good' day – thus these assessing 'experts' only saw a person at their best if they didn't have a history of contact with the person. People alternatively too acute or too well to be assessed as eligible.

j. Assessment processes do not provide a framework which allows for accurate assessment of psychosocial disability, but are <u>more geared towards physical or intellectual disability</u>.

Solutions posed

Person-centred supports need to be developed by both the NDIA and existing services to assist individuals through the application process:

- Necessary to work with existing services to develop a modified access route with additional supports for people whose psychosocial disability or other complexities means they cannot gather evidence
- Needs to be a dedicated support program with modified timelines to facilitate access. Needs to be a level playing field for choice and control to be achieved equally. This will mean extra supports for some
- Assertive outreach to communities or specific groups where there is a known lack of people applying. Assertive outreach should target places where people do currently access services e.g. food banks
- For people with complex needs there needs to be a multi-disciplinary approach to planning or facility for additional voices to enter the planning process where these are indicated. This could be PHNs or another network of support – should be person centred and understand their networks to work. The NDIA should learn the experiences of Partners in Recovery in undertaking this type of work with this community
- The evidence required and by whom needs to be provided from the NDIA at the beginning of the assessment process so the individual and organisation supporting the client so that they are clear and that there is an agreement on evidence needed, rather than going backwards and forwards on what evidence is needed

Structured training funded by the NDIA for those involved in assessment and planning:

- Professional development for NDIA staff to assist with understanding complexity, the context of psychosocial disability, rehabilitation and recovery so that they have an understanding of the life contexts of those applying
- Fund LACs to have psychosocial disability-trained staff or work with existing service providers to provide specialist psychosocial disability-related assessment and planning
- Training of LAC staff and assessment staff to adequately understand the impact of someone's psychosocial disability over a longer term as well as the immediate situation. This is particularly important given the fluctuating nature inherent to psychosocial disability
- Training through the PHNs of GPs and Allied Health professionals in assessment in psychosocial disability and functional disability

> *There needs to be a level playing field for choice and control to be achieved equally.*
> *This will mean extra supports for some.*

Evidence process needs to be clarified by the NDIA and better funded for clients and those creating reports:

- Develop a cohort of specialists for organisations/clients to access known as experts in NDIS assessment processes
- GP and specialist assessments, required by NDIA for NDIS eligibility assessments, should be made Medicare billable with an NDIS-related item number
- Training in intercultural understandings of psychosocial disability for those involved in assessing applications and providing reports on level of disability as part of the application process
- Better clarification about the information required in reports from specialists to go with requests so that they do not have to be recreated if the information is incomplete

- Creating a facilitation aspect to the application process (or fund another service already working with this group such as PIR to do it) for those who are not able to bear the cost or process of gathering specialist reports.
- Develop a standard way of measuring functional impairment, for example via LSP 16 (**https://www.amhocn.org/publications/life-skills-profile-lsp-16**) and WHODAS (**http://www.who.int/classifications/icf/whodasii/en/**), backed up by a report from the support worker so that extra assessments are not generally needed
- There are three parts to the evidence process, each best dealt with by different expertise and processes: Demonstrate the presence of a diagnosis/illness that is likely to be permanent; Assess or evidence the presence of functional impairment and reduced functional capacity, because of that illness/diagnosis; Demonstrate the impact that the functional impairment has on the individual's social or economic participation. Different knowledge may be needed for each of these parts of the process

Funding and facilitation of extra assessments should be made available through the NDIA where the person appears eligible but there is not enough information given in reports.

- Funding and facilitation of extra assessments should be made available through the NDIA where the person appears eligible but there is not enough information given in reports
- Allow organisations holding ring-fenced in-kind funds to utilise these to cover the costs of assessment by practitioners with a speciality in psychosocial disability. Funding has been set aside for in kind support to the NDIS and is not being used

Changes to NDIA assessment processes for people with psychosocial disability:
- Training of assessors so that they remove the expectation that someone needs to have a diagnosis for a particular time period to be eligible for NDIS as this same measure does not apply to other forms of disability
- For those that are socially or geographically isolated or because of their disability need specialist assessment there should be a government funding stream for alternate processes. Fly in fly out teams may need to do assessments in rural and remote areas

The NDIA needs to develop a framework which allows for fluctuating illness:
- Needs to be a specific acknowledgement by the NDIA of the fluctuating nature of psychosocial disability – review meetings should be able to function as a way of addressing this, but only if they are able to be reactive to situation changes, and not just take place on an annual basis. The NDIA should develop a wider definition of 'permanence'. Permanence doesn't mean unchanging. Changing eligibility criteria to meet the needs of people in different stages of recovery
- Assessments should draw on information from services which have seen people over a longer period and can reflect on the ups and downs of their mental health
- Having a discrete section of the NDIA which can be called on as an alternative eligibility step for people with fluctuating mental illness - trained staff, or staff who have worked in the mental health sector assess applicants for appropriateness to receive NDIS supports

Inconsistent, poor quality assessments of eligibility

Stakeholders spoke about the high numbers of people being assessed as ineligible as well as the seemingly ad hoc, inconsistent, ill-informed nature of the NDIA assessment process and thus decisions:

   a. Many people with severe, persistent and disabling mental illness are assessed as ineligible. A consistent story across the country was that a great many people had been assessed as ineligible even if they had a disability support pension that had been granted based upon equivalent criteria – in terms of their condition having a disabling impact on the ability to undertake day-to-day tasks - and when those with extensive mental health experience and knowledge of the person knew that

they were 'perfect' candidates for the Scheme and had been able to provide that evidence to NDIA.

b. <u>Eligibility assessments demonstrate poor understanding of psychosocial disability:</u> Stakeholders repeatedly talked about the clear lack of psychosocial training and knowledge of those assessing people's eligibility and the Local Area Coordinators (LACs). The fluctuating nature of psychosocial disability was not understood by NDIA assessors and they appeared unable due to lack of understanding to align this with NDIS language of permanence of functional impairment.

Some assessors are using diagnostic labels to justify (or not) eligibility. Diagnostic labels do not provide a very good simulacrum of functional impairment and that there exists no shared functional assessment tool which can be used to assess functioning in the context of mental ill-health[16]. Some people were also not ruled ineligible for NDIS funding because their mental health condition was too 'unstable' or their illness too acute[17].

c. <u>Eligibility assessment was inconsistent across different sites.</u> The lack of assessors' understanding and expertise in psychosocial disability led to inexplicably inconsistent outcomes for people. Stakeholders provided many examples of differing outcomes for individuals with equivalent diagnosis, equivalent permanence and equivalent level of functional impairment.

d. <u>There was poor understanding of co-morbidity.</u> This included the interlinked relationship between psychosocial disability and chronic disease and issues related to drug and alcohol use, and the co-occurring impacts that these have on people's functional ability.

Solutions posed

Changes to review processes:

- Assessment of the reason/s for their ineligibility (e.g. lack of evidence) so that people are able to identify and counter this with further evidence
- Review process needs to be more streamlined and strict timelines enforced
- Funding should not be frozen during the review process. There should be a presumption that they are eligible, not ineligible
- Look at providers already working with the applicant as useful experts and engage with them in the review process to understand the clients they support and to seek their advice

Developing and implementing an NDIS Plan once eligible

The planning meeting

The planning meeting is another stage in the NDIS process where service gaps emerge. In some cases this is undertaken at the same stage as the assessment meeting. Stakeholders identified the following key issues:

1. **Extensive time delays:** Time delays of up to one year were reported between when a person was assessed as eligible and the planning meeting. Delays were further exacerbated when additional specialist assessments (such as occupational therapist assessments) were identified as being needed by planners to evaluate people's functional capacity at initial assessment or as a 'proxy' for the person's first plan. Stakeholders reported that the delays in establishing plans were due to NDIA staff catching up with a back-log of plan reviews and appeals.

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[16] Community Mental Health Australia (2017) Submission to the National Audit Office. Decision-making controls for sustainability – National Disability Insurance Scheme access. **http://cmha.org.au/wp-content/uploads/2017/06/ANAO-decision-making-controls-for-sustainability-NDIS-access-CMHA-submission.pdf**.

[17] Mental Health Australia (2017) Response to the Productivity Commission National Disability Insurance Scheme (NDIS) Costs Position Paper.

2. **If individuals were acutely unwell and unable to attend the planning session they had to restart the application process.** Stakeholders relayed accounts of people who had been deemed eligible, but after needing to decline their planning interviews due to acute illness, having to restart the whole application process again. **Extensive delays contribute to the gap relating to the NDIS as other funding must be found to fund services during these delays.**

3. **Planners lack training and understanding of psychosocial disability.** Stakeholders repeatedly talked about the lack of mental health training and knowledge of planners. This lack of knowledge and translated to a lack of understanding of the episodic and fluctuating nature of psychiatric disability and led to plans being made based upon naïve judgements of how the planner believed the person seemed to present on the day.

4. A lack of cultural understanding amongst NDIS staff is leading to **culturally inappropriate plans for Aboriginal and Torres Strait Islander people.** This results from a lack of training.

5. **Planning tool used in a simplistic, tick-box way.** Whilst perhaps intended only as a guide for planners, we heard repeatedly that they lacked the capacity to do more than read questions off the tick-box tool to people. Planners did not ask open ended questions to facilitate dialogue and thus establish a more nuanced understanding of applicants' yes or no responses to tick-box questions. They did not help the applicant to reflect and provide a fuller and more accurate response.

6. A lack of training and understanding means that **plans are created which don't meet the needs of people from culturally diverse communities.**

7. **Face-to-face planning meetings denied.** People were often denied or not given the option for face-to-face planning meetings. As described above in relation to the over-the-phone initial NDIA contacts, this heightens anxiety and distress for many people living with psychosocial disability who may feel less comfortable and safe speaking over the phone to someone they have never met, and less able to effectively articulate and advocate for their needs.[18]

8. **Planning sessions occurred without support.** Repeatedly we were told of people receiving a phone call out of the blue, having a conversation with the person on the other end of the line and then realising or not realising that it had in fact been a planning or assessment meeting. This leads to people being unsupported and not even given the option of support, with consequent impacts being no understanding of the process and an inability to adequately explain their situation.

> *Repeatedly we were told of people receiving a phone call out of the blue, having a conversation with the person on the other end of the line and then realising or not realising that it had in fact been a planning or assessment meeting.*

9. **Support people present not allowed to offer support.** Some people did have staff or support people present from services that they had engaged with over a long period of time and who therefore knew them well. However, repeatedly we heard that these support people were not allowed to speak at the meeting or to actively support them to better understand what was being asked and add depth to their responses. Without stakeholder support they therefore missed out on supports they should receive.

10. **Expert functional assessments and recommendations ignored.** Many stakeholders described with frustration having invested time and resources to get specialist assessments to support people's applications only to discover down the track that they had been ignored by planners. This also related to the lack of understanding and expertise of assessors, particularly where experts information is either being ignored or questioned.

11. **No opportunity to review the plan before NDIA sign-off.** A consistent issue raised by stakeholders – as has been done in formal reports by the Productivity Commission – was that people were not being allowed to view a plan before it was finalised. This meant that people were unaware of what they had agreed to and in some instance, thought they had agreed to certain supports and goals which then did not appear in the plan. This then creates a need to request a plan review, causing further delays to finalising a plan

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[18] The NDIA have now committed to ceasing this over-the-phone practice and to now assessing and developing plans with people face to face.

and accessing services. It also leads to a situation where services must provide necessary services without being paid.
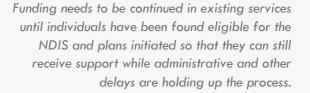
Those that have worked with this target group with high needs state that it is difficult to develop a plan without first developing relationships with people but this time is not available within the NDIS planning process[19]. Hunter PIR (2015) estimate that it takes between 22 and 25 hours per client. This lack of support for assessment may lead to more people with psychosocial disability being deemed to be ineligible for the NDIS and therefore falling into the 'gap' around the program[20].

A small number of providers mentioned that they had a good relationship with planners and that the planning process was quite collaborative. This was because they worked in small communities, rural and remote and because they had existing relationships with people now working for the NDIA.

Solutions posed

Continued investment during delays in transition:

- Funding needs to be continued in existing services until individuals have been found eligible for the NDIS and plans initiated so that they can still receive support while administrative and other delays are holding up the process
- There needs to be training and higher levels of qualifications for NDIA staff so that they are able to process applications faster and more effectively

> *Funding needs to be continued in existing services until individuals have been found eligible for the NDIS and plans initiated so that they can still receive support while administrative and other delays are holding up the process.*

- Short term funding of additional LACs should be provided in order to clear backlogs. With collection of timeframe data this would be able to be monitored and extra staffing and resources allocated
- Funding of advocacy bodies to support complaints and reviews via state government funding

Train planners in working effectively with psychosocial disability:

- Planners need to be professionally registered and be required to access ongoing training including in psychosocial disability, recovery and person-centred care
- The NDIA create teams of planners which are specially trained in psychosocial disability or are recruited because of their existing knowledge of psychosocial disability
- Planners engage with the providers who already work with people to understand them better
- Planners need to have a higher level of base knowledge (e.g. university level or equivalent experience or training in a relevant field) so that they can take on and use concepts such as psychosocial disability or recovery
- Planners need training in how to get information out of people about what they want e.g. motivational interviewing
- Training for planners to understand assessments and recommendations as they may not actually understand the information provided. Planners to include staff who have expertise, skills and qualifications within the field. For example, must have a minimum qualification in related field (i.e. human services, community services)
- Supports such as carers, family members and paid workers familiar to the individuals must be involved

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[19] Partners in Recovery Tasmania (2017) Submission to the Joint Standing Committee on the National Disability Insurance Scheme: the provision of services under the NDIS for people with psychosocial disabilities related to a mental health condition; Hunter Partners in Recovery (2015) *Partners in Recovery and NDIS Interface: A data report from the Hunter and Perth Hills trial sites.* Available online: **https://hunterpir.com.au/wp-content/uploads/2015/12/PIR-NDIS-Interface.pdf**.
[20] Hunter Partners in Recovery (2015) *Partners in Recovery and NDIS Interface: A data report from the Hunter and Perth Hills trial sites.* Available online: **https://hunterpir.com.au/wp-content/uploads/2015/12/PIR-NDIS-Interface.pdf**.

- An official easy to interpret flow chart should be created and used throughout process to demonstrate to applicants what is happening and when
- Practice should align with the Disability Standards of Australia

NDIA to implement strategies to ensure culturally competent workforce:
- There needs to be Aboriginal and Torres Strait Islander people working as planners in all areas, with more in areas with larger Aboriginal and Torres Strait Islander populations
- Necessary to build the cultural competence of staff through mandatory training for all those employed in NDIS related roles
- There needs to be incentives for organisations to employ Aboriginal and Torres Strait Islander people in key roles
- Planners should work alongside Aboriginal and Torres Strait Islander workers and Local AMS staff already working with communities

Greater flexibility in developing, implementing and reviewing plans:
- Greater flexibility in planning processes to allow for fluctuating illness. Need kindness and ability to call on next of kin with permission
- Accommodations in process (much as would be expected for people with a disability in employment) which allow for Skype, written correspondence etc.
- The NDIA should develop policy that clarifies the criteria for eligibility, aligns these criteria with the concept of functionality, and clarifies the degree to which diagnosis may influence eligibility decisions
- However no plan should be developed for anyone without suitable support present as standard, and no amount of cultural training will make up for this
- Face-to-face meetings need to be default except where people need accommodations for disability which change this
- Meetings should be arranged around the individual so that they can have a support person present
- The implementation timeframe needs to be adjusted and made more realistic
- Appeal processes should be provided with plans
- It is necessary to allow people time (and advice on how) to review their proposed plan prior to signing off on it – or introduce a cooling off period. The LAC should be an intermediary between planner and applicant (and carer/next of kin if needed)
- Minor changes or mistakes should not trigger a full review
- As choice and control is, purportedly, one of the foundations of the NDIS where people are not allowed to review plans before signing off this should trigger the immediate review of the plan and retraining/investigation of the relevant NDIS staff member
- Needs direction from NDIA National office to local offices to ensure support people are actively involved with the consent of the individual to plans

Ongoing, systematic and transparent data collection to inform improvement activities:
- The NDIA needs to monitor timeframes and publish them in order to make services aware of where they are against other services and mandated timeframes
- NDIA staff and LAC performance needs to be monitored e.g. audits of plans, monitoring of planner competency via a professional body
- The NDIA should conduct a review into the allocation of NDIS packages for people with psychosocial disability to determine whether participation in the NDIS, and expenditure on this group, is lower than expected. If participation and/or expenditure is relatively low, the NDIA should take steps to identify the barriers to participation for this group and address them

The quality and utility of the plan received

NDIS plans have been very positive and life-changing for many people living with psychosocial disability. Stakeholders all agreed that for some people this was the first time that they had access to services and resources they needed. However gaps also emerged as a result of poor quality plans received:

a. **Plans do not align with needs identified in assessment.** Poor practices at the planning meeting stage detailed above, led to many people receiving inappropriate plans and a high volume of time-consuming, costly and distressing appeals. Some people's packages were inadequately low while others just did not align with their expressed needs. For example across the country, we frequently heard that transport and travel supports, fundamental to peoples' ability to engage and participate in the community, were lacking in peoples' packages. Rigidity of what supports were and were not able to be included limited the usefulness of plans as they resulted in needs half met. Some supports were deemed to be health-related and not included when this was not the case. People also received expensive items in their packages that they didn't need and hadn't asked for.

b. **Confusion around Support Coordination.** Stakeholders struggled to understand and were frustrated by the inconsistent and seemingly ad hoc allocation of support coordination as well as the amount of support coordination hours allocated in plans. Stakeholders talked about ongoing changes in policies and practices around support coordination. This may have resulted from a different conceptualisation of support coordination to that currently offered in programs such as PIR. It typically related to a lack of clarity and understanding about these policies and practices, including who was responsible – LACs or providers - and incorrect or unclear communications from the NDIS and LACs. For example, there is an ongoing lack of clarity about the ongoing role of LACs in providing support connection – which requires lower level expertise - and support coordination and special coordination – which requires high level expertise; and the apparent blurring of lines between the different categories of support coordination.

> *Stakeholders struggled to understand and were frustrated by the inconsistent and seemingly ad hoc allocation of support coordination as well as the amount of support coordination hours allocated in plans.*

c. **Many plans are not being activated.** Across the country we heard repeatedly that many people had received plans but have not actually activated or used them. This was most common when people received their plans in the mail but: 1. didn't realise or understand it was a plan when they opened it; 2. didn't actually open the letter because they were either frightened or thought it was junk mail and threw it away; 3. Opened the letter and were overwhelmed with what the letter was saying; or 4. simply did not having any idea of how to get 'started' or who to contact. This may result from a lack of support coordination.

d. **Confusion around capacity for choice and control.** People under protective guardianship were being offered to self-manage their plans, whilst others with capacity to do so were not availed with this choice.

Solutions posed
Coordination of planning:
- Have independent service providers (who do not provide NDIS services) support people with disability to create tailored plan (due to potential conflicts of interest)
- Support coordination should be standard unless people opt out. This should be federally funded as PIR was.
- The NDIA should produce clear information regarding the roles of LACs in relation to support co-ordination versus the role of PIR in delivering support co-ordination
- Planners to maintain contact until the plan is activated. This should be monitored and recorded and needs to be followed up by the NDIA through LACs to understand why plans are not being activated (i.e. is it due to lack of services available or the client is unable to activate it for themselves)

- Support coordination should be built into first two plans at least or this should be provided as standard unless they opt out
- Review of plans as mandatory
- Planners need to identify and connect an individual with a support coordinator

Clarification of plans and planning:
- Information/training to people in the community should be provided by the NDIA and LACs to give a more realistic understanding of plan contents
- The NDIS provider should provide clear communication in the form of brochures around what the participant could expect and not expect
- PHNs to work with the NDIA to clarify support co-ordination and who is delivering this (i.e. LACs or PIR). This information should be provided in an accessible form
- Family members and carers should be involved as standard so that someone who knows their needs can check them
- Planners need to be able to explain in a clear but kind way what can be included in a plan
- Carers and support people should be encouraged to be involved to help to interpret what is available and how to access it
- Training for planners to understand assessments and recommendations as they may not actually understand the information provided. Planners to include staff who have expertise, skills and qualifications within the field. For example, must have a minimum qualification in related field (i.e. human services, community services)

A person receives an appropriate NDIS Plan – but it can't be serviced

Even for those people who received a comprehensive plan that aligned well with their needs and desires, there were a number of barriers in terms of actually being able to use the plan.

a. **Lack of provider services available.** Stakeholders described a frequent inability to find an available provider for services in the plan. This particularly applied to the following contexts:

1. **Missing services.** The services that stakeholders highlighted as particularly hard to find NDIS approved providers for included psychology, short term respite, particularly those able to deal with complexity of health-related needs, hoarding and squalor services with an understanding of mental health and trauma-related needs.

2. **Weekend services.** Stakeholders also said that trying to find weekend services for people was even more challenging because providers could not make weekend services financially viable.

3. **Rural and remote services.** While this lack of providers was a national issue, it was particularly emphasised in rural and remote contexts often no service providers existed at all. Where services did exist, the market was so thin that consumers had no choice of provider. Some stakeholders explained that their organisations had decided not to provide

Some stakeholders explained that their organisations had decided not to provide services in rural and remote environments because they were unable to provide quality, safe service within the pricing structures.

services in rural and remote environments because they were unable to provide quality, safe service within the pricing structures. Some of the reluctance to work in rural and remote regions was blamed upon the slow roll out of the Scheme and thus not a work-load high enough to make it viable. The lack of recognition of the extensive time involved in travel in rural and remote regions within NDIS pricing structures also greatly impacted on the ability to deliver financially viable service.

4. **Appropriate staff not available.** Another reason for the lack of providers, providers withdrawing services, and providers saying they were at capacity and thus not available for service, was the difficulty finding and retaining quality staff with the level of skill required within the pricing structure.

5. **Lack of service funding for travel** meant that organisations would not/could not accept clients that lived further than 20 minutes away.

b. **Cost-related issues.** The lack of services described above repeatedly came down to a lack of financial viability of providing services within the costing structure of the NDIA. Even if the services they were seeking for clients were available, providers struggled and often were unable to find people/organisations to provide services within the funding structure. Services highlighted included cleaning, support workers, self-care and gardening. Stakeholders also reported that only a small percentage of organisations who had registered to provide services within NDIS were in fact actively doing so. The unit costs defined by the NDIA are incongruent with employment conditions i.e. SCHACDS award, because the sector is regulated.

c. **Errors and unscrupulous organisations.** Inflexibility and errors in the on-line NDIS systems as well as un-scrupulous organisations are collectively resulting in people not being able to access the supports detailed in their plan because other services have stepped in and drawn down on the same line items, leaving the person with no funds to engage with other organisations or services. This is particularly problematic where assessors and planners are associated with providers.

Aboriginal and Torres Strait Islander people were particularly marginalised in the planning processes as a result of these issues. This is of particular concern because they are already under-serviced in mental health but experience high levels of disadvantage and need. The following areas were highlighted in the conversations with stakeholders:

a. **Aboriginal and/or Torres Strait islander community controlled organisations are missing as service providers.** We heard many stories of Aboriginal clients not engaging with NDIS or activating their plans because they were unable to be connected to Aboriginal provided services.

b. Aboriginal and Torres Strait Islander people living in more rural or remote communities were particularly impacted by **lack of service funding for travel.**

c. Due to NDIA funding structures **the financial viability** for services which provide expert services, including culturally-relevant Aboriginal and Torres Strait Islander services, is limited.

Solutions posed

- A service of last resort should be provided as promised by the NDIA so that individuals are not left with some parts of their plan not activated

The federal government to stimulate the market where no service is being provided:
- Tendering for services to meet specific needs
- Federal government to provide funding and support for service providers to set up the business for specific needs
- Providing funding/incentives and support for service providers to set up businesses in rural and remote areas – federal government
- Need to provide funding through the NDIA for services to travel or for group travel

Implement process to ensure quality systems safeguards:
- Some organisations are acting unscrupulously to cash in via planning which will benefit the organisation. Needs to be auditing and ability to review more regularly. Those organisations found to be involved need to be investigated and retrained or sanctioned by the NDIS Quality and Safeguards Commission
- Adopt the model used by most NSW insurance companies and government insurance bodies e.g. Lifetime Care and Support: services are requested; approval granted along with an approval number, detailing number of hours in a given time period; providers invoice for services as they are provided until the

hours are used up/time period is complete. This makes it impossible for excess hours to be claimed, or for providers to claim from other line items, as all usage is monitored by the funding body

Workforce development:

- Training and creation of career pathways
- Workforce development and planning via the NDIA and federal government
- Incentivising workforce development within organisations
- National employment awards (SCHACDS) need to be matched to unit costs as defined by the NDIA. This should be part of ongoing pricing reviews

National employment awards (SCHACDS) need to be matched to unit costs as defined by the NDIA. This should be part of ongoing pricing reviews.

Community designed and delivered NDIS processes will enhance NDIS accessibility and cultural relevance:

- Aboriginal and Torres Strait Islander health workers need to be involved in the planning processes as advocates where clients or carers request this
- Funding through the ILC to set up Indigenous-focused services or equip existing services to offer Aboriginal and Torres Strait workers for Aboriginal and Torres Strait Islander clients
- Incentives for employing Indigenous staff within provider organisations
- Funding for services to travel as many Indigenous people may not have money to be able to spend on travel (e.g. if income comes via a Centrelink Basic Card)
- Co-design services with communities to identify cost savings and multi-purpose services. Where Indigenous-focused services are not available then the NDIA needs to work with individuals to make the existing services more able to meet their needs. An Indigenous service coordinator may be appropriate for this

Review of the Plan – routine reviews and appeal reviews

Stakeholders talked about multiple problems at the point of plan reviews. This included delays in plan reviews, and reviews occurring without notification and over the telephone. Collectively these inadequate and inappropriate plan reviews have resulted in ill-informed reasoning to drastically reduce people's plans. Reductions in plans occurred for most people at their review and the services that they were no longer deemed eligible for were terminated immediately.

a. **Time delays and in-flexibility.** Stakeholders reported waiting up to 7 months for a review request. Plans were only able to be corrected or amended via a formal review. There were no other mechanisms for adjustments to obvious errors in a plan. Requests for urgent reviews typically took months.

b. **Invariable reduction of plans stemming from inadequate understanding of psychosocial disability.** Across the country we heard that people's plans were almost invariably reduced at review. Stakeholders across the country described a number of ill-informed reasons given by plan reviewers and NDIA for these reductions in people's plans. Lack of transparent, consistent reasons for plan reductions was common. The primary reason given was that people had not used their full plan amount the year before. What was not understood by the reviewer is that this 'under-utilisation' of the plan was typically directly related to the person's psychosocial disability. It included things like:

> 1. Periods of hospitalisation or imprisonment at which times they were unable to use community-based services in their plan;
> 2. The nature of psychosocial disability means that it took time for people to develop rapport, trust and thus engage with service providers, and
> 3. A lack of available service providers rather than a lack of service need.

The superficial calculation of second plans based upon what people used in the previous year is leading to the costly and unhealthy but understandable practice of pushing people to use all of their hours of service whether they currently needed them or not in order to reduce the risk of reduced plans in the future when they might need that additional support.

c. **Support coordination is typically removed from plans at review.** Stakeholders reported that coordination of support was typically phased out after the first plan and this demonstrated a lack of understanding of the complexity of people's needs as well as the ongoing barriers to accessing services that people with psychosocial disability often faced.

d. **No support during reviews.** Support coordinators were not permitted or paid to advocate for a person at review or appeal leaving many without help to argue or articulate their needs.

e. **Reviews not transparent and conducted over the phone.** Service provider's report that plan reviews occur over the phone and in most circumstances, clients are not aware that the phone conversation is a review. In the Northern Territory when the NDIS rolled out in January phone interviews were being conducted and interviews from car windows, this practice has now stopped due to complaints from the community, NT Government, the Australian Medical Association and the local AMS to the Federal and Local Ministers responsible.

f. **Plans are inflexible and difficult to review when needs change suddenly.** Poor system responsiveness means that plans cannot quickly be changed when needs change (e.g. people go through crises), thereby creating an internal gap where the system no longer completely meets the needs of clients[21].

Solutions posed

Train reviewers in working effectively with people with psychosocial disability:

- Training for LACs and planners in psychosocial disability, recovery and language around both in the context of the NDIS

Changes to NDIA related processes:

- The NDIA needs to monitor timelines for reviews and where applicable apply more staff or tender out reviews to an appropriately trained NGO for the short term to allow for catch up
- Must state to clients the reasons why delays are occurring, and regularly update progress. Check safety of client, and ensure that they are receiving what they need
- Appeals should be reviewed by someone with expertise in psychosocial disability. Development of a specialist pool of staff who can be consulted with by planners to understand what is relevant
- Reviews should be face to face as standard and only conducted remotely as a last resort when it is requested as an accommodation by client. In remote areas Local Councils or community based services should be offered equipment or technical support and funding to provide this service
- Where phone interviews take place they should be investigated to ensure it was for a valid reason
- Need to collect indicators which compare number of plans with number of appeals, practice and timing of reviews, outcome of reviews, client satisfaction.
- Many of the service provision issues relate to pricing – needs to be an ongoing review of pricing

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[21] Partners in Recovery Tasmania (2017) Submission to the Joint Standing Committee on the National Disability Insurance Scheme: the provision of services under the NDIS for people with psychosocial disabilities related to a mental health; Occupational Therapy Australia (2017) Submission by Occupational Therapy Australia to the Parliament of Australia Joint Standing Committee on the National Disability Insurance Scheme. The Provision of Services under the NDIS for people with psychosocial disabilities related to mental health condition.

Flexibility:
- There should be a mechanism where plans can be changed quickly where there has been a sudden change in circumstances
- Implement a contingency fund in plans, so additional funds which can be accrued and accessed in a crisis or sudden change of need based on simple criteria

Implement a contingency fund in plans, so additional funds which can be accrued and accessed in a crisis or sudden change of need based on simple criteria.

Delivery of support coordination:
- Support coordination should be standard in at least the first 1 or 2 plans or for the first year. Should not be removed from plans unless expressly requested by client
- Choice and control need to be understood and respected and in some cases facilitated
- Clients need to also understand the purpose of support coordination – and planners need to be able to explain this

Clarify the role of the support person as understood by the planner and participant:
- There should be the option built into the system for people to nominate a contact or support person at the time of a review being submitted and these people should be automatically included in all discussions to make sure that they are being supported (don't leave it up to the individual to notify support people for each meeting)

Utilise existing psychosocial disability knowledge experts or existing models:
- The mental health workforce including peer workers need to be trained to be able to provide support for people with psychosocial disability entering the NDIS
- The NDIA needs to have a professional mental health body assist and advise them on psychosocial disability
- The NDIS should analyse how existing Schemes such as Lifetime Care and Support (NSW), Lifetime Support Authority (SA), and TAC (VIC) operate. Lifetime Care and Support, for example, use a model where the annual plan is developed, however if additional services are required there is a mechanism to request additional services (via a specific form), that are then added to the original plan. A similar mechanism needs to be in place for the NDIS

The NDIS journey for carers and family members

Supporting carers also stops people from needing other services – therefore keeping down costs to the NDIS. Stakeholders (which included advocacy groups) identified the following gaps related to family members and carers:

a. **Lack of inclusion at the assessment and pre-planning stages.** Family and carers have typically not been informed about or included in their loved one's assessment and planning processes. NDIS does not have a broad understanding of who might constitute a person's family, carer or other significant support person. These critical informal supports are often 'hidden' and include children or community members in culturally diverse communities.

b. **Supporters overwhelmed by complexity of process.** Families and carers who are trying to support their loved one to apply, are overwhelmed by the complexity of the application process. Stakeholders described these concerns often being raised in community consultations and through direct feedback.

c. **Multiple barriers to carer needs being included in a plan.** Carer support services would only be included in an NDIS package if the participant requests funding for such services. When family members or carers are not included in the planning stage, their needs are typically not addressed. Even when they are included, there are multiple barriers to their needs being identified and included in the funding plan:

1. Many **barriers exist to understanding or acknowledging the caring role taken on by family and friends** exist. This includes stigma; a blurring of family roles and responsibilities; or simply different perspectives on how a person is supported. Discussion of what supports are provided and what burden is taken on by families and friends to provide the support required are **straining these relationships**.

2. **Most families and carers are unaware that they can be supported through the plan** of the person they support. They are unaware that they can submit a Carers' Statement and that they can request a separate meeting with the planner.

3. **Supports and services available to families and carers** through Individual Support Packages and the funding which will be available through the ILC **is severely limited**. Within the NDIS Scheme, there are not the resources, scope or capacity to deliver the services required to adequately support families and carers. There is **very little scope for the emotional, social and physical wellbeing of families and carers**.

4. **Funding previously available to support carers to sustain their own well-being (e.g. Mental Health Carer: Respite) is ceasing** as it is transferred to the NDIS Scheme.

The replacement cost of labour of those informally supporting someone with mental illness is estimated at $13.2 billion on a national level[22] – breaking the back of this support network by removing the little assistance and respite they receive (as a result of Commonwealth Respite/MHCSS funding being rolled into NDIS) could produce huge cost blowouts in Health, Mental Health, Justice, Housing and Homelessness, Alcohol and other Drug services which will be forced to respond as a consequence.

Solutions posed

Reimplementation of carer support and education programs:

- ILC funding needs to be actively used to support carers.
- Current programs for carers which sit alongside the NDIS need to be adjusted to fit with the new model. Should be funded by the federal government as part of the adjustment to the NDIS
- Respite and carer needs included in plans as standard except where client states that this is not needed
- The NDIA should conduct research to consider if it is possible for the NDIS to provide adequately for carers. If that is not the case the government needs to ensure that alternative funding streams are developed
- Introduce the previously scoped but not yet developed National Integrated Carer Support Services. Build more services into NDIS for carers, e.g. psychosocial education for carers and children of parents with mental illness and so forth

Plans need to consider carer burden and ways to redress this:

- Should be default inclusion, with client consent, of carer or support person in assessment, planning and review
- Assessment and planning tools should locate the person within a support network and the NDIA should develop family centric/relational assessment processes as occur in health and psychosocial disability settings

A carer statement must be a default requirement of the process only excluded if client states directly that they do not want it included.

- Carer consultants in the LACs to support the process
- A carer statement must be a default requirement of the process only excluded if client states directly that they do not want it included. A carer statement template needs to be provided on the NDIA website co-designed and developed by carer organisations

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[22] Diminic S., E. Hielscher, Y. Lee, M. Harris, J. Schess, J. Kealton, H. Whiteford (2017). The economic value of informal mental health caring in Australia: summary report. Commissioned by Mind Australia.

- Having a planner/assessor/ support officer that is allocated to each individual participant by the NDIA that their family/supports could contact directly

Train planners in culturally aware family inclusive practices:
- Should be specific family-centred support of Aboriginal and Torres Strait Islander people
- Training should focus on developing an holistic understanding of psychosocial disability amongst planers and assessors so that they understand the consumer as part of a larger network of support
- Necessary for more information on NDIS available to carers and family members and community members so that they can be better involved
- Training of NDIS staff on the importance of support people
- NDIA should simplify the process and ensure plain English is used in written and spoken communication, and translations and interpreters available for culturally and linguistically diverse carers and families
- Tailored and co-designed information for carers needs to be explicit on the website and provided at all information sessions and online. Should provide information on what is supported and the process
- Training about the importance of carers will assist with these being involved

The NDIS journey for service providers – an NGO system in a precarious and un-sustainable position

1. **Collapsing, merging and avoiding the NDIS.** Smaller non-government organisations described collapsing and merging. They also repeatedly talked about waiting to see how things go before offering services through the NDIS or choosing not to engage with NDIS at all. In combination, this is resulting in loss of programs and services developed to meet the needs of local communities and appears to be in direct contrast to national policies and directions promoting a localised approach to service development (e.g., the PHN approach).

2. **Running at a loss.** All non-government stakeholder organisations providing services through the NDIS described running at a loss that was not sustainable because clients needed services which were not covered by the NDIS. All organisations described covering these additional costs by drawing on reserves and donations with an understanding that there was a time-limit before the organisation would 'step away' from engagement with the NDIS Scheme.

    i. They commonly described **offering and providing 'free' or unfunded services to many clients** because they were not in the NDIS Scheme and no other funded services were available.

    ii. They commonly described providing **unfunded service to support people in the pre-planning and application phases** due to many having no support allocated, and those within programs transitioning, having insufficient hours of support provided.

    iii. They commonly described **paying their NDIS service delivery staff more than the hourly rate 'allocated'** within the NDIS pricing structure in order to maintain staff quality, mental health knowledge and skill. Services are paying according to SCHACDS Awards and are in line with national awards but these are too high when considered against the pricing of services provided under the NDIS.

    iv. Stakeholders described **providing more services to clients than was allocated in NDIS approved plans** and to 'plug' gaps in services available and, as above, covering the costs for these 'extensions' of service while understanding this was not sustainable long-term.

    v. The extent of **un-funded work is further exacerbated by repeated delays and complexity for people along the NDIS journey**: the complexity of the application process, the poorly understood complexity of time involved in building trust and rapport with many clients with psychosocial disability; the delays in the planning, review and appeal processes and so on. Stakeholders described continuing to provide

un-funded services at these various points of delay for both ethical reasons and in the hope that they would be 'reimbursed' later on.

Some of the confusion about funding relates to cost shifting taking place between the federal and state and territory governments. Funding changes are impacting the jurisdictions in different ways, with some states and territories choosing to continue to provide particular community-based psychosocial supports, but others bot doing so[23].

3.   Losing a talented mental health work-force including peer workers. All organisations described the distress of **'shedding' talented, well trained staff** that they had invested time and resources in building and training. Stakeholders have consistently raised concerns around the lack of understanding within the NDIS structure of the qualifications and expertise required to provide services and support or people with psychosocial disability. This once talented workforce is being replaced by a casualised and unstable workforce increasingly un-skilled and inexperienced in mental health. Staff retention was a challenge repeatedly raised.

> *All organisations described the distress of 'shedding' talented, well trained staff that they had invested time and resources in building and training... This once talented workforce is being replaced by a casualised and unstable workforce increasingly un-skilled and inexperienced in mental health. Staff retention was a challenge repeatedly raised.*

4.   Staff training and supervision reduced to risky levels. Most stakeholders talked about having to drastically reduce the quality of staff training, support, supervision and services to try and get closer to alignment with the NDIS funding model. They described radically changing, or in some cases ceasing, staff induction, orientation, supervision, support and training. Typically these were now delivered as on-line modules with limited or no capacity to confirm completion.

5.   Poor communication between NDIA and organisations. Communication from the NDIA national office, NDIA regional offices and LACs has been raised as on ongoing issue for stakeholders which frequently causes confusion; incorrect information or interpretations of information; and a lack of clarity on who is responsible for what. Stakeholders described that a risk to staff arising from poor training and supervision was exacerbated by poor communication between NDIA staff and service provider organisations. This meant that sometimes information about complex behaviours or people's histories of violence were not shared with providers.

6.   Bending and breaking rules to survive: Stakeholders invariably described their organisations **'bending the NDIS rules' to survive financially, or to extend the time before they would withdraw from the NDIS.** This had a negative impact on their culture and morale and created a growing sense of need for secrecy rather than cross-organisational connection, collaboration and sharing (hiding clearly questionable but deemed essential-to-survival practices).

7.   Lamenting the loss of a person-centred model for this new business-driven model. Stakeholders believed that a very different culture was now driving the community managed or non-government mental health system across the country, with a business model rather than people at the centre. For example phone calls are now billable in 15 minute increments, which distorts this type of communication. Funding, and thus opportunity, for organisations to connect, collaborate and build integration has been lost. This also impacted on capacity to develop relationships and partnerships beyond the community-mental health sector, such as with Aboriginal organisations and communities.

8.   For some organisations current contracts to provide services (e.g. PHaMS) end before the NDIS begins in their region, which means that they must work out how to be financially viable and retain staff during this gap, which can be many months.

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[23] Community Mental Health Australia (2017) Submission to the Joint Standing Committee on the NDIS – The provision of services under the NDIS for people with psychosocial disabilities related to a mental health condition.

A report by NEAMI into the collapse of the Pathways mental health service provider in the Barwon NDIS trail site used interviews with key stakeholders in order to identify what led to the failure of the business[24]. They found that 'cashing out' of existing funding streams by the Victorian Government in order to pay for the NDIS contributed to the demise of the organisation. The business failed to adapt to the new financial demands of the NDIS which paid much less per hour than they able to deliver services for (less than half the cost). Another factor attributable to the 'gap' was that Pathways continued to provide services which met the needs of clients receiving support from the NDIS where the NDIS did not cover supports:

> "Service boundaries and roles were not renegotiated with Barwon Health during the trial and Pathways continued to do work that was not funded in NDIS plans. If staff believed a consumer needed a particular service/support they provided it, irrespective of whether it was part of the person's NDIS plan"[24].

These had to be funded separately by Pathways. NEAMI point out that poor financial management was not unique to this organisation with 22% of businesses providing similar services in the Barwon trial site were operating at a loss.

The ongoing viability of existing services operating under the new NDIS pricing model has also been raised as a significant concern by the NT Mental Health Coalition[25]. Because services which aim to reach indigenous people with mental ill-health in rural and remote communities are more costly to run any cuts in funding related to the implementation of the NDIS is likely to impact more heavily on these services.

Solutions posed

- Many of the problems listed relate to the pressure to increase enrolments into the Scheme. This pressure should be reduced to allow both the mental health sector and the NDIA to put in place adaptive rather than reactive systems

Immediate price guide review:
- An urgent objective review of the fees structure by a respected third party is needed. The work in the current pricing review duplicates work already done that clearly shows that NGOs are negatively impacted by increased exposure to the NDIS. It is clear that an independent body needs to review and set prices. The NDIA cannot set the prices it wants to pay
- Recommendations from the Productivity Commission NDIS Costs Final Report Oct 2017 and the Joint Standing Committee on the National Disability Insurance Scheme (NDIS) Report Aug 2017 regarding pricing reviews need to be implemented
- Ongoing pricing reviews with a particular focus on rural and remote service provision
- NDIA to work with organisations and peak bodies to actually understand the real costs involved in running a disability service
- Better understanding of the needs of participants with psychosocial disability could potentially lead to a review of prices or support items to better reflect needs. A project to document needs could be undertaken in longer-term trial sites with more experience of the NDIS
- Pricing reviews to increase funding in line with SCHACDS increases

Recommendations from the Productivity Commission NDIS Costs Final Report Oct 2017 and the Joint Standing Committee on the National Disability Insurance Scheme (NDIS) Report Aug 2017 regarding pricing reviews need to be implemented.

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[24] NEAMI National (2017) *Learnings from Pathways: A retrospective analysis of one business failure in the Barwon NDIS Trial.* NEAMI: Preston.
[25] NT Mental Health Coalition (2017) Submission to the Joint Standing Committee on the NDIS - The provision of services under the NDIS for people with psychosocial disabilities related to a mental health condition.

Implement viable strategies for workforce (including peer) development and retention:

- The federal government to provide flexible additional funding so that service providers can recruit staff instead of cutting staff/asking existing staff to do additional jobs
- Government and the NDIA need to work together to consider the context of the NDIS and develop a workforce strategy
- Rulings on the minimum/maximum wage or hourly rate staff can be paid in line with NDIS price guide
- Staff to be trained to think outside the box and make effective use of the time allocated. Potential for synchronising with other group activities to be considered
- Peer workforce needs to be integrated into the NDIS processes of assessment and planning
- Up-skilling the management of NGOs in workforce planning to enable more workforce diversification, including maintaining some talented staff in specialist and better remunerated roles – NDIS pricing needs to take this into consideration
- Peer workforce development needs to continue, and be expressly funded through the federal government
- Incorporating a small 'Administration Fee' or similar from the NDIA that can cover workforce development and monitoring through participants' plans
- Government to fund innovative and cost-effective model development which can be rolled out more extensively such as group supervision, self-managing teams, etc.
- Services should not bend or break rules, but be able to request support from the NDIA or government when struggling financially

NDIA and federal government to invest in sector change management strategies to ensure quality services are delivered:

- The federal government needs to support boards and managers to be able to adapt more effectively to the new environment
- The community mental health system should be reviewed in relation to the NDIS to determine what roles are needed to support those that cannot access the NDIS or do not have all of their needs supported by the NDIS
- Establishment of a professional body (covering both peer and other workers) which will monitor the workforce for poor practice, support worker rights, monitor mandatory training and determine collective issues which need to be taken to the NDIS
- Federal government support for businesses to transition to the new model and to understand how the funding can be used and allocated
- Services need to develop new models to adapt to the new circumstances, but should be supported by the NDIA and government to do so

Changes to NDIA processes:

- The NDIA and governments need to clarify the NDIS/health system interface. Each to take responsibility for funding supports required of the respective systems
- Planners need to work with service providers to understand just what is involved in all aspects of service provision so it can be funded appropriately in plans
- Introduction of contingency funds in plans to be accessed in case of crisis or sudden increase in need for clients
- Timelines need to be monitored by the NDIA and extra staff allocated to backlogs so that service providers are not providing long-term unfunded services to cover gaps while plans are reviewed
- Designated individual as contact for client will develop a personal connection which will make this more likely
- Clients should be able to agree to have their needs discussed by the NDIA and any services and carers that should be involved

- Client confidentiality should not be used as an excuse not to discuss. Training of planners and NDIA staff, planners, LACs will assist with this
- Governments to articulate and publish what 'Continuity of service' guarantee means in practice
- This new model's philosophy looks good (providing choice and control) but the implementation process is against this philosophy – needs to be evaluated and reviewed from the perspective of person-centred care
- Need stronger communication between NDIA and services so that they can easily communicate about specific (client-focused) and general (organisational, systemic) concerns

Investment in the experienced community based mental health sector:

- There needs to be a Federal government strategy for retaining community mental health services which sits alongside and ties into the NDIS
- The sector as a whole will be weakened if the workforce and services are not able to receive enough revenue from the NDIS
- Unfunded work across the sector needs to be quantified by the NDIA
- A professional organisation arrangement which will maintain safe standards
- PHaMS and other services (PIR, D2DL) need to be fully funded until the NDIS is fully rolled out in each area, then before services ceased there needs to be an evaluation of what will happen to those who are left without services
- DSS to look at suspending PHaMS roll out and with the remaining funding, model an in-kind contribution similar to PIR and D2DL. This will work towards reducing some of the barriers associated with reduce services for people accessing the NDIS, being declined etc. as well as issues with staffing levels (decreased staffing capacity as funding is reduced)

> *The sector as a whole will be weakened if the workforce and services are not able to receive enough revenue from the NDIS.*

The gaps at the edge of the NDIS: the impact of the NDIS on people who are ineligible and services which are not funded

Impact on existing services

There is considerable concern in the non-government and government community about the transfer of funding (either wholly or partly) for existing programs to the NDIS while individuals, including those unable to access the NDIS are still receiving services from them[26]. A lack of block funding means that **people are unable to get supports outside of the NDIS for services that they previously received** – supports which are localised and individualised, administered by their own regions[27]. **Many of the existing programs are "low barrier to service"** meaning that they are able to be accessed without stringent criteria such as that which governs NDIS accessibility, so are more broadly available for people with a wider range of psychosocial needs[26]. Phasing out of existing programs to fund the NDIS will mean that those who received them but are unable to meet the eligibility criteria for NDIS will miss out on services that they need[27]. The services which will be phased out or wound back significantly include, the Personal Helpers and Mentors Scheme (PhaMS), Day to Day Living (D2DL), Partners in Recovery (PIR) and Mental Health Carer: Respite Support[28]. MHCC (cited in CMHA 2017a) estimate that around 6000 people across NSW who are currently receiving support through PIR, PHaMS and D2DL will not be eligible for the NDIS.

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[26] Community Mental Health Australia (2017) Submission to the Joint Standing Committee on the NDIS - The provision of services under the NDIS for people with psychosocial disabilities related to a mental health condition.
[27] Commonwealth Ombudsman (2017) Submission by the Commonwealth Ombudsman. Joint Standing Committee on the NDIS. The Provision of services under the NDIS for people with psychosocial disabilities related to a mental health condition.
[28] Mental Health Coordinating Council (2017) *View from the peak*, Mental Health Coordinating Council: Canberra.

A response from the NDIA to a Question on Notice from the 2017-18 Budget Estimates Hearings regarding the number of people applying and being found eligible for the NDIS in PHaMS stated that the Department of Social Services advised the NDIA to expect around 800 current PHaMS clients to move to the NDIS over the 2016-17 period. As at 31 March 2017, 748 (93%) made an access request and 281 (35%) had an approved plan.[29] However, as at June 30th 58 PHaMS clients withdrew their request, 162 declined to move to the NDIS and 35 did not return their form.[30] This demonstrates that a significant number of people who are in programs where funding is being transferred to the NDIS will not be able to access NDIS services and will therefore be left without these services in the future.

As demonstrated above the NDIS will only ever be available to approximately 64,000 people living with mental illness at full Scheme implementation which leaves a very significant number of people with mental illness sitting outside the Scheme. However, due to funding re-allocations to support the NDIS, previously available programs and **support pathways for the vast majority of people living with mental illness are rapidly 'drying up' or disappearing.** This is compounded by slow uptake of the NDIS. For example the problem of transitioning from block funding to competitive tendering has been made more difficult due to slower than expected take-up of NDIS support plans - organisations are losing block funding, but do not have sufficient NDIS plans to cover costs. This is having a very major impact on services for most people living with psychosocial disability who fall outside of the NDIS Scheme.

1. **Hidden loss of services.** To some degree, it appears that this impact has been hidden for the short term because organisations are providing non-sustainable, 'free' services that were once funded through funding streams transitioning over to the NDIS. They are doing this because of a sense of ethical responsibility to people they were once funded to support. This good will was temporarily 'plugging the gaps'.

2. **There has been a dramatic loss of services for the vast majority of people living with mental illness.** The alarming reduction in service support options for people living with mental illness who were not applying or assessed as ineligible for an NDIS support package was a national issue amongst stakeholders. Most stakeholder organisations described **ceasing to offer and run services and programs** due to them being de-funded as resources were shifted to the NDIS.

    Some of these 'closed or closing' services included: homelessness outreach program; emergency accommodation; youth residential programs; transport for people to attend services, and a diverse range of centre-based services.

    The way in which the NDIS has been funded is resulting in a mental health system that is in direct contrast to state and national mental health commission reports calling for a shift in funding and services towards increased community, recovery-oriented, early intervention services and supports that will, over time, reduce the financial burden of more acute services as well as social security costs.

3. **Loss of services is contrary to the values of existing policy frameworks.** The way in which the NDIS has been funded is resulting in a mental health system that is in direct contrast to state and national mental health commission reports calling for a shift in funding and services towards increased community, recovery-oriented, early intervention services and supports that will, over time, reduce the financial burden of more acute services as well as social security costs.

4. **Creates a second class of people with psychosocial disability who cannot access services** they were previously eligible for. The loss of programs such as PHaMS (the original model) is having a huge effect on individuals who were reliant on a PHaMS level of support which assisted in keeping them well in the

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[29] Australian Government (2017) Social Services Portfolio: Senate Estimates.
https://www.aph.gov.au/Parliamentary_Business/Senate_Estimates/clacctte/estimates/bud1718/SocialServices/index
[30] Question on notice no. 50 Portfolio question number: SQ17-000236 2017-18 Supplementary budget estimates.
Community Affairs Committee, Social Services Portfolio

community. Some former PHaMS participants have tested their eligibility for NDIS and been unsuccessful. They are now left with no support.

Service gaps or losses have had the following impacts:

i. **Services with a low threshold or minimal requirements for engagement** impacted. These services, where people could previously just turn up and seek support, are one group of services that are being lost to people not eligible or not accessing the NDIS. These services were identified as assisting those often with the greatest barriers to gaining support – people with multiple disabilities including drug and alcohol addiction; homeless; from non-English speaking backgrounds; and with fear or paranoia about government bureaucracies. A plethora of evidence demonstrates how challenging it is to engage this cohort of people with any service support (less than 50% of people engage with clinical mental health supports).

ii. **Community-based rehabilitation and recovery services.** A diverse range of community-based services supporting recovery have been impacted by these cuts. These services were staffed by those with expertise in mental illness (both through training and through lived experience such as peer workers). Programs worked in a **recovery-focused** way to engage with and support people over time, **building capacity within the individual, facilitating self-directed, strengths-based ways of living with and managing their mental ill-health.**

iii. **Increasing use of clinical services rather than alternative community-based services.** Due to the reduction in recovery-focused, and peer-support service options for people, stakeholders anticipated and reported starting to see an **increase in the use of clinical pathways in the absence of recovery-focused and peer-supported community-based pathways**. These is an alarming trend given that these are **more expensive and 'reactive' and clinical rather than 'preventative, self-help, peer-supported and health-promotion' pathways**. Lived experience workers were also not included as 'support' option in individuals' plans.

iv. **Capacity building services are not funded.** Whilst the NDIS provides resources within a person's environment to maximise their participation and inclusion, much of the ability of the person to engage with and access NDIS support packages is dependent upon the capacity building of psychosocial rehabilitation services, however these have been de-funded in the move to the NDIS.

v. **Peer support and peer-communities of support:** Services that created opportunity for, or supported people to connect with and learn from others living with mental illness, in particular peer support services were being lost as a result of funding shifting to the NDIS. We heard repeated stories of this **leading to increased isolation** for people living with mental illness – both for those who were in the NDIS Scheme and those who were not.

vi. **Carer and family support services.** For people assessed as ineligible, **the quality and sustainability of the informal yet critical care they receive from family, carers or friends is at serious risk**. These support people will no longer receive the services that they could previously access in order to maintain their own well-being.

vii. **Restriction on funding for individuals unless they have tested their NDIS eligibility.** Consumers who 'do not engage' or are assessed as ineligible are further disadvantaged due to state or territory health policies or directives to not fund services until NDIS applications have repeatedly resulted in an 'in-eligible' assessment.

These disappearing tiers of the mental health service system are only 'covered' in a tokenistic way within the ILC funding provided within the NDIS Scheme.

Solutions posed

Currently funded services should not be discontinued for people who are eligible for them but are not eligible for the NDIS:

- The federal government must continue to fund a flexible, low barrier to entry service (as per PIR, D2DL and PHaMS) that sits outside of the NDIS for people who need ongoing community and coordination support for people whose fluctuating illness means that they need additional supports when NDIS cannot offer enough support
- There should be a fundamental principal that no one should be left without support because of the transition of existing services to the NDIS
- PHNs to commence contracting for programs for mental health that will target those who are not going to be NDIS eligible or wanting to apply for the NDIS. Programs currently coordinated by PHNs should not lose funding until 12 months after the NDIS has been introduced into the area to allow for transition and support in application from these programs

Fund gaps that has arisen from reform, particularly for those not eligible:

- Specific outreach program (such as that already offered by PIR) needs to be funded federally to meet the needs of those not eligible. Part of this outreach can be ensuring that those deemed ineligible are indeed not eligible and evaluating and assisting them with their needs
- Mainstream state, territory and federal governments must acknowledge and provide for the gap that the reform process has given rise to
- The transition of funding to the NDIS should not leave people with no support as this discriminates against them.
- Information Linkages and Capacity building funding should be used to provide services to people who are not eligible for the NDIS. In WA, this funding has only been used to market the NDIS while a vacuum exists for those not eligible
- Commissioning of an independent investigation to delineate what the gap between NDIS and clinical sectors is, both in terms of the composition and size of unmet need: i.e. that can demonstrate the impact of broader reform (PHN, state government-based reforms) at the same time as the introduction of NDIS

Continued funding of existing programs:

- All existing services should remain while the client is testing their eligibility as this could take months/years. They may need the advocacy of existing services if they are going to feel able to test eligibility
- The state departments of health and the federal government must work collaboratively to continue funding a low barrier to entry, flexible programs for people living with a mental illness who will not be eligible for the NDIS

> *The state departments of health and the federal government must work collaboratively to continue funding a low barrier to entry, flexible programs for people living with a mental illness who will not be eligible for the NDIS.*

- Partners in Recovery and Day 2 Day Living programs have been provided with a capped (maximum) number of people they are allowed to help. This practice contradicts the Standard Funding Guidelines (which seek value for money). It is recommended that the cap on these and other programs (that are cost neutral) be lifted so that new people can be included in programs and offered support to either get into the NDIS or be linked into other services
- Data collection should be undertaken by the federal government on transfers from existing programs (PIR, PHaMS etc.) on rates of NDIS eligibility/ineligibility and where people are transitioned to if they are ineligible
- Continuing to fund existing programs (PHaMS, PIR etc.) outside of the NDIS will be cost effective as it will assist with keeping individuals well and out of clinical services

- Extend end dates of funding for existing programs (PHaMS and PIR etc.) until everyone is transitioned to the NDIS or their needs are being met by other programs

Apply different funding models to programs for those deemed ineligible:
- Fund required programs as part of a separate mental health services system and as block funded ILC programs. The ILC cannot fund all the services needed for those who are ineligible
- The federal government should clarify how services are to be implemented regarding the 'mainstream services' avenue for people considered low level in support need. This could look like generalist services modelled on PHaMS with a faster roll through process (i.e. support provided for 3-6 months centred on early intervention or reducing need for ongoing support)
- Increasing capacity of mainstream services to take up this role through increases in funding. There is a need to increase the capacity of community mental health teams to deal with the demand for services addressing low level needs
- Increasing piloted programs such as LikeMind as alternate community mental health programs to work with low level needs. This could include mental health nurse programs. Partnerships could be developed between NGOs running these styles of services, the NSW Department of Health and the NDIA to ensure the transition of consumers to this model to continue with continuity of supports
- Continuing to provide funding for those existing programs who can provide non-clinical services, like social and recreational respite, well-being, education and training or developing the ILC better so that it can provide these on an ongoing basis

Invest in peer workforce development:
- Support and foster the mental health and psychosocial disability workforce, including peer workers, with training and scholarships
- NDIS providers should increase their peer work force, but train them through the Certificate IV in Peer Work to deliver services on a professional level

Invest in sector development:
- Governments should fund communities of practice through sector peaks
- Governments to cooperate through COAG to resolve deadlocks regarding delivery of the Commonwealth Government's 'Psychosocial Disability Supports' program ($80M to be matched by state and territory governments)
- There is a need to fund capacity and continuous improvement training within services. There should be broader access to sector development dollars through NDIA funding streams

Conclusion

The gaps and solutions raised in this report should not be seen as a fundamental criticism of the NDIS or the NDIA which is an important step forward in disability reform in Australia. Instead they should be viewed as a way of adding national psychosocial disability expertise to the ongoing development of the Scheme and the mental health and community care systems operating in relation to it. It is up to the NDIA and federal, state and territory governments to now make coordinated progress on implementing the actions suggested in this report. The community mental health sector, consumers, carers and academics all with psychosocial disability and mental health expertise are important partners in taking this forward.

About the Sydney Policy Lab:

The Sydney Policy Lab is a new multi-disciplinary centre at the University of Sydney that addresses complex local and global challenges and in so doing contributes to the development of a society that works for everyone. It achieves this by bringing diverse people together to spark new ideas, reframe issues and transform the policy options on the table. The Sydney Policy Lab harnesses the multidisciplinary strengths of the University and uses its convening power to drive or support projects that influence policy outcomes in a meaningful and significant way, including improving the quality of public debate around the issue.

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